



Community Engagement in *Ethics and Ebola: Public Health Planning and Response*

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I. Introduction

In [*Ethics and Ebola: Public Health Planning and Response*](#) (*Ethics and Ebola*), the Presidential Commission for the Study of Bioethical Issues (Bioethics Commission) focused on ethical challenges raised by the 2014-2015 Ebola epidemic in western Africa.¹ In this report, the Bioethics Commission addressed the pressing need to improve key elements of U.S. planning and response capabilities for future public health emergencies including leadership, transparency, and explicit ethics integration at all levels of public health decision making. A range of different and sometimes conflicting values can complicate decision making in a pluralistic society and therefore several approaches to community engagement should be considered, depending on whether we are in the midst of a public health emergency or planning for the next one.

¹ Presidential Commission for the Study of Bioethical Issues (PCSB). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI.



II. Learning Objectives

Students should be able to:

1. Discuss the importance of community engagement as it relates to public health emergency planning and response efforts.
2. Identify ways in which community engagement can facilitate ethical public health planning and response.
3. Consider different ways to engage communities in public health decision making both domestically and internationally.

III. Background

Community engagement has been defined as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people.”² Community engagement in the context of public health emergencies is important for both domestic and international policy making. The 2014-2015 Ebola epidemic in western Africa and subsequent public health response demonstrate how rationales premised solely on prudential health security grounds might fail to address human suffering that cannot be directly connected to national interests. Likewise, public health action justified on purely humanitarian or ethical grounds might fail to garner sufficient political and public support. As a process of reaching consensus for decision making, democratic deliberation is well-suited to public health emergency preparedness because it fosters public-spirited conversation and generates decisions that can be revisited in light of new information and engagement with specific affected communities.

The Bioethics Commission’s recommendations in *Ethics and Ebola* are framed around ethical principles, including the principle of democratic deliberation, described in the overview:

A process of democratic deliberation includes providing justifications for actions grounded in mutually acceptable reasons for pursuing specific courses of action, facilitates policy making that can incorporate multiple justifications for engagement...A deliberative democratic approach based

² Clinical and Translational Science Awards Consortium and Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. (2011). *Principles of Community Engagement*, Second Edition. (NIH Publication No. 11-7782). Bethesda, MD: National Institutes of Health (NIH), p. 7. Retrieved from <http://www.atsdr.cdc.gov/communityengagement/>.



on best available scientific evidence suggests that stakeholders economize on moral disagreement and seek complementary or convergent approaches when possible.³

Inclusive and respectful practices are important aspects of community engagement, as reflected in four of the Bioethics Commission's recommendations in *Ethics and Ebola*.

In Recommendation 2, the Bioethics Commission articulated the importance of engagement in strengthening domestic and international public health capacities.

Recommendation 2

The United States should strengthen key elements of its domestic and global health emergency response capabilities. These include (1) strengthening the capacity of the World Health Organization to respond to global health emergencies through provision of increased funding and collaboration with other international, national, and nongovernmental public health organizations.⁴

As part of its analysis leading to this second recommendation, the Bioethics Commission observed how the Ebola epidemic highlighted strengths and weaknesses in U.S. federal public health governance and infrastructure. U.S. federal public health agencies as well as state and local health departments have faced declining funding. In addition, bureaucratic and organizational challenges to coordinated public health emergency preparedness have affected responsiveness, both domestically and globally.⁵ Engagement with global partners can bolster existing public health infrastructure necessary for preparation and response. In addition to local, state, federal and international stakeholders, philanthropic and other nongovernmental organizations play important complementary roles in global health. Nevertheless, non-governmental agencies cannot replace government-led public health efforts.

The Bioethics Commission's third recommendation highlights the importance of communication and the role of community engagement in effective public health communication.

³ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, p. 8.

⁴ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, p. 17.

⁵ Lakoff, A. (2010). Two regimes of global health. *Humanity: An International Journal of Human Rights, Humanitarianism, and Development*, 1(1), 59-79.



