

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

**Meeting of the Ethics Subcommittee of the Advisory  
Committee to the Director (ACD),  
Centers for Disease Control and Prevention (CDC)**



**Summary Report  
June 29, 2012**

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## Acronyms Used in this Document

<b>Acronym</b>	<b>Expansion</b>
ACA	Affordable Care Act
ACD	Advisory Committee to the Director
APHA	American Public Health Association
CDC	Centers for Disease Control and Prevention
DFO	Designated Federal Officer
DGMQ	Division of Global Migration and Quarantine
DHS	(United States) Department of Homeland Security
IOM	Institute of Medicine
IRB	Institutional Review Board
MAPP	Mobilizing for Action through Planning and Partnerships
MDR-TB	multi-drug resistant tuberculosis
NACCHO	National Association of County and City Health Officials
NALBOH	National Association of Local Boards of Health
OSTLTS	Office of State, Local, Tribal and Territorial Support
PHAB	Public Health Accreditation Board
RWJ	Robert Wood Johnson (Foundation)
STLT	State, Local, Tribal and Territorial
TB	Tuberculosis
XDR-TB	Extremely Drug-Resistant Tuberculosis

## Introductory Remarks and Overview of Meeting Goals

### **Ruth Gaare Bernheim, JD, MPH Chair, Ethics Subcommittee**

At 9:29 am on June 29, 2012, Drue Barrett, PhD, Designated Federal Officer (DFO), Ethics Subcommittee, Advisory Committee to the Director (ACD), Centers for Disease Control and Prevention (CDC), called roll of Ethics Subcommittee members, CDC staff, and guests participating in the teleconference. She established a quorum of Ethics Subcommittee members. A list of meeting participants is provided with this document as Attachment 1.

Ruth Gaare Bernheim, JD, MPH, Chair, Ethics Subcommittee, greeted the group. She reviewed the meeting agenda (see Attachment 2) and asked that Ethics Subcommittee members declare any conflicts of interest. No Ethics Subcommittee members indicated any conflicts of interest.

Ms. Bernheim recognized Dr. Norman Daniels, Dr. Nancy Kass, Dr. Pamela Sankar, and Dr. Leslie Wolf who will be retiring from the Ethics Subcommittee as of June 30, 2012. Dr. Barrett indicated that four new members would join the Ethics Subcommittee as of July 1, 2012: Dr. Janice Allen Chilton, Dr. Alan Melnick, Dr. Matthew Stefanak, and Dr. Ani B. Satz.

Ms. Bernheim noted that the new members of the Subcommittee represent the group's movement toward integrating ethics into the practice of public health, developing tools and approaches for ethics that can be used by health officers.

## Addition of Ethics Standards to the Process of Accreditation of Public Health Departments

### **Kaye Bender, PhD, RN, FAAN President and Chief Executive Officer, Public Health Accreditation Board**

Dr. Bender greeted the group and presented background information on the Public Health Accreditation Board (PHAB) and the accreditation process. Public health accreditation is the measurement of health department performance against a set of nationally recognized, practice-focused, and evidence-based standards. PHAB is a nonprofit organization that was founded in 2007, and it is located in Alexandria, Virginia. Their work is based on consensus. Currently, 82 health departments are in the process of accreditation, which is a strong start for a program that was launched in September 2011.

PHAB set out to establish a national voluntary accreditation program for health departments in a manner that was based on advancing the quality and performance of health departments. Rather than adopting a regulatory approach, PHAB focuses on working with health departments to identify areas for improvement and then to “raise the bar” on their performance.

The first call for setting standards for local health departments was published in the 1930s. The movement gained momentum in 2003, when the Institute of Medicine (IOM) called for an examination of public health accreditation. CDC and other partners had worked on the development of performance standards for the public health system, but those efforts emphasized monitoring by the health departments and their stakeholders and partners.

PHAB’s logic model, which is under revision, includes short-, medium-, and long-term outcomes. The short-term outcomes include creating a strong, credible, and sustainable accreditation program, as well as increasing organizational accountability. Intermediate outcomes include improving the quality of service and consistency of practice. The short-term and intermediate outcomes lead to improved conditions in which the public can be healthy. The notions of ethics, social justice, and health equity are important in PHAB’s work.

PHAB created a number of materials to support health departments in the accreditation process. These materials include a guide to describe the process, the public health accreditation standards and measures, readiness checklists, and documentation guidance. An online orientation is required for the accreditation coordinator and health department director. It has four modules: an introduction, an explanation of the accreditation process and what is expected, a description of the accreditation coordinator’s role, and a detailed explanation of the standards and measures.

The accreditation process for PHAB is similar to other processes for other accrediting bodies. The first step is pre-application, which includes a statement of intent from the applying health department. This planning document is non-binding. The next step is the application, and it includes an in-person training. The third step is submission of documentation. After a preliminary review by PHAB, a team of peer site reviewers visits the health department. Their site report is submitted to the PHAB Accreditation Committee. If a health department is accredited, then it must reapply in five years. Accredited departments are required to provide annual progress reports. If a health department is not accredited, then it has the opportunity to provide an improvement plan within 90 days and to implement the plan within one year.

Three prerequisites must be in place before a health department applies for accreditation:

- Community health assessment
- Community health improvement plan, which should be developed with stakeholders and should establish priorities for the health department and for the community
- Health department strategic plan

Even if a health department is not accredited, the process of completing the prerequisites will improve the department. PHAB staff review the prerequisites for completeness; the site reviewers review them for content and quality.

