Subcommittee on Population Health,
Subcommittee on Privacy, Confidentiality and Security
Subcommittee on Standards
of the
National Committee on Vital and Health Statistics

Joint Roundtable on
Health Data Needs for Community Driven Change
April 30 – May 2, 2013

National Center for Health Statistics
3311 Toledo Road
Hyattsville, MD 20782

Purpose of Roundtable:

Building on previous work by the NCVHS concerning community uses of data to improve health, the NCVHS seeks to: 1) advance its understanding of access to and use of data by communities to improve population health; 2) refine its Stewardship Framework for the Use of Community Health data to support the needs of various types of community initiatives; 3) better understand the role of government in providing data, tools, and resources to promote community driven change; 4) understand current state and possible gaps in data content and variable standardization for community data collection and use.

Day 1 – April 30, 2013

Time	Topic	Moderator
9:00 - 9:15am	**Welcome and agenda review** **Note:** *Members of the Committee (only) will introduce themselves and state whether they have any ethical conflicts.*	Linda Kloss, Co-chair, Privacy, Confidentiality & Security
9:15 - 9:35am	**The Community as a Learning Health System Report and 2013 Environmental Scan** • High-level findings from the 2011 Report http://www.ncvhs.hhs.gov/111213chip.pdf • Insights from 2013 Environmental scan • Input from Feedback Tool on data access and use, tools for working with data	Sallie Milam, Co-chair, Population Health
9:35 – 9:55am	**A Stewardship Framework for the Use of Community Health Data** • Issues explored at 2012 hearing http://www.ncvhs.hhs.gov/120417ag.htm • Stewardship Framework Letter to Secretary Sebelius, December 2012 http://www.ncvhs.hhs.gov/121205lt.pdf	Leslie Francis, Co-chair, Privacy, Confidentiality & Security

9:55 – 10:15am	**Framing the major issues for this Roundtable** • How do communities collect and compile data? • How do communities use data and incorporate them into priority setting and decision-making to create change? • How can stakeholders promote and support information-enabled community-driven change? • What standards exist for data collection, data content harmonization, data security, and data compilation, and where are the gaps?	Bruce Cohen, Co-chair, Population Health
10:15 - 10:30am	**Break**	
10:30 – 11:30am	**Panel 1: Collection and Compilation of Data** • Andrew Bazemore, MD, MPH *Director, Robert Graham Center for Policy Studies in Primary Care* *American Academy of Family Physicians* • Bridget Catlin, PhD, MHSA *Senior Scientist & Program Director,* *Mobilizing Action Toward Community Health (MATCH)* *Population Health Institute, University of Wisconsin* • Barbara Zappia, EdD, MPA *Senior Program Officer* *Greater Rochester Health Foundation*	Paul Tang Privacy, Confidentiality & Security
11:30 – 11:45am	**Review Logistics** • Plan for breakouts • Assignment of groups (Blue, Yellow, Red) • Room numbers and locations	Debbie Jackson Lead Staff, NCVHS
11:45am – 12:45pm	**Lunch**	
12:45 – 2:00pm	**Small Group Discussion #1:** **NOTE:** *At the beginning of the first Small Group Discussion, we will take 15 minutes or so for introductions and an overview of the group process* How do communities collect and compile data? a. How do communities find and use data? Where are there gaps? b. With the proliferation of data/data sources that already exist, how does a community know how to choose data? What are the methodologies for asset/resources assessment? c. How best to promote openness, transparency, and choice when collecting data? d. What analytic and technical support can local, state and Federal governments provide? e. How do communities partner with health care providers and academia? f. How do communities deal with the lack of data content standards and variability across data sources? What can be done to address these challenges?	Blue group: Room 1406 Yellow group: Auditorium A/B Red group: Room 1404
2:00 - 2:15pm	**Break to reconvene**	

2:15 – 2:45pm	**Report out from Small Group Discussion 1**	Linda Kloss, Co-chair, Privacy, Confidentiality & Security

2:45 – 3:45pm	**Panel 2: Using Data for Decision Making**
	
	• Lacey Hart, MBA
	  Director, BSI PMO & Program/Project Manager, Mayo Clinic Rochester, MN
	• Ninez Ponce, PhD (via videoconference)
	  Associate Professor
	  School of Public Health
	  University of California – Los Angeles
	• Eve Powell-Griner, PhD
	  Confidentiality Officer
	  National Center for Health Statistics, CDC
	• [or Al Zarate, PhD
	  Former Confidentiality Officer
	  National Center for Health Statistics, CDC]
		Jack Burke, Privacy, Confidentiality & Security, and Population Health