Recommendation 3

Public officials have a responsibility to support public education and communication regarding the nature and justification of public health responses. Communication efforts should serve the following three interrelated purposes: (1) provide the public with useful, clear, accessible, and accurate information about the response, including what is known about what communities and individuals can do to protect their health; (2) provide those most directly affected by public health policies and programs with an appreciation of the values reflected in, and reasoning behind, their implementation; and (3) mitigate stigmatization and discrimination associated with many public health emergencies.⁶

To implement this recommendation, the Bioethics Commission acknowledged public health communication specialists have long recognized that communication cannot be unidirectional, nor should “the public” or “the community” be considered a homogenous entity.⁷ The importance of engaging stakeholders as active and respected partners in communication, as well as building on ongoing relationships with trusted community members, has been repeatedly demonstrated.^{8,9}

In Recommendation 6, the Bioethics Commission focused on how community engagement can be incorporated into public health clinical research during emergency response:

Recommendation 6

Research during the Ebola epidemic should provide all participants with the best supportive care sustainably available in the community in which the research is conducted. Trial designs should be methodologically rigorous and capable of generating results that are

⁶ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, p. 19.

⁷ Glik, D.C. (2007). Risk communication for public health emergencies. *Annual Review of Public Health*, 28,

33-54; MacQueen, K.M., et al. (2001). What is community? An evidence-based definition for participatory public health. *American Journal of Public Health*, 91(12), 1929-1938.

⁸ Covello, V.T. (2003). Best practices in public health risk and crisis communication. *Journal of Health Communication*, 8(S1), 5-8; Gayle, H.D., President and CEO, CARE USA. (2015). Public Health Perspectives on the Current Ebola Epidemic in Western Africa. Presentation to the Bioethics Commission, February 5. Retrieved February 18, 2015 from <http://bioethics.gov/node/4591>.

⁹ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, pp. 18-19.



clearly interpretable, acceptable to the host communities and, to the extent possible, minimize delays to completing the research. Properly designed placebo-controlled trials can meet these conditions, and innovative designs, such as adaptive randomization, ought to be considered as a means of addressing these research goals. Research teams should actively engage with affected communities while planning research to determine the trial design that best reflects these ethical and scientific requirements.¹⁰

The Bioethics Commission’s analysis of such public health clinical research states:

For the long-term benefit of communities likely to be affected by Ebola epidemics in the future, reliable and accurate scientific data about the effectiveness of vaccines and treatments for Ebola is critical; alongside other principal areas of research, such as factors associated with survival, disease natural history, the most effective way to deliver care from a cultural perspective, and the long-term impact of the disease on survivors and communities. Without such evidence, these and other communities might be deprived of lifesaving interventions in the next Ebola epidemic, or be economically harmed by using scarce health care resources for interventions that are ineffective against the disease.¹¹

Lastly, the Bioethics Commission addressed community engagement in the sharing of biospecimens for research:

Recommendation 7

The U.S. government should ensure that Ebola virus related biospecimens are obtained ethically, including addressing the challenges of obtaining informed consent during a public health emergency and ensuring adequate privacy protections. The U.S. government should also, in collaboration with partners, facilitate access to the benefits that result from related research to the broadest group of persons possible. This can be achieved by engaging in dialogue with global partners and working collaboratively with local scientists whenever possible to develop effective strategies for

¹⁰ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, p. 42.

¹¹ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, pp. 41-42.



ensuring equitable distribution of the benefits of research both in the United States and abroad.¹²

The Bioethics Commission considered engagement with local scientists and communities a crucial element of international biospecimen sharing. Collection, use, and international sharing of biospecimens requires that researchers and other stakeholders be ethically attuned to the challenges of collecting biospecimens during a public health emergency and ensure equitable access to the benefits that result from research using those shared biospecimens. Sharing and storing biospecimens and associated data raises concerns about the privacy of those who donate samples. In addition, reciprocity and humanitarian justifications encourage ensuring access to the benefits of research to all who contribute, and justice compels the equitable sharing of research results. Involving local researchers and community members from the early stages of research also can strengthen research design by accounting for local attributes that could help shape the research question to more directly address the needs of the community.

