Joint Roundtable on Health Data Needs for Community-Driven Change

A Summary Report of the National Committee on Vital Health Statistics

U.S. Department of Health
and Human Services

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Joint Roundtable on Health Data Needs For Community-Driven Change

April 30–May 2, 2013 at the National Center for Health Statistics, Hyattsville, MD

—Summary—

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EXECUTIVE SUMMARY

Members and staff of the National Committee on Vital and Health Statistics (NCVHS) gathered with invited experts at a recent Roundtable on Health Data Needs for Community-Driven Change to discuss information-enabled, community-driven change and how it can be supported. NCVHS advises the Department of Health and Human Services on health information policy. The invited presenters contributed perspectives from their work with local initiatives, privacy and public health law, and national organizations. (The meeting agenda is in Appendix 1.)

Over two and a half days, the participants explored what types of data and support would enable community members to improve health where they live, work, and play. Their focus on "community-driven" change emphasized the key roles of community members in identifying priority problems, determining relevant geographic boundaries, and driving solutions.

The major findings of the discussion, described further in the summary below, were as follows:

- Communities vary considerably in the amount and types of assistance they need to bring about data-based improvements in local health. Understanding these variations can make it possible to prioritize and tailor assistance to individual communities.
- To inform local projects, data and information should correspond to authentic boundaries, have relevant granularity, and be actionable. In many cases, communities may need to conduct their own data collection to augment the secondary data available from state, federal, and other sources.
- Communities need assistance with data stewardship to help them protect residents' privacy and confidentiality and optimize data quality as they use data to zero in on needed improvements. Attorneys can play key roles in helping communities find appropriate ways to use public data for community benefit.
- A growing number of intermediary organizations provide Web-based resources to facilitate local action. Together, these resources are part of an evolving infrastructure supporting community-driven change.
- The federal government should support community-driven change through its policies, research, direct assistance, and collaboration with intermediary organizations. Optimally, such federal activities should be part of a comprehensive Health Statistics Modernization Initiative (or Act) designed to transform national health statistics and create a workforce of sophisticated data scientists.

The NCVHS Roundtable took place in Hyattsville, MD, from April 30 to May 2, 2013, and was co-sponsored by the Subcommittees on Population Health; Privacy, Confidentiality and Security; and Standards. The findings on how communities acquire, protect, manage, and use data for community-driven change and what types of assistance they need to do so successfully will inform future NCVHS recommendations for a heightened federal role in this area.

Summary

INTRODUCTION

The Joint Roundtable on Health Data Needs for Community-Driven Change brought together members and staff of the National Committee on Vital and Health Statistics (NCVHS), a dozen invited experts, and others for an extended discussion of what can be done to promote and support community-driven, information-enabled change. NCVHS is a public advisory committee that advises the Department of Health and Human Services on health information policy.

At this meeting, which took place in Hyattsville MD from April 30 to May 2, the participants considered what data and supports community members need to be able to improve health and the factors that influence it where they live, work, and play. Their discussions about how communities acquire, use, manage, and protect data for decision-making, action, and evaluation laid the groundwork for forthcoming NCVHS recommendations on a heightened federal role in this area.

The Roundtable was co-sponsored by three NCVHS Subcommittees: Population Health; Privacy, Confidentiality and Security; and Standards. Several members of the NCVHS Working Group on HHS Data Access and Use also participated. The invited panelists, who work in various capacities to support local health improvement efforts, are affiliated with foundations, universities, government, and national and local organizations.

Building on its previous work on this subject, NCVHS set four goals for the meeting:

- To advance its understanding of access to and use of data by communities to improve population health;
- To understand the current state, possible gaps, and variable standardization in community data collection;
- To refine the NCVHS stewardship framework for community health data use, to support the needs of various types of community initiatives; and
- To better understand the role of government in providing data, tools, and resources to promote community-driven change.

The Roundtable generated a strong message that it is time for the federal government to meet engaged communities where they are and help them to get, use, and reuse data to guide their work.