PHAB's standards and measures were developed by a workgroup that included state, local, and tribal public health practitioners from across the country. The development process took over two years and included an alpha test and a beta test. The current version of the standards and measures had over 4000 comments before it was released. The 12 domains in the standards and measures include the 10 essential public health services, plus two domains to address the administrative and management capacity of the health department and a strong and effective relationship with the health department's governing entity.

Each of the 12 domains includes a number of standards and measures by which the health departments are assessed. The site reports are based on scoring and qualitative components. Each standard includes a measure, some of which are applicable to all health departments, and some of which are unique to state, local, or tribal departments. A purpose and significance is provided for each standard and measure. Examples of required documentation and guidance are also provided. The accreditation process is all electronic and uses a system called e-PHAB.

The public health accreditation program was developed with support from CDC and the Robert Wood Johnson Foundation (RWJ), but like any other accreditation program, there is a fee schedule. The fee schedule is based on the population size of the health department's jurisdiction, which serves as a proxy for the cost of conducting the review. Health departments requested flexible means of payment of the fees. If the departments pay the fee up-front, they receive a 5% discount. Payment schedules of three to five years are also available. Thirty percent of the departments have elected to pay the fees upfront. The fees do not cover the operation of PHAB, but serve to offset the costs of conducting reviews. CDC and RWJ continue to support PHAB's research and development.

As PHAB developed the accreditation process, they focused on standards in public health that had been tested, or could be tested or developed by PHAB. Ethics and social justice are elements of the overarching framework for PHAB, but the standards do not incorporate concrete ethical areas for which health departments should be held accountable. The standards include some measures that address offering culturally and linguistically appropriate services. They also address disability and the concept of an Institutional Review Board (IRB). The current version of standards and measures will apply to health departments that apply for accreditation through 2013. The next version will be implemented in the accreditation cycle beginning in 2014 and must be published six months in advance. PHAB's collaboration with the Ethics Subcommittee on the development of ethics standards is both welcome and timely.

### **Discussion Points**

- Dr. Leonard Ortmann asked about the process for making changes to the next version of the standards and measures.
- Dr. Bender answered that PHAB's Executive Committee will meet in July 2012 to finalize the components of the process. They are gathering ideas and information via a range of mechanisms. They will probably utilize an oversight committee to collect recommendations and, in keeping with their consensus-based approach, in 2013 they will post potential changes to the standards in a public setting for comments. The oversight committee will review the comments and turn the results to the Board of Directors for the final determination.
- Dr. Ortmann noted that the PHAB process is not regulatory, but is a process of improvement. He asked about steps in the improvement process.
- Dr. Bender said that the standards and measures incorporate the concept of the process of improvement. For example, the pre-application stage focuses on the process by which the health department conducted the community health assessment and developed the improvement plan. The process should be sustainable over time.
- Ms. Bernheim observed that accreditation processes often require applicants to create a mission or vision statement. Ethics and values drive the development of the mission or vision statement, and she wondered whether mission or vision statements are part of the public health accreditation process.

- Dr. Bender said that the prerequisite regarding the health department's strategic plan requires an articulation of the department's mission, vision, and values. The community health improvement plan addresses health equity, requiring health departments to document how they have engaged their communities. This requirement has engendered a robust series of discussions regarding how health departments engage members of their communities that are not easy to engage, or that they may not have identified. For instance, the Los Angeles County Health Department jurisdiction includes almost 10 million people, and approximately 145 different languages are represented in the population.
- Dr. Ortmann asked about the sizes of the health departments that have applied for accreditation and whether a minimum size has been identified.
- Dr. Bender said that while PHAB has not identified a minimum size because evidence is not available to support or define a minimum size, many health departments across the country are too small to administer a comprehensive array of public health services and programs as described by the ten essential services of public health. Accreditation procedures have been completed for a multi-jurisdictional application category. This move was inspired by small rural health departments that work together on preparedness issues. If several health departments collaborate to render public health services, and if they have a longstanding relationship and interdependence in providing services, then they will be eligible to apply for joint accreditation.
- Ms. Bernheim noted that PHAB members have expressed a desire to integrate ethics into the standards. She asked whether the conversation should start in the areas of mission, vision, and values, as well as community engagement.
- Dr. Bender agreed. Communication with the community is a longstanding challenge for health departments, especially as communities become more diverse. Effective communication means providing relevant health messages that the community can understand. Another important area is health education, which incorporates ethics and social justice. Domain 10 of the standards and measures asks health departments to report on how they contribute to strengthening the evidence base for public health by partnering with researchers, which brings ethical questions. She encouraged the Ethics Subcommittee not to be confined to the areas identified by PHAB.
- Dr. Barrett suggested that Domain 5, which addresses policies and plans, could be an area for the Ethics Subcommittee to target as well.
- Dr. Bender agreed and noted that all 12 domains of the standards and measures have ethical elements. Their challenge will be determining where

to start. PHAB's main questions are: For what will health departments be held accountable, and where should health departments start in order to build and improve?

