

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

Subcommittee on Population Health, Subcommittee on Privacy,  
Confidentiality and Security and Subcommittee on Standards

Report to NCVHS  
September 16, 2013



# Purpose of the Roundtable

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; and
4. Understand current state and possible gaps in data content and variable standardization for community data collection and use.



# Convergence of themes

- The Federal government wants to 'liberate' its data
- Communities are becoming more sophisticated data users
- NCVHS is integrating its work on population health, security, privacy, standards, and quality



# The Program In Brief: Local Initiatives

- Barbara Zappia, Greater Rochester Health Foundation, Neighborhood Health Status Improvement Initiative
- Lacey Hart, Southeast Minnesota Beacon Community
- Ninez Ponce, California Health Interview Survey



# Program in Brief: Privacy

- Eve Powell-Griner, NCHS Confidentiality Officer
- Sharona Hoffman, Case Western Reserve University
- Denise Chrysler, Mid-States Regional Center, Network for Public Health Law



# Program in Brief: National Perspective

- Andrew Bazemore, Robert Graham Center
- Bridget Catlin, County Health Rankings and Roadmaps
- Carladenise Edwards, Zero Divide
- Donald Malec, NCHS, Small area estimation
- Chris Fulcher, Community Commons
- Denise Love, National Association of Health Data Organizations



# Emergence of themes

- **The meaning of community** *A community is an interdependent group of people who share a set of characteristics and are joined over time by a sense that what happens to one member affects many or all of the others, sometimes combined with recognition of mutual responsibility*
- **A continuum of readiness** *Most communities need some assistance and support. Participants agreed that an assessment of readiness will help better target technical assistance. A populations subcommittee work group has been formed to pursue this topic.*
- **Development of standards** *Communities would benefit enormously from standards: standard sets of measures and standards for data collection, analysis, and dissemination*



# Emergence of themes

## Common steps in community driven change

*(1) The impetus or entry-point may be a disturbing statistic, event, or condition that impels residents to come together. (2) They assess what is already known and what else they need to know to move forward. (3) This may lead to a more formal assessment and fact-finding process (4) The critical next step is to synthesize and integrate the many streams that tell a meaningful story. (5) On this basis, community partners can identify priorities and goals, (6) The important final step is to evaluate actions and outcomes and make needed modifications.*





# What Communities Need

- Technical assistance
  - Need varied amounts and combinations of financial support, tools, expert training and technical assistance
  - Collaborations and partnerships



# What Communities Need

- Local data and practices
  - Data meets their definition of authentic community, includes contextual data.
  - Use of qualitative and existing data
  - Need to be able to generate primary data
  - Need to develop and adopt data standards
  - Need collaborations to best gather, assemble, analyze and disseminate results of data
  - Need to turn data into actionable policies
  - Need to align clinical and public health practices



# What Communities Need

- Data stewardship
  - focusing on small areas or population groups requires the use of granular and/or linked data, thus raising the risk of identifying individual residents
  - need for techniques, models, and best practices to guide communities in their data stewardship



# The Evolving Role of the Federal Government

- ‘Redefiner’ of public health to put communities at the center of the data universe
- Facilitator/Convener with all levels of government and non-government agencies operating in this space



# The Evolving Role of the Federal Government

- Modernize infrastructure to support data enabled community health: focus on what it does best:
  - funding,
  - research,
  - policy,
  - technical assistance, and above all,
  - maintenance of the high-quality data that form the backbone for all other activities



# The Evolving Role of the Federal Government

- Specific possibilities include:
  - Developing extension centers to make technical assistance available in communities;
  - leveraging and expanding the community health needs assessments that are currently mandated by IRS for non profit hospitals
  - developing and disseminating the NCVHS stewardship framework
  - research to support – core set of indicators, small area estimation, integrating data sets



# Next Steps

- Promoting and disseminating of roundtable summary
- Drafting letter to the Secretary focusing on new federal role and highlighting upcoming areas of focus from roundtable
- Exploring community readiness/assessing current technical assistance
- Working with data work group on Solvathon to assess creative/integrative data uses at the community level (*added after Roundtable*)



# Community Health Product Dissemination Plan

- Send products to all participants involved in the Roundtable and Hearing
  - Community as a Learning System for Health (Feb. and May 2011)  
<http://www.ncvhs.hhs.gov/110208ag.htm>  
<http://www.ncvhs.hhs.gov/130512ag.htm>
  - Next Step for Community Data Use (April 2012)  
<http://www.ncvhs.hhs.gov/120417ag.htm>
  - Health Data Needs for Community Driven Change  
<http://www.ncvhs.hhs.gov/130430ag.htm>
- Encourage members and staff to share on their various listservs
- Specify and target organizations and groups, using suggestions from members and staff