The Bioethics Commission considered how ethics review committees should familiarize themselves with the concerns distinct to the locality from which the samples and data are collected and, whenever possible, seek local parallel review and approval. Attending to local concerns might include community members who can articulate concerns or priorities, express reservations about the research, or identify vulnerable populations (groups in which the individuals are unable to protect fully their own interests) that might not be readily discerned by researchers. Such engagement also can identify potential implications or consequences of the research not yet foreseen. If a research location lacks an established ethics review committee structure, foreign researchers and funders alike should carefully consider additional steps to protect participants.¹³ Neutral third-party ethics review bodies, perhaps through WHO or another group, could help with pre-review or could monitor research while local capacity improves.¹⁴

The Bioethics Commission acknowledged that ensuring access to the benefits that accrue from research using shared biospecimens is not easy. Their analysis indicated that U.S. government should play a leading role in establishing best practices for sharing the benefits of research through international, agency, and private agreements. Collaboration efforts should engage various stakeholders, including but not limited to the communities

¹² Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, p. 50.

¹³ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2011, September). *Research Across Borders: Proceedings of the International Research Panel of the Presidential Commission for the Study of Bioethical Issues*. Washington, DC: PCSBI, p. 10.

¹⁴ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2011, September). *Research Across Borders: Proceedings of the International Research Panel of the Presidential Commission for the Study of Bioethical Issues*. Washington, DC: PCSBI, p. 10.



that ought to benefit, geographic communities affected by the current epidemic or likely to be affected in future outbreaks, local scientists conducting research on the ground, health care personnel likely to be exposed in future epidemics, and the individuals who contributed biospecimens.^{15,16}

IV. Reading

For the purposes of discussion, students should download and read the following Bioethics Commission materials (reports can be found on the Bioethics Commission’s website at www.bioethics.gov under “Projects”):

Ethics and Ebola: Public Health Planning and Response, pp. 8-15 (“Proactive Democratic Deliberation and Education,” “The Current Ebola Epidemic,” and “Ebola in the United States”).

Ethics and Ebola, pp. 16-20 (“Ethical and Prudential Justifications for U.S. Engagement in Global Health Emergencies: Analysis and Recommendations”).

Ethics and Ebola, pp. 37-43 (“Research Ethics During Public Health Emergencies: Analysis and Recommendation”).

Ethics and Ebola, pp. 49-51 (“Collection, Use, and International Sharing of Biospecimens for Research: Analysis and Recommendation”).

V. Discussion Questions

The following questions are based on the information provided above and in the indicated reading. They are intended to reinforce important aspects of community engagement that are highlighted in the Bioethics Commission’s *Ethics and Ebola* report. Important points are noted with each question to help the instructor guide a group discussion. The “Additional Resources” section will be helpful in answering these questions.

- 1. Engaging the affected community in public health decisions can be particularly challenging in the midst of or in the immediate aftermath of an emergency. What is distinct about public health emergencies that makes this the case?**

¹⁵ Calain, P., et al. (2009). Research ethics and international epidemic response: The case of Ebola and Marburg hemorrhagic fevers. *Public Health Ethics*, 2(1), 7-29.

¹⁶ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, pp. 49-51.



Starting points for discussion:

- a. *Unpredictability*: Challenges might result from rapidly changing circumstances and information, uncertainty, and urgency.
 - b. *Agility*: In the context of an emergency, policies are implemented and might be revised based on new information or their impact on affected communities. At such times, community engagement and transparency are especially important for instilling public trust.
 - c. *Democratic deliberative processes*: Acknowledging the tension between principal values, such as freedom and health, can facilitate community engagement by fostering consensus building and highly collaborative partnerships between civic groups and public health organizations.
 - d. *Historical context*: Although the public health response and best method of community engagement will vary during different outbreaks, the lessons from previous successes and failures should always guide open and transparent public engagement during subsequent epidemics.
- 2. What are potential challenges to international collaboration during an emergency? What are the potential benefits that could accrue from such collaborations domestically or globally?**

Starting points for discussion:

- a. *Domestic challenge*: U.S. federal public health agencies and state and local health departments have experienced declining funding, and collaborative efforts confront bureaucratic and organizational hurdles.
- b. *Benefits to domestic responsiveness*: Strengthening local and regional public health infrastructure to address ongoing public health problems can serve to mitigate conditions that make public health emergencies more likely and, when they do occur, less likely to have devastating long-term health and societal implications.¹⁷