- Ms. Bernheim commented that these questions overlap with discussions held by the Ethics Subcommittee's Evaluation Workgroup. That group has discussed how to demonstrate measurable ethics-related outputs or outcomes.
- Dr. Norman Daniels, Ethics Subcommittee member, suggested that conformance to ethical requirements could be measured. Certain ethical issues may have broad agreement regarding how a health department ought to behave. A measure of performance could be developed by looking at a range of policies and practices to assess whether they conform to ethical requirements. Further, capacity must be developed so that health department personnel can bring ethical deliberations to bear on their cases and issues. He envisioned accreditation requiring some training or capacity-building in ethics and assessing whether the efforts are taking place.
- Dr. Bender said that the standards and measures include a domain addressing workforce development. PHAB assembles "think tanks" of experts to discuss recommendations and requirements, and a group is currently working on strengthening requirements around workforce capacity. A think tank was recently held on emergency preparedness. PHAB wants to be consistent with national programmatic requirements and not to be duplicative. An ethics think tank would present an opportunity to dig down into the PHAB standards and measures and to create formal recommendations to the PHAB Board.
- Craig Thomas, PhD, Director, Division of Public Health Performance Improvement, Office for State, Tribal, Local, and Territorial Support (OSTLTS), CDC, agreed that a think tank on ethics would be a good next step. The efforts of the Ethics Subcommittee Evaluation Workgroup will be helpful, as the think tanks are more productive when they focus on concrete concepts and specific ideas and measures. Timing may be an issue, as other think tanks are being planned.
- Ms. Bernheim suggested an intermediary step in which Dr. Bender and representatives from PHAB serve as consultants to the Ethics Subcommittee to develop the concepts further.

- Dr. Bender appreciated that approach. PHAB conducted preliminary work in emergency preparedness before that think tank was convened, and that work improved the productivity of the think tank. PHAB members will be willing to consult with the Ethics Subcommittee.
- Ms. Bernheim said that the next Ethics Subcommittee would take place in October 2012. A workgroup and PHAB consultant could engage in preliminary work to present to the Subcommittee at that meeting. The think tank could be convened in the spring of 2013.
- Dr. Bender felt that the timeline was appropriate.
- Dr. Daniels said that another issue could be the question of whether public health measures that are undertaken at the local level discriminate against particular groups. There is national consensus regarding non-exclusion, and cases in this area could serve as a frame for accreditation issues.
- Dr. Ortmann added that resource allocation is another important topic, both because of the state of the economy and because of its relationship to the Affordable Care Act (ACA) and the community needs assessment.
- Dr. Ken Goodman, Ethics Subcommittee member, added that the CDC and the American Medical Informatics Association have collaborated in the area of ethical issues in public health informatics. A number of people could contribute to the discussion on the unique ethical issues that arise in technology and public health.
- Dr. Nancy Kass, Ethics Subcommittee member, suggested a process checklist or other means to examine whether a public health department gives explicit attention to ethical issues related to any, or at least two, of the domains in the standards and measures. For instance, the departments could address the relevance of program interventions to those who are least well-off; strategies to minimize harms in implementing a new program; or other widely-accepted ethical goals.
- Dr. Barrett said that Dr. Kass's suggestion raises the question of whether ethical standards should be developed as new domains, whether ethics should be built into each of the existing domains, or a combination of both.
- Dr. Bender said that thus far, PHAB has integrated new measures into existing domains. Their goal is to adequately address public health around a framework that health departments understand, which is why the process is based on the 10 essential public health services. Either approach would work for ethics, and she encouraged the Ethics Subcommittee not to feel restricted. When they decide for what health departments should be accountable and how to measure it, it should become clear how the ideas should be integrated

into the standards and measures. For instance, one of the domains focuses on quality improvement, which is one of the ten essential services of public health. Quality improvement is imbedded in the other domains as well.

- Dr. Barrett suggested that the Evaluation Workgroup be charged with developing recommendations regarding ethics standards for the accreditation process as that group is already addressing complementary ideas. All agreed with this recommendation.
- Ms. Bernheim thanked Dr. Bender and hoped that she could attend the next Ethics Subcommittee meeting in October 2012.

### Update from the Evaluation Workgroup

#### **Eric Meslin, PhD Member, Ethics Subcommittee**

Dr. Meslin said that the objectives of the Evaluation Workgroup are to gain clarity on the activities and intended outcomes of a general public health ethics activity; develop a simple and consistent “roadmap” logic model; identify the key accountable outcomes that are measurable and attainable by public health officials and field personnel; develop potential indicators and performance measures; and develop an evaluation plan.

The group has developed a “roadmap” for a general public health ethics activity and identified key accountable outcomes. They have also identified other key components of a public health ethics activity that should be monitored to track performance and have begun to review the indicators and measures that will be used to monitor the activity.

The workgroup generated some key assumptions, which are as follows:

- Public health ethics activities may differ in their emphasis or formality of structure between health departments (e.g., some may want to emphasize consultation while others may focus on training).
- The process that is used in decision-making is as important as the “lenses” that are used for that process.
- It is not only important to monitor the effect of public health ethics, but to realize that the time horizon for assessment is often far away, and monitoring distant impacts is difficult.

- The focus should be on mediate outcomes, such as increased public credibility, the quality of decisions, and the quality of the review and consultation process.
- The efficacy of the public health ethics activity in one setting may be related to leadership, economics, and other outside factors, and different settings may have different expectations about how ethical decision-making will inform outcomes. Should performance measures be included for these moderating factors?

The workgroup discussed attributes of an ethical process. A process is ethical if it:

- Is open, honest, and transparent
- Makes facts, values, principles, and assumptions explicit
- Prioritizes values according to a fair, inclusive process
- Gives stakeholder interests, values, and moral claims a fair hearing
- Consistently applies standards across people and time
- Appropriately engages stakeholders in decision-making
- Involves affected, informed, experienced and neutral individuals and representatives of communities
- Provides information to affected stakeholders in a timely manner and in culturally and linguistically appropriate ways
- Uses the best available scientific evidence
- Monitors and evaluates the process to allow for updating, revision, or correction of procedures in the light of new information, questions, criticisms, et cetera.

