

# **The Community as a Learning System for Health: Using Local Data to Improve Community Health**

*Summary of Workshop II—May 12, 2011*

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## **Introduction and Workshop Themes**

The National Committee on Vital and Health Statistics Subcommittee on Privacy, Confidentiality and Security and Subcommittee on Population Health co-hosted a second workshop on *The Community as a Learning System for Health: Using Local Data to Improve Community Health* on May 12, 2011. This workshop, held at the National Center for Health Statistics headquarters in Hyattsville, MD, focused on privacy and confidentiality issues in data use for community health. The first workshop, held in Washington, DC, on February 8, established the broad context by focusing on communities' experiences in using multiple data sources to improve local health (see separate summary). The presenters' slides or written testimony for both workshops are posted on the NCVHS website, located using the date of the meeting.

The May workshop featured illustrative community health and community engagement initiatives, advice from a national data organization, and research findings and analysis regarding different approaches to privacy and confidentiality protection. The panelists work with individual and population health information in the domains of research, clinical care, and community health. In the context of those domains, the workshop explored the distinct policy and ethical issues associated with data collection, linkage, use, release, and dissemination, as well as those associated with data sharing for uses other than the originally intended ones.

An overarching finding of the workshop was that technological approaches such as de-identification may not assure public trust. This important goal must be approached through a combination of community education, community engagement, and governance mechanisms in addition to technological solutions to assure that the data are used for appropriate community purposes and that privacy and confidentiality are adequately protected.

The significant impact of educating and engaging community members around the intended purposes of data use as well as the value of transparency in data use practices were strong and related themes. The presentations revealed that consumers want to know how data about them and their communities will be used, and to be asked for permission to use the data and/or to participate in decisions about data uses. How far in time and space such consents should apply was identified as a question requiring further investigation. Participants agreed about the im-

portance of being able to use data to improve health care and community health, and stressed the need for appropriate data protection policies to ensure the continued availability of data.

The Director of the National Association of Health Data Organizations focused on the challenges of gaining access to and using multi-source data for health care and population health. She urged NCVHS to lead a national discussion aimed at resolving privacy and confidentiality issues, in order to facilitate data sharing and use for public benefit.

NCVHS members raised a number of significant questions in discussions throughout the day, on topics that included evidence of harm vs. the fear of harm; how to define and identify data misuse; what governance mechanisms are needed; what constitutes adequate community engagement; how to enable the use of multiple data sources; and whether consent is a relevant model in a community health context. A broad question that may help guide future NCVHS work in this area was, "What is needed to enable communities to be learning systems for health using local data?"

A brief summary of each presentation follows.

### **Panel I: Engaging Communities**

- Michelle Justus, MS, RD, LD, Director, Arkansas Obesity Initiatives, Arkansas Center for Health Improvement

Ms. Justus described a statewide initiative to measure BMI in children. It was mandated in 2003 and is conducted in collaboration with the Department of Education, the University of Arkansas Medical School, and the Arkansas Children's Hospital. It has been web-based for several years, with the data stored in a secure system. Schools are responsible for sending or giving the individual child health reports (in English or Spanish) to the parents, who are encouraged to follow up with a physician if appropriate. The findings have been consistent over the eight years of the initiative. This assessment initiative is paired with state initiatives to enhance school nutrition and children's physical activity.

- Jeffrey R. Botkin, MD, MPH, Professor of Pediatrics, University of Utah

Dr. Botkin described a project to engage the public with the ethical, policy, and personal issues associated with research using biobank tissue samples. Research that combines tissue analysis and medical records has great potential for benefit but also some potential for harm, especially at the group level. His research project, which is aimed at promoting public dialog in the Intermountain area, compared different forms of public outreach and used a video to educate people on the risks and benefits of research using tissue samples. The investigators found that the public has substantial concerns about privacy and control, and people want to be asked for consent (which most expect to grant). They also found that educating the public, rather than the more

customary approach of “trying to fly below the radar,” increases support for authorized sample use for research. He recommends development of a governance structure to foster public trust.

## **Panel II: Data Management, Governance, and Uses**

- Staal Vinterbo, PhD, Biomedical Informatics, University of California, San Diego

Dr. Vinterbo focused on the limitations of de-identification for providing “believable” privacy protection in conjunction with personal health information use. He introduced the idea of a finite “privacy budget” in which the more information that exists on a patient, the fewer queries are possible before entering a sensitive area where privacy may be violated. He said his major take-home point was that a general and purely technological solution to privacy-preserving sharing of patient data may not be possible. He suggested leveraging the environment to extend the “budget”—for example, by cultivating trust and/or substituting punishment for prevention.

- Denise Love, BSN, MBHCA, Executive Director, Natl. Assn. of Health Data Organizations (NAHDO)

Ms. Love discussed the barriers to data use for health care and public health related to data gaps, interoperability issues with using multiple sources, the typical “lockbox mentality” of many agencies with regard to their data, the lack of consistent patient and provider identifiers, and other problems. She highlighted the need for standards in the collection of identifiable, granular data in uniform formats; for standard release practices; and for standardized identifiers for patients and providers. She offered eight NAHDO recommendations as part of a call for NCVHS leadership of a national discussion about privacy and confidentiality issues, aimed at achieving more cooperation in maximizing the utility of data.

- Rosamond Rhodes, PhD, Professor of Medical Education, Mt. Sinai School of Medicine, NY

Dr. Rhodes discussed privacy and confidentiality in human subject research. She stressed the distinction between privacy and confidentiality and observed that good public policy has to balance “goods” and “harms” and navigate between the two. She recommended that in clinical and biomedical research, information about people be treated according to the standards of confidentiality that govern other medical interactions. Further, she extended this principle to what she called “research that is given other names,” including public health surveillance, registries, and quality assurance and improvement. She advocated the increased research use of samples, with appropriate protections and initial informed consent when samples are taken, arguing that the public will benefit from such uses.

## **Panel III: Communicating Results**

- Debbi Main, PhD, Professor, Department of Health and Behavioral Sciences, University of Colorado Denver; Janet Meredith, MBA, ED, 2040 Partners for Health, Denver; Tracey

Stewart, Economic Self-Sufficiency Project Coord., CO Center on Law and Policy; George Ware, MS, CO Department of Public Health and Environment

Dr. Main and her colleagues described their work to engage community members in five Denver neighborhoods in an ongoing research initiative to collect and disseminate neighborhood-level health data. The data and community organizing provide the foundation for a range of community-driven efforts to improve community health and its determinants. The presenters stressed that enhancing confidentiality, trust and the relevance of community-based health information is best addressed early and in an ongoing, meaningful way. They do this by engaging community members in decisions about data collection, interpretation, and dissemination as well as about the development of future projects using the data.

- Kathy Alexis, MPH, CHES, Clinical Quality Initiatives Manager, Community Health Care Assn. of NY State (CHCANYS)

Ms. Alexis described an initiative by this consortium of federally qualified community health centers, aimed at spurring system changes to improve the BMI screening rate for children aged 2-18. The goal is to reduce the prevalence of childhood obesity. Over three years starting in 2007, CHCANYS led 11 health centers in 20 New York City sites in improving the screening and treatment of childhood obesity. The objectives involved not just more consistent BMI screening but also nutrition referral, clinical follow-up, behavior change, and ultimately helping children reach a healthy weight/BMI. After engaging health center leaders and developing partnerships, the project has used trained “parent ambassadors” on health center teams as well as young “peer mentors.” Despite challenges from staffing shortages and funding cycles, the initiative has had a measurable impact, and CHCANYS hopes to expand it state-wide.