THE PROGRAM IN BRIEF

The meeting agenda, with the questions posed for the group, is in Appendix 1. Subcommittee Co-chairs set the stage for the discussions by reviewing the Committee's previous work on community data use. As they explained, NCVHS released its report, *The Community as a Learning System for Health: Using Local Data to Improve Local Health,* in late 2011, based on findings from two hearings earlier that year.[1] Then in 2012, the Committee sent

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[1] A link to this report is posted on the homepage, http://www.ncvhs.hhs.gov/

recommendations to the Secretary on a stewardship framework for community data use.[2] In 2013, two information-gathering efforts helped NCVHS prepare for this Roundtable: a scan of existing supports for community health data use, and a feedback tool on community health data use to which 95 groups responded.

The Roundtable agenda alternated panel presentations with breakout sessions in which attendees could talk in small groups and then report back to the plenary. The expert presentations, which provided the major fuel for the discussions, are briefly described below. (For more detail, the speakers' slides and a transcript of the plenary sessions are posted on the NCVHS website.[3]) The remainder of this meeting summary outlines the major themes that emerged in the Roundtable discussions.

Local Initiatives

This group of presenters gave concrete examples of community-driven change that grounded and provided reference points for the more theoretical discussions.

- **Barbara Zappia, MPA, Greater Rochester Health Foundation, Neighborhood Health Status Improvement Initiative (slides)**

Ms. Zappia introduced the Neighborhood Health Status Improvement Initiative in Rochester, NY, a resident-driven project supported by the Greater Rochester Health Foundation. The Initiative empowers residents to be "co-producers of health," a process that requires knowledge of the physical, social, and economic environments of their neighborhoods and the community assets they have to work with. The Rochester projects leverage a broad range of primary and secondary data sources on health and its determinants, including data collected by community members. Dr. Zappia also described how the projects use data for evaluation, as outlined in its Evaluation Framework (see Appendix 3).

- **Lacey Hart, MBA, Southeast Minnesota Beacon Community (slides)**

Ms. Hart described the communities of practice in Southeast Minnesota's Beacon Community that are delivering community-driven care through partnerships among health care organizations, public health departments, and school districts. The Community accommodates the fact that while all partners have data to contribute, their infrastructure capacities are at different levels of robustness. A Community Data Repository is used in projects including care transition coordination, heat-related illness reporting, and management of a school-based "cocoon of care" for children with asthma. The Community has developed novel approaches to patient consent and privacy protection to enable services and research, and she reviewed a number of legal considerations related to these activities.

- **Ninez Ponce, MPP, PhD, UCLA Center for Health Policy Research; Principal Investigator, California Health Interview Survey (slides)**

Dr. Ponce described the California Health Interview Survey (CHIS), which is designed to make data meaningful for counties, racial and ethnic groups, and legislative districts. She gave examples of community-driven uses of CHIS data for policy development and advocacy. In one example, community members used data on BMI and fast food establishments to analyze the

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[2] A link to the letter to the Secretary on a stewardship framework is posted at http://www.ncvhs.hhs.gov/
[3] http://www.ncvhs.hhs.gov/130430ag.htm

Los Angeles food environment and successfully advocate for zoning changes. In another, a coalition analyzed data on coverage, insurance markets, and language barriers and used the findings to advocate successfully for language services during the open enrollment period for the Affordable Care Act. As a general principle, she emphasized that “Community is the most sophisticated with identifying the priority problems to be solved.”

Privacy and Public Health Law Experts

These presenters and their organizations are developing understanding of how data stewardship and protection can align with and support data use for community health improvement.

- **Eve Powell-Griner, PhD, Confidentiality Officer, National Center for Health Statistics (slides)**

Ms. Powell-Griner characterized her work as “upholding the promises that we make when we collect the data.” Noting that NCHS has “competing mandates” to disseminate data as widely as possible *and* protect the confidentiality of the information, she reviewed the requirements and restrictions that constrain the public dissemination of data. She explained the reasons that the granular and linked data that many communities want can raise privacy issues: First, the smaller the population, the more likely an individual or institution can be unique; and second, the greater the number of variables pertaining to an individual, the greater the likelihood that combinations of data will identify the individual. She cited research documenting the risks of re-identification based on these realities. Finally, she shared possible strategies for wider data dissemination and for sharing non-disclosive data.