¹⁷ Gayle, H.D., President and CEO, CARE USA. (2015). Public Health Perspectives on the Current Ebola Epidemic in Western Africa. Presentation to the Bioethics Commission, February 5. Retrieved February 18, 2015 from <http://bioethics.gov/node/4591>; Bah, C., Youth Engagement Officer, A World at School; Chair, Youth Advocacy Group, Global Education First Initiative. (2015). How U.S. Public Attitudes and Policies Intended to Prevent Ebola in the United States Impact Affected Communities. Presentation to the Bioethics Commission, February 5. Retrieved February 18, 2015 from <http://bioethics.gov/node/4592>; Henwood, P.C., Director of Global Health Initiatives, Department of Emergency Medicine; Assistant Professor, Perelman School of Medicine, University of Pennsylvania. (2015). How U.S. Public Attitudes and Policies



- c. *Global challenge:* The World Health Organization (WHO) is underfunded and its effectiveness is hampered by politicization and an unwieldy organizational structure and bureaucracy—vulnerabilities underscored by the 2014-2015 Ebola epidemic in western Africa.¹⁸
- d. *Benefits to global responsiveness:* As a key international public health organization, WHO could become well-positioned to provide both strong global coordination and direct on-the-ground support before, during, and after public health emergencies.

3. Promoting community engagement requires that information about public health emergencies and various viewpoints be shared during deliberation. What common characteristics of public discourse might hinder effective communication and policy making during public health emergencies? How might participating individuals overcome these challenges?

- a. *Example challenge:* There can be many obstacles to clear communication during public health emergencies. During a global crisis, key actors might lack the vocabulary and tools to understand cultural differences. Local communities might be suspicious of outsiders' motivations to help. Effectively communicating public health risks also must involve psychologically and socially mediated understandings of the magnitude, likelihood, and importance of hazards to human health or safety.¹⁹

Intended to Prevent Ebola in the United States Impact Affected Communities. Presentation to the Bioethics Commission, February 5. Retrieved February 18, 2015 from <http://bioethics.gov/node/4592>;

¹⁸ Fink, S. (2014, September 3). Cuts at W.H.O. hurt response to Ebola crisis. *New York Times*. Retrieved February 11, 2015 from http://www.nytimes.com/2014/09/04/world/africa/cuts-at-who-hurt-response-to-ebolacrisis.html?_r=0;

Gostin, L.O., and E.A. Mok. (2009). Appendix E: Commissioned Paper. Global Health Governance Report. In *The U.S. Commitment to Global Health: Recommendations for the Public and Private Sectors* (pp. 203-246). Washington, DC: National Academies Press.; Lancet. (2014). WHO AFRO: In need of new

leadership. *Lancet*, 384(9954), 1550; Oxfam. (2015). Improving International Governance for Global Health

Emergencies: Lessons from the Ebola Crisis. Retrieved February 17, 2015 from <http://www.oxfam.org/sites/>

www.oxfam.org/files/attachments/dp-governance-global-health-emergencies-ebola-280115-en.pdf.

¹⁹ Bradbury, J.A. (1989). The policy implications of differing concepts of risk. *Science, Technology, & Human*

Values, 14(4), 380-399; Moussaïd, M. (2013). Opinion formation and the collective dynamics of risk perception.

PLoS ONE, 8(12), e84592; Petersen, A., and D. Lupton. (1996). *The New Public Health: Health and Self in the*

Age of Risk. Thousand Oaks, CA: Sage Publications.



Example resolution: Public health communication should be an integral part of public health responsiveness—not an additional step taken after responses are identified and implemented. Communication efforts can be deeply connected to community acceptance and uptake of public health policies.

- b. *Example challenge:* As has been long recognized among public health communications specialists, communication cannot be unidirectional, nor should the community be considered a homogenous entity.

Example resolution: Researchers have shown the importance of engaging community members as active and respected partners in communication, as well as building ongoing relationships with trusted community members.²⁰ Public health messages can play an important role in anticipating and countering the tendency to stigmatize those most affected by or associated with a disease or an epidemic.

4. In Recommendation 6 of *Ethics & Ebola*, the Bioethics Commission noted the importance of community engagement to determine the clinical trial design that best fits both ethical and scientific requirements. How might researchers best engage affected communities to promote related dialogue?