The key ethical dimensions for decision-making should also be specified, including:

- Benefits versus harms, costs, and risks of a decision
- Rights, values, interests, and needs of individual communities versus obligation to protect the public good
- Least restrictive measures necessary to protect the public good
- Fair distribution of public health benefits/burdens
- Health equity/protection of vulnerable populations

❑ Social justice

### **Discussion Points**

- Regarding the attributes of an ethical process, Dr. Daniels wondered whether the list should include an explicit item on publicity regarding rationales for decisions that are made.
- Dr. Barrett suggested that the second bullet could include the words “justification for decision-making” in order to make this concept explicit.
- Mr. Thomas Chapel, Chief Evaluation Officer, Office of the Associate Director for Program, CDC, said that an ethical process has two dimensions: ensuring that the decision-making process has ethical attributes, and ensuring that the decision itself is ethical. An ethical process could be inclusive and transparent and could still produce results that are not ethical. Conversely, a conclusion that takes into account social equity and social justice could not have been reached in a manner that was transparent, inclusive, and participatory. A good process will take into account such issues as social justice and balancing benefits and harms. Regarding potential measures, he noted that the public may not be aware of the process, but will see that the decision is ethical.
- Dr. Meslin said that the workgroup’s goal was to create a logic model that could be operationalized and communicated to public health officials in a substantive way.
- Regarding the key ethical dimensions for decision-making, Dr. Daniels asked about the difference between the fair distribution of public health benefits and burdens and the benefits versus harms, costs, and risks of a decision.
- Dr. Meslin confirmed that the difference lies in the emphasis on fair distribution as opposed to the relative weighting of benefits versus harms, costs, and risks. The former is an emphasis on the mechanism, where the latter is a description.
- Dr. Daniels commented that any group of stakeholders will have reasonable disagreement regarding “what counts” as the weighting of the different benefits versus harms, costs, and risks, and about the notion of “less restrictive.”
- Ms. Bernheim said that the workgroup recognized that specification is important and struggled with the categories. In an accreditation setting, each health department could define its own terms. Training could be provided regarding the general concepts.

- Dr. Daniels said that when the categories are suggested, it should be articulated that there is not agreement regarding what they will lead to.
- Mr. Chapel said that the measures of the attributes of an ethical process take these issues into account. Some of the attributes recognize that the key aspects of a process include, for instance, bringing a range of perspectives to the table with the understanding that different stakeholders will weigh issues differently.
- Dr. Meslin asked the Ethics Subcommittee whether any of the key ethical dimensions for decision-making should be eliminated, or whether the list is lacking items.
- Ms. Bernheim commented that fair distribution, health equity, and social justice are somewhat related and wondered whether all three should be listed.
- Dr. Daniels said that social justice is a broad term that can mean different things to different people. The items related to distribution and equity raise specific issues that should be addressed.
- Dr. Meslin said that the workgroup discussed whether “social justice” is implied as part of the other items on the list and whether it is substantive on its own.
- Dr. Goodman said that the item regarding least restrictive measures is the consequence of a decision as opposed to part of the decision-making process.
- Ms. Bernheim said that social justice is an important term because of the constituency of public health who believes strongly that health is part of social justice and that public health has a responsibility to social justice in a larger sense. Social justice includes a range of issues, such as housing. The term can be specified within a given context.
- Dr. Daniels said that if the intention is to reach broader issues of distribution of goods and their impact on health and their intrinsic value, then social justice may not be the appropriate term to use.
- Ms. Bernheim asked whether the dimensions should include only social determinants and pathways to health to capture a public health goal or mission. Standing alone, it is difficult to help people understand how to be accountable for social justice.

- Dr. Daniels suggested that a mention of fair or just distribution of broader determinants of health in a population might be warranted. Such a mention would raise questions of social justice, where the phrase “social justice” alone may not trigger awareness of those concerns.
- Dr. Meslin noted aspirational outcomes. One hope is that the public’s health will be improved in measurable ways as a result of this ethics initiative. Another hope is for a system that is ethically rigorous, socially just, and fair. These outcomes are not identical and not necessarily commensurable. A “win-win” situation would achieve both outcomes. Including “social justice” as a bullet may not serve the concept well. Rather, the concept could be included in the preamble or initial statement regarding the ethical dimensions that are highlighted. All of the bullets can be linked to social justice in some way.
- Ms. Bernheim agreed, noting that “social justice” is the most broad and difficult to operationalize of the listed dimensions. This question also addresses how broadly or narrowly public health itself should be measured.
- Dr. Daniels suggested changing the wording to read, “the just distribution of the broader determinants of health.”
- Dr. Goodman was concerned that distribution is a grand policy matter aimed at society, and the ethics process may not be responsible for it.
- Ms. Bernheim said that public health practice is moving in this direction, working for instance on issues of placement of grocery stores in poor neighborhood.
- Dr. Barrett suggested the phrase, “just distribution of resources that act as determinants of health.”
- Dr. Goodman noted that poverty is a determination of health.
- Dr. Daniels added that poverty is a result of income or wealth distribution, which can be altered through tax policy or other mechanisms, which will affect the levels of poverty in a society.
- Dr. Meslin directed the Ethics Subcommittee’s attention to a column in the Potential Indicators for Program Components focusing on Data Collection/Method/Source. The workgroup discussed the ethics of research design and how some types of data can provide better information than other types. The list is intended to be comprehensive, but not exhaustive.