- **Sharona Hoffman, JD, Case Western Reserve University (slides)**

Ms. Hoffman proposed that the concept of the common good, rather than privacy and autonomy, should be the prevailing value in public health initiatives and non-interventional research. The alternative is to have “free riders” on medical and public health advances. However, public buy-in to this principle depends on confidence in privacy protection, which requires data security, identity concealment, and possibly more regulatory interventions. She pointed out that the construction of “big data” often bypasses privacy and security regulations such as HIPAA, and she reviewed the facts about the risk of re-identification. One workable approach, she said, is federated systems, which enable queries of data that stay in the control of cooperating organizations. Finally, she noted the need for new models of consent that are relevant to community data use, and she reviewed the data quality problems that can result when consent is withheld.

- **Denise Chrysler, JD, Mid-States Regional Center, Network for Public Health Law (slides)**

Ms. Chrysler advanced the idea of using law to solve public health problems, which is the mission of the RWJF-funded Network for Public Health Law. While acknowledging the risks, challenges, and constraints involved in data liberation and sharing, she also pointed to the risks of “hoarding the data”; and she urged the federal government and NCVHS to help expand the mindset of attorneys and privacy officers to enable data use for community health improvement. In particular, she asked for help developing workable community-level consent models that “comfort and engage” the community. After describing an opt-in, informed-consent model developed for the Michigan BioTrust for Health, she reiterated that everyone benefits from data and respect for individual rights must be balanced with protecting the common good.

National-scale Organizations and Activities

The following presenters and their organizations are connecters, researchers, and facilitators who are providing strategic expert assistance and helping to build a nationwide infrastructure to support community-level work.

- **Andrew Bazemore, MD MPH, Robert Graham Center (slides)**

The Robert Graham Center works for the integration of public health and primary care, with attention to social determinants. Citing examples from across the U.S., Dr. Bazemore described the Center's use of merged datasets from multiple sources and GIS maps to help community stakeholders locate safety net clinics and make other decisions. He pointed out that "real access" to data depends on having downloadable data at the small area level. He stressed that empowering communities and improving community health requires not just "data liberation" but also data integration, translation of data into tools, community stakeholder engagement, and improvement of the data based on community input.

- **Bridget Catlin, PhD, MHSA, University of Wisconsin Population Health Institute/ County Health Rankings and Roadmaps**

Dr. Catlin gave an overview of County Health Rankings (CHR), which provide information on health rankings and the underlying data on health and determinants for all U.S. counties, drawn from multiple sources and using a broad-based model of population health. She stressed the critical importance of maintaining federal data resources. The rankings, she said, can serve as a call to action that starts a conversation among community members about priority issues and draws the attention of funders and policy-makers. She noted that communities need help in interpreting data to determine what is most important and how to move to action. The CHR program has partnered with the Robert Wood Johnson Foundation's Roadmap program to support communities in using data. She pointed out that communities also need to evaluate progress and see change, and this requires timely, granular data, collected locally or derived from estimates and/or electronic health records (EHRs).

- **Carladenise Edwards, Ph.D., Zero Divide (slides)**

Dr. Edwards discussed the Roundtable topics from the perspective of Zero Divide's goal of "transformation through technology" for underserved communities. Zero Divide is working for e-health equity, which it sees as a stepping-stone to health equity. The organization considers this NCVHS project important because it promotes connectivity within and between communities. She showed findings on social media usage and attitudes, and challenged the Committee and government to pay attention to information and behavior related to social media. In the Roundtable discussions, she asserted that communities already have access to enough data to work for local health improvement and health equity; in her view, the focus should instead be on giving them the help they need to use the data.