Starting points for discussion:

- a. Research should be conducted to better understand the course of the disease, providing the best supportive care available in the host communities, and building public health and health care infrastructure.
- b. In the short term, patient access to evidence-based supportive care and stable health care infrastructure is imperative. For the long-term benefit of communities likely to be affected in the future, reliable and accurate scientific data about the effectiveness of vaccines and treatments is critical. Ethical public health emergency research also should consider how communities can help identify and address the different ethical variables of short- and long-term goals.

²⁰ Covello, V.T. (2003). Best practices in public health risk and crisis communication. *Journal of Health Communication*, 8(S1), 5-8; Gayle, H.D., President and CEO, CARE USA. (2015). Public Health Perspectives on the Current Ebola Epidemic in Western Africa. Presentation to the Bioethics Commission, February 5. Retrieved February 18, 2015 from <http://bioethics.gov/node/4591>.



5. What ethical concerns might arise when researchers engage with communities that employ substantially different ethical frameworks regarding the sharing of biospecimens and data?

Starting points for discussion:

- a. Sharing and storing biospecimens and associated data can raise concerns about the privacy of those who provide samples.
- b. Reciprocity and humanitarian justifications encourage ensuring access to the benefits of research for individuals or communities that provide samples.
- c. A concern for equitable sharing of research benefits might reflect beliefs about global justice.

VI. Problem-Based Learning

Scenario A.

In 2008, deliberative democratic processes were employed in Adelaide, Australia as a form of community engagement regarding pandemic planning for influenza. Participants deliberated in independent small groups and as a large group. School children were included in the process because they are affected differently by restrictive measures and often selected as target populations for influenza containment due to the strategic value of school closings. Public health experts and policymakers developed materials that provided important information for participants. Community views were elicited with the assistance of independent facilitators. Deliberative fora concluded with a citizen “verdict” and participants later participated in a post-forum evaluation process. One forum considered the ethics of allocation of scarce resources while another studied the ethical aspects of quarantine and social distancing measures.

Below is an article that provides brief summary of the project. You can read more about including the public in pandemic planning and community engagement here:

Braunack-Mayer, et al. (2010). Including the public in pandemic planning: A deliberative approach. *BMC Public Health*, 10, 1-9.



1. How can community engagement through deliberative democratic processes anticipate and address ethical dimensions of public health emergency planning and response?

Starting points for discussion:

- a. Democratic deliberation processes include providing justifications for actions grounded in mutually acceptable reasons for pursuing specific courses of action. Democratic deliberation facilitates policy making that incorporates multiple justifications for engagement. Participants tend to economize on moral disagreement and seek complementary or convergent approaches when possible.
- b. Processes that employ democratic deliberation can help anticipate policy decisions that might generate future agreement and disagreement. By eliciting the views of the community such processes generate public debate and facilitate policy making before controversies arise.
- c. Community perspectives ascertained through deliberative processes can yield policy that is responsive to community concerns and reflective of democratic values.

2. How can deliberative democratic processes inform public health emergency plans concerning the use of restrictive measures or social distancing?

Starting points for discussion:

- a. By employing fair and respectful discussions that encourage providing reasonable grounds for justifying a decision, informed deliberation can foster the perceived legitimacy of the decisions that result.²¹
- b. By eliciting feedback and input from the public regarding concerns and potential risks, deliberation can help address these concerns.
- c. By understanding that community members' support of restrictive measures can be influenced by their perception of risks, deliberation can

²¹ Presidential Commission for the Study of Bioethical Issues (PCSBI). (2015, February). *Ethics and Ebola: Public Health Planning and Response*. Washington, DC: PCSBI, p. 8.



address these perceptions and help shape a more accurate conception of risks.²²

3. According to the authors of the article, what implications do their findings have for policymakers?

Starting points for discussion:

- a. Community members can articulate beliefs and values, which can have an important influence on the public health response strategies employed.
- b. Research findings reflect possible responses to the government's use of restrictive measures to limit the liberties of some for the protection of others, such as quarantine and social distancing measures.²³ These findings, and the responses to these findings, can influence policymakers' actions during subsequent public health crises.
- c. Early engagement with the public about ethical dimensions of pandemic planning might increase the legitimacy and acceptability of policies informed by the process.²⁴

Scenario B.