- Dr. Barrett asked the Ethics Subcommittee to review the Potential Indicators and provide additional comments and additions to her via email to share with the workgroup.

### Update from the Public Health Law Collaboration Workgroup

**Ken Goodman, PhD**  
**Member, Ethics Subcommittee**

**Jeffrey Kahn, PhD, MPH**  
**Member, Ethics Subcommittee**

Dr. Goodman reported on the activities of the Public Health Law Collaboration Workgroup. The workgroup has held a number of conference calls, and one of the recommendations that emerged from their conversations is to broaden collaborations with the Network for Public Health Law and to include members of that organization in educational activities. Ethics Subcommittee members Ruth Gaare Bernheim and Dr. Leslie Wolf will make a presentation at the Public Health Law Conference in October 2012. He asked for suggestions for other collaborations.

The workgroup encourages developing training materials to be used in various settings to make clear the interesting and important issues that lie at the intersection of public health law and ethics. Dr. Wolf and Mr. Matthew Penn of CDC have collaborated on this material. Public health practitioners will benefit from a deeper understanding of what ethics and law are used for, their interrelationships, and what happens when they are in conflict or when one is silent.

The workgroup has also discussed the development of a framework to distinguish legal and ethical issues. Dr. Kahn noted that the discussion regarding evaluation was helpful in thinking about how to create this framework. The framework could clarify what is legally permissible, the range of options available on the basis of ethical principles, and which ethically acceptable option is best in relation to the context and stakeholder values.

Other suggested focus areas for the workgroup include developing cases that highlight the distinction between legal and ethical issues and exploring other areas for collaboration, such as accreditation, cross-sectorial areas, and community engagement.

## **Discussion Points**

- Ms. Bernheim noted that in their conversations with local public health officials, they learned that the officials frequently consult lawyers when they face ethical questions. Dr. Goodman commented that many of the concerns relate to liability.
- Dr. Barrett asked the Ethics Subcommittee whether they supported the list of suggested activities for the Public Health Law Collaboration Workgroup.
- Dr. Daniels said that distinguishing “legal” from “ethical” is an important and difficult endeavor. He observed that ethical concerns have more degrees of freedom than legal constraints. Appeals to lawyers come from risk management concerns, and at times ethics can seem like a framework for risk management as determined by the law. However, the question of what the legal framework should be is also important.
- Ms. Bernheim agreed that the distinction is important. The workgroup has mostly operated in examples in which the law allows an action, such as quarantine, with room for professional discretion and judgment. Ethical considerations are important when implementing the law. The idea of critiquing law or policy has not been addressed.
- Dr. Wolf said that helpful cases focus on when the law allows an action that public health may not want to carry out. This may result in discussion that will lead to the law being changed.
- Ms. Bernheim said that discussions about changing laws are politically charged, and they have not developed the fortification for those deliberations as much as they have for discussing how to utilize professional discretion and to operate within the law. Providing tools to help local and state health officials think through these issues is important.
- Dr. Goodman said that in civil society, the population wants legislators to pass ethically optimized laws. For instance, the law that permits quarantine was passed with the understanding that restricting people’s movement for the greater good is acceptable in the case of the release of a contagion: ethics was the antecedent to the law. Ethics can also be used to critique the law. In Florida, a law was passed forbidding physicians to ask about firearms in households with children. The law has been suspended by a judge who offered ethical arguments as well as arguments about medical professionalism.
- Dr. Kahn agreed that ethics grounds good laws. Laws largely provide boundaries, but there could be occasions in which the laws should be changed.

- Ms. Bernheim noted that accreditation is one of the options for further exploration by the workgroup. Policymaking is one of the essential services of public health, and she wondered whether the tools that the Ethics Subcommittee develops will allow for the development of ethical considerations for policies and laws.
- Dr. Meslin asked whether the workgroup had discussed the notion of what is meant by the law and whether “law” includes the panoply of public policy. Public health activities are impacted by regulations in addition to statutes. He felt that they should discuss their scope and emphasis. For instance, the Supreme Court’s upholding of most of the ACA is a separate issue from how the law will be implemented at the state level, which is a separate issue from how the law will be implemented at the local level and at individual institutions. He suggested that they discuss various components of public health and law and then decide collectively where to place their emphasis. Public health law and public health ethics can be most useful when they focus on implementation rather than on a statute. Law means different things to different people.
- Dr. Goodman said that Dr. Meslin’s point could be incorporated into a number of cases as they examine the different interpretations of law and how they influence, and are influenced by, ethical discussion. He hoped that the Subcommittee would provide ideas for cases to develop.

### Update on Development of Public Health Ethics Tools for State, Tribal, Local and Territorial (STLT) Health Officials

#### **Ruth Gaare Bernheim, JD, MPH Chair, Ethics Subcommittee**

Ms. Bernheim said that a case on community health needs assessment was developed in response to a discussion at the February 2012 meeting of the Ethics Subcommittee. The topic concerns the ACA requirement that tax-exempt hospitals conduct community health needs assessments. The case focuses on a real-world scenario in which a hospital is conducting its community health needs assessment. The public health accreditation process also requires that health departments conduct a community health needs assessment, and NACCHO has suggested a process as well.