3:45 – 3:55pm	**Break - move to breakout rooms**	
3:55 – 4:55pm	**Small Group Discussion #2** How do communities use data and incorporate them into priority setting and decision-making? a. Is there a basic set of standard measures, variables that all communities should use? b. What is the need for standardized approaches for generating qualitative information? c. How to promote secure practices, data Integrity, creative use of de-identified data, and reduced risk of "enhanced" data sets when using data? d. How are communities transforming data into policy actionable information and priorities? e. How do communities choose among existing planning tools or decide to use own approach?	Blue group: Room 1406 Yellow group: Auditorium A/B Red group: Room 1404
4:55 – 5:05pm	**Break to reconvene**	
5:05 - 5:35pm	**Report of Small Group Discussion 2** Summary of insights from Day 1 Plan for Day 2	Llewellyn Cornelius, Population Health
5:35pm	**Adjourn Day 1**	

Day 2 – May 1

Time	Topic	Moderator
9:00 – 9:10am	**Review work plan for Day 2**	Bruce Cohen, Co-Chair, Population Health Leslie Francis, Co-chair, Privacy, Confidentiality & Security
9:10 – 10:10am	**Panel 3: Using Data to Promote Community Driven Change Needs** • Carladenise Edwards, PhD *Senior eHealth Advisor* *Zerodivide, Inc* • Sharona Hoffman, JD *Professor of Law and Bioethics* *Case Western Reserve University* • Donald Malec, PhD *Mathematical Statistician* *National Center for Health Statistics, CDC*	Len Nichols, Population Health
10:10 – 10:20pm	**Break – move to breakout rooms**	
10:20 – 11:20am	**Small Group Discussion 3** How do we promote information-enabled community-driven change? a. How best to promote community engagement and participation? b. What role does government have in promoting and supporting community change? c. What specific analytic and technical resources can state and Federal governments provide? d. How can local health care organizations, academia, and other organizations partner to support community change?	Blue group: Room 1406 Yellow group: Auditorium A/B Red group: Room 1404
11:20am 12:30pm	**Lunch**	
12:30 – 1:00pm	**Report of Small Group Discussion 3**	Vickie Mays, Population Health and Privacy, Confidentiality & Security

Time	Topic	Moderator
1:00 – 2:00pm	**Panel 4: Recommendations for Supporting Health Data Needs for Community Driven Change** • Denise Chrysler, JD *Director, Mid-States Regional Center* *Network for Public Health Law* • Christopher Fulcher, PhD *Co-Chair* *Center for Applied Research and Environmental Systems* *University of Missouri (Community Commons)* • Denise Love, BSN, MBA *Executive Director* *National Association of Health Data Organizations*	Walter Suarez, Co-Chair, Standards
2:00 – 2:15pm	**Break**	
2:15 – 3:15 pm	**Small Group Discussion 4** What recommendations might NCVHS advance to support data-enabled community health? a. Which priorities are most important? b. What steps can the federal government take to advance community health? c. What is the role of state government? d. What can communities do?	Blue group: Room 1406 Yellow group: Auditorium A/B Red group: Room 1404
3:15 – 3:30 pm	**Break to reconvene**	
3:30 – 4:45 pm	**Report of Small Group Discussion 4** And general discussion of recommendations	Linda Kloss, Co-chair, Privacy, Confidentiality & Security
4:45 – 5:00pm	**Public Comments**	Debbie Jackson, Lead Staff, NCVHS
4:45 – 5:00 pm	**Summary of insights from Day 2** Plan for Day 3	Bruce Cohen, Co-chair, Population Health
5:00pm	**Adjourn Day 2**	

Day 3 – May 2

Time	Topic	Moderator
9:00 – 11:45 am	**Review and refine options for potential Committee action.** **Draft a specific plan and timetable for carrying out the work.**	Leslie Francis, Co-chair, Privacy, Confidentiality & Security Sallie Milam, Co-chair, Population Health
11:45 – 12 noon	**Public Comments (if necessary)**	Debbie Jackson, Lead Staff, NCVHS
12:00 pm	**Adjourn Roundtable**	