- **Donald Malec, PhD, National Center for Health Statistics (NCHS) (slides)**

Dr. Malec explained that small area estimation is valuable because policy decisions, funding allocations, and interventions are often based on quantifiable needs, and statistical estimates of small geographic areas or population domains can fill data gaps. Although this approach allows uniform quality, it may not fit well for areas with unusual characteristics; he noted that the best approach is to combine model-based estimates with local data. After discussing the methodology and the reasons for using it to fill in missing data, he described several current NCHS projects and the directions the research is headed.

- **Chris Fulcher, Ph.D., CARES/University of Missouri/Community Commons (slides)**

Calling Community Commons "a unifying public-good utility," Dr. Fulcher described its evolution from separate Web-based systems for many organizations to a national GIS data engine designed to inform communities and connect them in a national public conversation. Community Commons' free tools and functionalities include mapping, social media, "prosumer" (user-generated) content, blogs, reports, and feature stories. It presents data on a broad range of health determinants and the built environment as well as on health status and human services. Noting the disparate uses and frames of reference for the term "data," despite the fact that "we're all talking about the same community," he called for the development of a holistic assessment framework that encompasses all the information relevant to community members.

- **Denise Love, National Association of Health Data Organizations (NAHDO)**

Ms. Love offered cautionary remarks about the sustainability of the infrastructure needed to support and inform community-driven health assessment and improvement. NAHDO works with states and private organizations to improve health care data collection and use. A major current project is helping states to build all-payer claims databases. Saying that "we worry about the data every day," she warned that "we can't assume the data will always be there" because data collection is minimally funded and the analytic infrastructure is "pretty rickety" due to a lack of support. She stressed the need to train the workforce in the concepts of big data integration and data sharing in order to transcend the current silos of practice. She called attention to issues of data quality and data ownership and to the need for shared directories, national standards, and identifiers; and she called for a "corps of data scientists" to support the activities envisioned in these discussions.

MAJOR THEMES

The Meaning of "Community"

The participants made an effort to clarify what they meant by "community" for the purposes of this discussion, because of the varied usage of the term. They converged around the following broad definition, used by NCVHS in its 2011 report: *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.*[4]

Geographically-defined communities are the major, though not exclusive, focus of this NCVHS project. In every case, the problems and solutions that community members choose to address are what determine the relevant boundaries, rather than given political or other jurisdictions. As the Rochester project illustrates, the relevant area may be a single neighborhood—a reality with data implications that resonated throughout the meeting.

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[4] NCVHS, The Community as a Learning System for Health, page 8.

As is evident in the presentation summaries above, the participants used a broad definition of public health that encompasses all the factors that influence health status—housing, jobs, environmental conditions, and so on. This aligns with the lens through which community members tend to view local health and wellbeing. Barbara Zappia, for example, noted that local residents are more likely to express their issues in terms of “what they see out their windows”—rats, trash, and drug dealers in one of her Rochester examples—than to use the more disease-oriented traditional vocabularies of public health and health care.

The group focused its explorations on a specific model of change, *community-driven* change. This reflects the widespread recognition among public health professionals, researchers, organizers, and others of the importance of stakeholder engagement in bringing about meaningful change. In community-driven change, local residents are the prime actors; they identify the desired improvements and take action, through partnerships, to bring them about.

“Co-production” and “co-ownership” were frequently invoked as core principles, representing the reality that effective community projects involve an alliance between the residents with the greatest stake in change and those who can help them achieve their goals. The case descriptions shared in the meeting illustrate some of the types of support, partnership, and expert assistance that can be embedded in local efforts. In one framing, Ninez Ponce observed that community-based participatory research projects can be either “researcher-driven with strong community input or community-driven with strong researcher input.” In either case, community members are heavily involved.

A Continuum of Community Readiness

The Roundtable participants linked their fluid definition of community to a recognition that every community can be placed on a continuum in terms of its ability to collect, interpret, protect, and use data and other tools to improve local health and well-being. Most communities need some forms of assistance and support; those with more limited capacities and resources need more help than others. Assessing itself with respect to such a continuum can be a useful part of a community’s initial process of identifying assets, capacities, and needs. The participants were in agreement that differential assessment of this kind could help direct national attention and resources to the places with the greatest need, in a way that meets communities where they are.