In the early 2000s Indonesia was affected at the beginning of the H5N1 pandemic. The country's virus samples were considered particularly valuable in tracking the global evolution of the virus and developing pharmacological treatments.²⁵ The Indonesian government learned that the virus samples they shared were being used by pharmaceutical companies to develop new vaccines to be sold at commercial rates that the Indonesian government believed it could not afford.²⁶ The Indonesian government responded by ceasing to share its H5N1 virus samples unless it could be assured of direct

²² Braunack-Mayer, et al. (2010). Including the public in pandemic planning: A deliberative approach. *BMC Public Health*, 10, 6.

²³ Braunack-Mayer, et al. (2010). Including the public in pandemic planning: A deliberative approach. *BMC Public Health*, 10, 9.

²⁴ Braunack-Mayer, et al. (2010). Including the public in pandemic planning: A deliberative approach. *BMC Public Health*, 10, 1-9.

²⁵ Elbe, S. (2010). Hagglng over viruses: The downside risks of securitizing infectious disease. *Health Policy and Planning*, 25(6), 476-485.

²⁶ Elbe, S. (2010). Hagglng over viruses: The downside risks of securitizing infectious disease. *Health Policy and Planning*, 25(6), 476-485



access to the benefits.²⁷ In March 2007, WHO and the Minister of Health of Indonesia jointly announced resumed biospecimen sharing after a high level technical meeting on responsible practices for sharing avian influenza viruses and resulting benefits.²⁸

Additional Reading

Ethics and Ebola: Public Health Planning and Response, pp. 43-49
("Collection, Use, and International Sharing of Biospecimens for
Research: Introduction and Background, Ethical and Practical
Challenges").

1. What are the benefits of collecting and sharing biospecimens? How should these benefits be distributed?

Starting points for discussion:

- a. Collecting and sharing biospecimens can facilitate development of and access to treatments for infectious diseases.
- b. Collection and sharing of biospecimens and related data can help advance research into potential therapeutic interventions (e.g., curative drugs and vaccines), benefiting persons who might be affected by disease in the current outbreak or during future epidemics.²⁹

²⁷ Elbe, S. (2010). Haggling over viruses: The downside risks of securitizing infectious disease. *Health Policy and Planning*, 25(6), 476-485; Fidler, D.P. (2008). Influenza virus samples, international law, and global health diplomacy. *Emerging Infectious Diseases*, 14(1), 88-94. The Indonesian government's position was based, in part, on Article 15 of the Convention on Biological Diversity, which affirms the sovereign right of nations to the genetic resources within their territories and fair and equitable access to benefits arising out of research and commercial use from these resources. Zhang, X. (2010). Attitudes towards transfers of human tissue samples across borders: An international survey of researchers and policy makers in five countries. *BMC Medical Ethics*, 11, 16.

²⁸ WHO. 2007, March 27. Indonesia to resume sharing H5N1 avian influenza virus samples following a WHO meeting in Jakarta. Retrieved September 25, 2015 from <http://www.who.int/mediacentre/news/releases/2007/pr09/en/>.

²⁹ Steenhuisen, J. (2014, November 5). U.S. Ebola researchers plead for access to virus samples. Reuters. Retrieved February 10, 2015 from <http://news.yahoo.com/exclusive-u-ebola-researchers-plead-access-virus-samples-120335606--finance.html>.



- c. Sharing biospecimen data, especially viral sequences, raises concerns about equitable benefit sharing. Reciprocity and justice suggest that those who provide the biological samples used in research should have access to the benefits that result from that research.
- d. The U.S. government should play a leading role in establishing best practices for sharing the benefits of research through international, agency, and private agreements. It should collaborate with the communities that ought to benefit, or are likely to be affected in future outbreaks; local scientists conducting research on the ground; health care personnel likely to be exposed in future epidemics; and the individuals who contribute biospecimens.³⁰

2. What are some ethical and practical challenges to collecting and sharing biospecimens illustrated by the case of Indonesia biospecimen sharing during the H5N1 epidemic? How would engagement help address these challenges?