In the scenario, a health department has already conducted a community health needs assessment using the Mobilizing for Action through Planning and Partnerships (MAPP) process, which is exhaustive and includes a great deal of stakeholder input. Through this process, the community identified its highest

priorities, which were mental health services, followed by chronic disease services, especially concerning tobacco use and obesity. The hospital participated in the MAPP process and contributed funds to further the obesity and tobacco-related efforts.

The scenario asks how the health department should partner with or contribute to the tax-exempt hospital that has demonstrated that it will provide resources that are not necessarily the community's highest identified need, but that may provide the most remuneration for the hospital. Major discussion questions address the goals of various stakeholders in forming partnerships and considerations for partnering with the hospital to conduct the needs assessment. The case also asks how health departments should work with hospitals to address what the community believes their health needs are, as opposed to the medical needs that the hospital chooses to address.

Dr. Barrett reported that the workgroup has worked with Ethics Subcommittee members and CDC staff to develop training regarding public health ethics and public health law for a variety of settings. The first training will take place at the NACCHO meeting on July 11, 2012. Additional cases have been developed and placed into a format with the background, scenario, discussion questions, and facilitator materials with additional discussion questions, points to consider, and ethical analysis. The training materials will be piloted at NACCHO and will also be used at the National Association of Local Boards of Health (NALBOH) meeting, the Public Health Law Conference, and the American Public Health Association (APHA) meeting. When the materials are complete, they will be available on the CDC website.

### **Discussion Points**

- Dr. Isham noted that not-for-profit hospitals are obligated to demonstrate that they are using their resources for community good. That perspective can be different from the perspective of the community that the public health department serves. The case should reflect the different perspectives of different stakeholders. An institution may choose a priority that aligns with their priorities, but is not highest on the list of public health priorities.
- Ms. Bernheim clarified that the case should emphasize the different perspectives of the stakeholders.
- Dr. Isham felt that this background information would help illuminate the legal constraints and responsibilities of all of the parties. Public health cannot control how hospitals fulfill their obligations under the ACA, but the requirement to conduct a joint needs assessment and to address public needs on the priority list is an important mechanism.

- Ms. Bernheim said that in the era of accountable care organizations and other approaches under ACA, they should take care not to create cases that generate antagonism, but that point toward a future where there is understanding of ethical dimensions that bring different perspectives together.
- Dr. Isham said that the provisions in the ACA bring opportunities to engage stakeholders in allocating resources for public health purposes that also align with their purposes.
- Ms. Bernheim asked for an example of an ethical issue that could highlight understanding of different perspectives of benefits and burdens and even of social justice, especially if a community identifies social determinants as a community need when hospitals are oriented toward downstream approaches.
- Dr. Isham said that healthcare providers do not necessarily see the full range of determinants of health. The ACA is an opportunity to encourage them to think about the other determinants, such as housing.
- Dr. Daniels commented on the ethical issue of the visibility of the need. People who work in healthcare deal with people who are visibly in need; people who work to prevent health conditions from arising, such as public health practitioners, are not dealing with issues that are identifiable or visible in the same way. This fundamental gap leads to differences in the demand for services, the willingness to pay for them, and a situation in which much of healthcare is viewed as more important than public health. This scenario addresses whether there is a way to connect the role of the hospital to concerns regarding prevention. Further, if health conditions are prevented, then hospitals do not have revenue sources. This issue was raised by the dental profession when fluoridation of water emerged and changed the prevalence of dental caries in the population. Dentists had to shift their professional focus to prevention. Lessons from that experience could inform this discussion.
- Ms. Bernheim asked Dr. Isham to work with the workgroup. Dr. Isham added that Ms. Sara Rosenbaum, Ethics Subcommittee member, could also provide valuable input.
- Dr. Ortmann asked about the extent to which the public health department takes the lead in a community health assessment. He also asked about potential concerns if a community identifies priorities that are not in line with the science.
- Dr. Isham said that such a scenario is a concern.

- Dr. Barrett said that new Ethics Subcommittee members Dr. Alan Melnick and Dr. Matthew Stefanak would be invited to join this workgroup.

**Request for Future Ethics Subcommittee Input on CDC's Standard Operating Procedures Relating to use of Travel Restrictions for the Control of Communicable Diseases**

**Clive Brown, MD, MPH**  
**Associate Director for Science**  
**Division of Global Migration and Quarantine**  
**National Center for Emerging and Zoonotic Infectious Diseases**  
**Centers for Disease Control and Prevention**

Dr. Clive Brown presented the Ethics Subcommittee with ideas from the Division of Global Migration and Quarantine (DGMQ) regarding making changes to current travel restriction criteria.

The Quarantine Branch within DGMQ has the authority to restrict travel as part of the Aviation and Transport Security Act. The branch works with the Department of Homeland Security (DHS) regarding the Do Not Board list, or the "Lookout Record." The branch determines when individuals are placed on the list, but the tool is owned by DHS.

In order to be placed on the list, individuals must meet three criteria:

- They are infectious
- They are non-adherent to treatment or unaware of their diagnosis
- They have expressed intention or strong motivation to travel

The only criterion for an individual to be removed from the list is for the person to become non-infectious. Some persons will not voluntarily complete treatment after they are removed from the list and will therefore become infectious again. In working with the travel restrictions, the branch must balance individual rights, using the least restrictive means, and protecting the public. Three case scenarios address these issues.