Steps in Community Driven Change

The discussion highlighted a number of common elements or 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 to start a conversation and move toward action. (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 that looks at local assets, brings together available secondary data, and may set in motion primary data collection to answer additional questions. (4) The critical next step is to synthesize and integrate the many streams and types of data and convert them into information that tells a meaningful story. (5) On this basis, community partners can identify priorities and goals, research what actions have produced good results in other communities, and decide on a set of actions to achieve their goals. (6) The important final step (before the cycle begins again) is to evaluate actions and outcomes and make needed modifications.

The County Health Rankings Take Action model in Appendix 2 is a schematic of the process that also shows the major sectors that work with community members. The Rochester project's evaluation framework in Appendix 3 provides another useful overview of the process; and a third visualization of the process, developed during the meeting, is in Appendix 4.

What Communities Need

Although participants had differing views about the adequacy of data for local decision-making, they were in agreement that communities need help to use the data. The presentations and discussions showed what community members need in the way of information, skills, resources, and access to trustworthy expertise to accomplish their health improvement goals. In addition to data to inform decision-making (discussed below), they need varied amounts and combinations of financial support, tools, and expert training and technical assistance. Such assistance may be needed for any or all of the steps outlined above, including forming workable partnerships, finding relevant secondary data, identifying data gaps, collecting primary data, using qualitative data appropriately, integrating and interpreting data, translating information into decisions and actions based on knowledge of what works, practicing appropriate data stewardship, and evaluating the process and outcomes.

The pivotal role of collaboration and partnership was a major theme of the meeting, which highlighted the joint efforts of a wide range of entities. As noted, researchers, funders, and intermediary organizations can play key roles in facilitating community-based efforts, along with government at all levels. In general, community-driven change can involve the contributions of public health, government, health care, philanthropy, academia, associations, business, education, law, and many types of community-based organizations at local, regional, and national levels. In discussing this theme, Roundtable participants stressed not only that such collaborations are critical, but also that it takes time and money to build and sustain them, a reality that should be reflected in the planning and funding for local initiatives.

The group heard several examples of the types of direct assistance local communities are receiving. For instance:

- The County Health Rankings and Roadmaps Program has three full-time "community coaches" who are available to help communities at no charge.
- The Greater Rochester Health Foundation provides grants and ongoing technical assistance and tools for local health improvement projects, and its evaluators serve as "evaluation coaches" with grantees and residents.
- The Robert Graham Center does data modeling and GIS mapping to inform local decisions on safety net development, the location of health centers, and other matters.
- The Southeast Minnesota Beacon Community has been instrumental in forming and sustaining the partnerships and "communities of practice" that are carrying out community-driven work.
- Besides funding local projects, many federal and state government agencies assist communities with data access and analysis as well as training and tools.

Implications for Local Data Needs and Practices

The Roundtable members identified the attributes of data and information that enable communities to carry out local projects. For example, the data must correspond to authentic boundaries and the operative definition of community, and have the relevant granularity (block, neighborhood, population group, etc.). They should be actionable, including having relevance to needed policy changes. They should include contextual data on the determinants and predictors of health. And they should make it possible to monitor progress. Maps and other visualizations have been shown to be powerful entry points.

These requirements point to the common need for primary data collection at the local level, a critical missing link for many communities and a major reason they need expert assistance. The story of primary data collection in Rochester provided an instructive example of how a community can augment secondary data. The city's Community Health Improvement Project engages local residents in identifying priorities; gives them training and tools for primary data collection around identified goals; and works with them to evaluate the impact of the resulting interventions.[5]

Qualitative data are a key dimension of community information. For example, residents may consult personal observations and key informants in their initial assessments, and then organize focus groups and community discussions as they delve further. The Greater Rochester Health Foundation provides its Project Hope grantees with discussion group guides along with other tools; and it helps participants use community surveys to query residents about their "attitudes, feelings and understanding" (Appendix 3). Stories are important at every stage, as Chris Fulcher emphasized.