Starting points for discussion:

- a. Obtaining informed consent for collecting and sharing biospecimens from persons affected by a disease is particularly challenging. Individuals from whom samples are being collected are often severely ill and focused on survival. Questions remain about the ideal form of consent—for example, whether broad consent for future uses of biospecimens is ethically acceptable or whether more specific consent or re-consent for future uses must be obtained.
- b. It is not always easy to identify opportunities to include and engage with members of the community. Ethics review committees that evaluate requests to conduct research on samples collected abroad should familiarize themselves with the concerns distinct to the locality from which the samples are collected and, whenever possible, seek local parallel review and approval.
- c. U.S. regulations currently do not recognize research using de-identified samples or data as human subjects research warranting ethics review or requiring informed consent from the individuals from whom the samples were obtained. Community engagement including members of affected

³⁰ Calain, P., et al. (2009). Research ethics and international epidemic response: The case of Ebola and Marburg hemorrhagic fevers. *Public Health Ethics*, 2(1), 7-29.



communities can assure that researchers are ethically attuned to the challenges of collecting biospecimens during a public health emergency and ensure equitable access to the benefits that result from research conducted using these shared biospecimens.

- d. Regardless of whether shared biospecimens and data include identifiers (e.g., name, address, or personal identification numbers), community engagement can identify processes consistent with the principle of respect for persons, which implies that biospecimens collected from persons should be covered by adequate privacy protections. Privacy protections are particularly important when the stigma is associated with disease.

VII. Exercises

Exercise A. *During Session 3 of the Bioethics Commission’s 20th public meeting in February 2015, speakers discussed how communities affected by the Ebola epidemic experienced public attitudes and U.S. policies that sought to prevent Ebola in the United States. Transcripts and archived video of the session are available on the Bioethics Commission’s website under Meeting 20, Session 3 through the first 18 minutes of the webcast video.*

1. **Ms. Oretha Bestman-Yates, President of the Staten Island Liberian Community Association, highlights examples of stigmatization of Liberian Americans and members of the Liberian diaspora during the outbreak. What are some of the public attitudes she identified and how might community engagement help to devise public policies that mitigate stigmatization?**
2. **Mr. Chernor Bah, Youth Engagement Officer at A World at School and Chair of the Youth Advocacy Group at the Global Education First Initiative, identifies some factors that render affected communities more vulnerable to the harms of the Ebola epidemic, including disintegration of communal ties, educational deficits, and economic burdens. How might community engagement help to devise better public health response efforts that are responsive to the needs of affected communities?**

Exercise B. *In a group, assign roles to reflect the different perspectives regarding international biospecimen sharing. For an example of community engagement from an international context, see the article below:*



Tindana, P., et al. (2014). Ethical issues in the export, storage, and reuse of human biological samples in biomedical research: Perspectives of key stakeholders in Ghana and Kenya. *BMC Medical Ethics*, 15, 76.

Roles can include, but are not limited to:

- *International researchers*
- *Local IRB (including scientists, non-scientists, and community members)*
- *Community leaders*
- *Prospective participants*
- *Prospective surrogate decision makers*
- *Members of the community who might be affected by research results*
- *Government representatives*

- 1. How might each perspective help identify ethical and practical considerations of conducting research?**
- 2. What additional information about the research might those involved in community engagement want to know? How might different perspectives shape the information desired?**
- 3. What mechanisms or practices could mitigate community member concerns about informed consent, privacy, and equitable benefit sharing?**

VIII. Glossary of Terms

Capacity building: Involving individual or a community in the research process or health intervention program with the goal of strengthening skills, competencies, and infrastructure.

Community advisory board: An advisory board consisting of community members that express the interests of the community by advising and communicating with health professionals or those involved with research.

Community-based participatory research: Research in which the community helps to identify the topic or issue to be studied based on local priorities, actively participates throughout the research process.

Community-engaged research: A mechanism to involve members of a community in the planning and execution of research, including individuals who will be affected by or who are in a position to influence the course of research.



Community engagement: The process of working collaboratively and engaging actively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people. [Adapted from Principles of Community Engagement, Second Edition (2011)].

De-identified data: Data that have been separated from information identifying the individual from which they were derived. A “key” or code connecting the two might still exist, but recipients of the data are not allowed to access the key.

Democratic deliberation: A method of decision making to address an open policy question in which participants consider both relevant information and ethical aspects, justify their arguments with reasons, and treat one another with mutual respect, with the goal of reaching an actionable decision for policy or law, open to future challenge or revision.

Informed consent: The process of informing and obtaining permission from an individual before conducting medical or research procedures or tests.

IX. Additional Resources

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