In the first scenario, an elderly male U.S. citizen is diagnosed with active tuberculosis (TB). He lives in the U.S.-Mexico border region and has been non-compliant with treatment. He has indicated plans to travel. He is therefore placed on the Do Not Board list. Customs locates him at a port of entry at the border, and he is placed in isolation and treatment for three months. After he becomes non-infectious, per the DGMQ criteria, he is removed from the Do Not Board list. One month later, he leaves the hospital and cannot be located for six

months. He is placed on the list again and found at the border again, and returned to treatment. He is sentenced to 180 days in detention to complete treatment. Dr. Brown noted that these situations are handled differently in different states and in different counties.

In the second scenario, a male U.S. citizen is hospitalized for a cough and diagnosed with TB. He leaves the hospital against medical advice. He is found and placed on home isolation. His treatment is intermittent, and he subsequently develops multi-drug resistant TB (MDR-TB). He misses numerous clinical and treatment appointments and is found to be non-compliant. He expresses an intent to travel, so he is placed on the Do Not Board list. He is placed on home isolation with electronic monitoring and becomes compliant. He is removed from the list after five months of treatment, when he becomes non-infectious. Over the next few months, his treatment again becomes erratic and intermittent, partially because of his reactions to drugs and partially because he refuses to comply with therapy. In the scenario, he again disappears and indicates an intent to travel. Based on his incomplete treatment, he is placed on the Do Not Board list, but there was a great deal of internal debate at DGMQ. At some stage, the patient will become infectious, but DGMQ did not know when. There was great concern because of his MDR-TB. Based on the criteria, he would not be placed on the list before he missed one month of therapy; however, some parties within CDC and at other agencies felt that he should be placed on the list earlier.

The third scenario is a composite of many different cases. In this scenario, an individual with active TB has a complicated social situation that is characterized by a lack of stable housing and longstanding alcohol and drug use. He lives in the U.S.-Mexico border region and frequently travels between the two countries. It is predicted that he will be noncompliant to treatment and the request not to travel, so it is requested that he be placed on the Do Not Board list. The request is refused because he has not indicated that he will travel and because his location is known. He subsequently disappears and becomes noncompliant, at which time he is placed on the Do Not Board list.

Even if individuals are current and non-infectious, there are often indications that they may disappear or become noncompliant in the future. DGMQ would like to propose changes to the Do Not Board algorithm that would allow them to place persons on the list once they have already been on it. One suggested change is that if a non-adherent individual is taken off the list and then put back on the list when they become non-adherent again, that individual would not automatically be removed from the list when he or she becomes non-infectious. Rather, DGMQ will work with their TB partners and state and local health departments to treat the individual to a certain point before removal from the list. If a person is incarcerated, then there is no need to place him or her on the list, but in other situations, the person may need to remain on the list. Another suggested change is that if an individual has MDR-TB, is not adherent and is on the list and then

taken off the list, and then becomes non-compliant and cannot be found, DGMQ should place that person back on the list within a one-month timeframe. MDR-TB is a dangerous condition. Individuals with MDR-TB who are not receiving constant therapy could develop extremely drug-resistant TB (XDR-TB). The third suggested change addresses situations in which there is a history or evidence of noncompliance. In these cases, future noncompliance with treatment can be predicted. On a case-by-case basis and in consultation with partners, DGMQ would like to put those persons preemptively on a Do Not Board list.

### **Discussion Points**

- Dr. Barrett said that the Ethics Subcommittee's Travel Restrictions Workgroup has served as a forum for discussing such issues. She suggested that the workgroup address the issues presented by Dr. Brown and noted that additional Ethics Subcommittee members were needed to join the group. Currently, Subcommittee members Dr. Jennifer Prah Ruger and Dr. Leslie Wolf serve on the workgroup, and Dr. Wolf is retiring from the Ethics Subcommittee. Former Ethics Subcommittee members Dr. Robert Levine and Dr. Kathy Kinlaw serve as external consultants to the workgroup. At least two Ethics Subcommittee members are needed to participate on the workgroup. She said that she would approach the new Ethics Subcommittee members and suggest that they join the workgroup.

### **Public Comment**

No public comments were offered during this meeting.

### **Wrap-Up and Review of Next Steps**

Dr. Barrett noted next steps for the Ethics Subcommittee:

- Even though Dr. Pamela Sankar is retiring from the Ethics Subcommittee, the Evaluation Workgroup still has sufficient representation from the Subcommittee to continue its work. However, she invited interested Subcommittee members to join the workgroup.
- The Evaluation Workgroup is charged with addressing next steps regarding the development of standards related to ethics in public health accreditation.

- ❑ The Evaluation Workgroup will also address how better to define the social justice issue. Ethics Subcommittee members should forward additional comments regarding the evaluation indicators to Dr. Barrett.
- ❑ Regarding public health law and public health ethics, a broader discussion is needed on what is meant by “the law.” The Ethics Subcommittee was in general agreement regarding the approach, and the workgroup will further develop the framework and cases.
- ❑ Dr. Isham and Ms. Sara Rosenbaum, Ethics Subcommittee members, are asked to provide input on how to better describe the perspectives and values of the different stakeholders in the community health needs assessment case, as well as the legal obligations of the different parties.
- ❑ At least one Ethics Subcommittee member will be added to the Travel Restriction Workgroup, and the group will consider revisions to the standard operating procedure for when people are taken off, or placed on, the Do Not Board list.