Throughout the Roundtable, the theme of the need for primary data collection was paired with the equally important theme of making better use of existing community-level data. The activities in Olmsted County, MN, provided one example, where the Beacon Community helped to systematize information-sharing among schools, health care providers, and parents to improve the care and health of children with asthma. Andrew Bazemore gave several examples of the ways in which his Center helps communities "capture the power of public data," often by repurposing and combining data.

The alignment of clinical and public health practices received a good deal of attention at the meeting, partly related to the largely untapped potential of EHRs. The group explored the possibilities for using both health information exchanges and new extension services to facilitate linkages among clinical data, population health survey data, and locally-generated data to improve community health—all in the context of the stewardship practices outlined below.

All of these approaches illustrate the fact that the *users* of data have proliferated along with the types, sources, combinations, and uses of data. Today, community-level data users include not only clinicians and public health professionals but also community based organizations, individual community members, policy-makers, funders, and other change agents. Many of these data users also play roles in contributing data, or could do so.

A recurring theme in the Roundtable was the importance of bi-directionality and reciprocity—that is, the need for feedback loops so that those supplying data also have access to the composite

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[5] The 2011 NCVHS report *The Community as a Learning System for Health* describes another example of community-based primary data collection in Denver CO (page 33-34).

data-based picture, to enhance their operations. A common complaint of community members, for example, is that while they are often the subjects of studies and surveys, they are rarely privy to the resulting findings and conclusions that could benefit their community. In another important area, participants pointed out that the efforts to integrate clinical and public health data should include mechanisms to feed data on community health back to the health care organizations supplying clinical data, to inform their clinical practices. Finally, it is important not only to garner policy-relevant data but also to share with policy makers the composite community picture and the priority issues that are revealed.

Enabling Data Use with Stewardship and Privacy Protection

Andrew Bazemore brought together several key Roundtable themes when he spoke of "evaluating small-area need based on what the community determines as its top priority." The implicit challenge is that focusing on small areas or population groups in order to zero in on needed improvements requires the use of granular and/or linked data, thus raising the risk of identifying individual residents. The question of how to address this challenge and the rightful balance-point between individual rights and the common good was a major Roundtable theme. While stressing the need for protections, the privacy and law specialists in the group also asserted that attorneys can play key roles in finding appropriate ways to make public health data available for community benefit—in Denise Chrysler's words, "using law to solve public health problems."

This framing pointed to the need for techniques, models, and best practices to guide communities in their data stewardship. In particular, participants called for a new model of community consent that is not based on the research model. Communities also need technical assistance on questions such as de-identification and the use of small-area or small-n data. The subject of mental health provided a reference point on the need to protect sensitive personal health information. The topic arose partly in relation to an interest in understanding quality of life and community resilience, and partly due to the impending integration of mental health into health care under the Affordable Care Act.

One response to the discussions of this theme was to encourage NCVHS to continue to develop and disseminate its stewardship framework to help guide community data use.

Intermediaries and the Evolving National Infrastructure

> *Facilitate v: expedite, speed up, accelerate, ease, simplify, help in, make less difficult, make easier, assist the progress of, lessen the labor of, lighten, smooth; forward, help to advance, promote, further, advance, aid, foster.* (Random House Roget's Thesaurus, 3rd ed.)

Many factors contribute to the prevailing sense that the local community is "where the action is"—the actionable nexus of need and opportunity. Accordingly, a growing number of intermediary organizations are using information technology to facilitate local action through centralized and cost-free data access, data visualizations, technical assistance, information on best practices, and communication opportunities. As noted, seven such organizations were represented at the NCVHS Roundtable. By providing tools for shared learning, advocacy, and action, these organizations are strengthening and adding value at the community level and also "connecting the dots" to build the national movement for healthy and sustainable communities.