### **Discussion Points**

- Dr. Nancy Kass, Dr. Pamela Sankar, Dr. Leslie Wolf, and Dr. Norman Daniels, retiring Ethics Subcommittee members, expressed their gratitude for participating on the Subcommittee. Dr. Barrett was particularly thanked for her leadership and facilitation.
- Dr. Barrett thanked the retiring Ethics Subcommittee members and said that certificates of appreciation would be mailed to them. She also expressed gratitude to the meeting participants for their flexibility in meeting via conference call. She asked for input regarding the meeting format, which customarily takes place over the afternoon of one day and the morning of the next.
- Dr. Meslin and Ms. Bernheim expressed a preference for holding the meeting all in one day. Ms. Bernheim suggested that if they meet in one day, they could have an informal group dinner the night before the meeting, taking advantage of social interaction, and meet early the next day.
- Dr. Barrett agreed that a social event the night before the Ethics Subcommittee meeting would be possible, and she indicated that they would likely hold the October meeting on one day rather than two.

With no additional comments or issues raised, the meeting officially adjourned at 12:31 pm, EDT.

## Certification

I hereby certify that to the best of my knowledge, the foregoing minutes of the June 29, 2012 Ethics Subcommittee meeting are accurate and complete.

Date: 8/20/12

Ruth Gaare Bernheim, JD, MPH  
Ethics Subcommittee Chair

**Attachment #1: Meeting Attendance**

June 29, 2012

9:30 am – 12:30 pm Eastern Daylight Savings Time

**Meeting Participants:****Ethics Subcommittee, Advisory Committee to the Director**

Ruth Gaare Bernheim, University of Virginia  
LaVera Marguerite Crawley, Stanford University  
Norman Daniels, Harvard University  
Kenneth Goodman, University of Miami  
George Isham, HealthPartners, ACD Representative  
Jeff Kahn, University of Minnesota  
Eric Meslin, Indiana University  
Jennifer Ruger, Yale University  
Pamela Sankar, University of Pennsylvania  
Leslie Wolf, Georgia State University

**Centers for Disease Control and Prevention**

Drue Barrett (Designated Federal Officer, Ethics Subcommittee)  
Michele Bohm  
Clive Brown  
Cynthia Cassell  
Nicole Cohen  
Catina Conner  
Sandra DeShields  
Laurie Dieterich  
Barbara Ellis  
Sonja Hutchins  
Lindsay Kramer  
Jennifer Legardy-Williams  
Leonard Ortmann  
Joan Redmond Leonard  
William Sexson  
Craig Thomas  
Mark Toraason  
David Williamson

**Members of the Public**

Kaye Bender, Public Health Accreditation Board

## Attachment #2: Meeting Agenda

### Meeting of the Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention (CDC)

**Friday, June 29, 2012**

**9:30 am – 12:30 pm Eastern Daylight Savings Time**

**Call-in Information: 1-877-928-1204, Pass Code 4305992#**

#### Meeting Agenda

- |               |   |
|---------------|---|
| 9:30 – 9:40   | <p><b>Introductory Remarks and Overview of Meeting Goals</b> – Ruth Gaare Bernheim, JD, MPH, Chair, Ethics Subcommittee</p> <ul style="list-style-type: none"> <li>• Welcome and introductions</li> <li>• Ethics Subcommittee members declaration regarding conflicts of interest</li> <li>• Recognition of retiring Ethics Subcommittee members</li> <li>• Overview of meeting goals             <ul style="list-style-type: none"> <li>○ Provide an overview of the public health department accreditation process and the role of the Public Health Accreditation Board, and discuss the possible role of the Ethics Subcommittee in developing ethics standards</li> <li>○ Provide updates on the work of the Evaluation and Public Health Law Collaboration Workgroups and the development of public health ethics tools for public health officials</li> <li>○ Provide information regarding the future need for input on ethical considerations relating to use of travel restrictions for the control communicable diseases.</li> </ul> </li> </ul> |
| 9:40 – 10:45  | <p><b>Addition of Ethics Standards to the Process of Accreditation of Public Health Departments</b></p> <ul style="list-style-type: none"> <li>• Overview of the Public Health Accreditation Board Process – Kaye Bender, PhD, RN, FAAN, President and Chief Executive Officer, Public Health Accreditation Board</li> <li>• Discussion of Ethics Subcommittee role in proposing ethics standards for the accreditation process</li> </ul>  |
| 10:45 – 11:15 | <p><b>Update from the Evaluation Workgroup</b> – Eric Meslin, PhD, Jennifer Ruger, PhD, and Pamela Sankar, PhD, Ethics Subcommittee Members</p>   |
| 11:15 – 11:45 | <p><b>Update from the Public Health Law Collaboration Workgroup</b> – Ken Goodman, PhD and Jeff Kahn, PhD, MPH, Ethics Subcommittee Members</p>   |
| 11:45 – 12:00 | <p><b>Update on Development of Public Health Ethics Tools for State, Tribal, Local, and Territorial (STLT) Health Officials</b> – Ruth Gaare Bernheim, JD, MPH</p> <ul style="list-style-type: none"> <li>• Development of case on community health needs assessment</li> <li>• New members for the Case Development Workgroup</li> <li>• NACCHO Training</li> </ul>  |
| 12:00 – 12:15 | <p><b>Request for Future Ethics Subcommittee Input on CDC's Standard Operating Procedures Relating to use of Travel Restrictions for the Control of Communicable Diseases</b><br/>- Clive Brown, MD, Associate Director for Science, Division of Global Migration and Quarantine, NCEZID, CDC</p>   |
| 12:15 – 12:25 | Public Comment  |
| 12:25 – 12:30 | Wrap up and Review of Next Steps  |
| 12:30         | Adjourn   |