A look across these organizations' activities shows the evolution of a supportive infrastructure that has many of the elements envisioned in the Committee's 2011 report—notably, training and technical assistance, data access and visualization, help with coalition development, and knowledge-sharing.[6] The difference is that what was then framed as the responsibility of the federal government is now being created through varied collaborations between non-governmental organizations and federal and state governments. This trend indicates a converging commitment to supporting community health improvement. And the growing community participation reported by networks such as County Health Rankings and Roadmaps and Community Commons, among others, suggests that communities are increasingly taking advantage of these resources.

System Issues and a Vision for a Modernized Federal Role

What is the role of the federal government in community-driven change, given the rapidly changing landscape and the emerging role of intermediary organizations? In essence, the Roundtable participants concluded that government should "redefine public health" to put communities at the center as actors and data users. With this focus, it can deploy the full range of federal functions including funding, research, policy, technical assistance, and above all maintenance of the high-quality data that form the backbone for all other activities.

The group identified many specific ways in which the federal government can support data-enabled community health. Three broad areas singled out for federal action echoed ideas that were advanced in the 2011 NCVHS report: first, using extension centers to make technical assistance available to communities; second, leveraging and expanding the community health needs assessments that are now mandated for non-profit hospitals by the IRS; and third, developing and disseminating the NCVHS stewardship framework.[7]

The Roundtable participants also identified areas for further federal research. They include developing a core set of community health indicators; continuing the NCHS work on small area estimation; and developing ways to help communities integrate the disparate streams of data needed to understand and enhance community life.

A number of suggested federal actions take the form of direct assistance to communities that meets them where they are. For example, the federal government could collect and liberate data on small areas and population subgroups, help communities assess local capacities, and provide GIS tools. It could develop a common set of measures and definitions by which communities and neighborhoods can assess how well they are doing. It could integrate into routine data collection the community-level measures that matter, and help support and systematize the appropriate use of qualitative data. Finally, to further these ends, it could collaborate with and use the power of intermediary organizations, providing support to ensure their sustainability and helping make sure that all U.S. communities know about these free resources and how to use them.

Rising to these opportunities requires bold new approaches. The Roundtable participants enthusiastically embraced the idea of a comprehensive *Health Statistics Modernization Act (or Initiative),* designed to transform national health statistics and create a workforce of sophisticated data scientists. Given the precarious state of the national data infrastructure and workforce, as described by Denise Love, many participants were persuaded that such an

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[6] See page 30 of the report.

[7] See "Envisioning a Federal Role," pages 31-32.

initiative is not only the most effective but possibly the *only* way to undergird and sustain data-enabled, community-driven health improvement.

NEXT STEPS

The National Committee on Vital and Health Statistics plans to develop detailed recommendations to the Secretary that build on the “first draft” ideas generated by the Roundtable. NCVHS members will work closely with the expert colleagues who contributed so much to the Roundtable discussions and helped craft possible recommendations. Many invited guests expressed interest in continuing to work together in this endeavor, and in recruiting others who belong at the table to further stimulate the development of creative solutions. This includes a commitment to learning more about the community health activities being supported by other HHS agencies including the Health Resources and Services Administration, the Centers for Disease Control, and the Substance Abuse and Mental Health Services Administration.

Indeed, the process has already begun: Several NCVHS members and panelists volunteered for two working groups that formed at the meeting, one to think further about a data stewardship model and the other to consider how the federal government can refocus its resources to help build community capacities.

APPENDIX 1

FINAL AGENDA
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	**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
11:45	**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: Rm 1406 Yellow group: Aud A/B Red group: Room 1404
2:00	**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 teleconference) *Associate Professor* *School of Public Health* *University of California – Los Angeles* • Eve Powell-Griner, PhD *Confidentiality Officer* *National Center for Health Statistics, CDC*	Jack Burke, Privacy, Confidentiality & Security, and Population Health
3:45	**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: Rm 1406 Yellow group: Aud A/B Red group: Rm 1404

4:55	**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

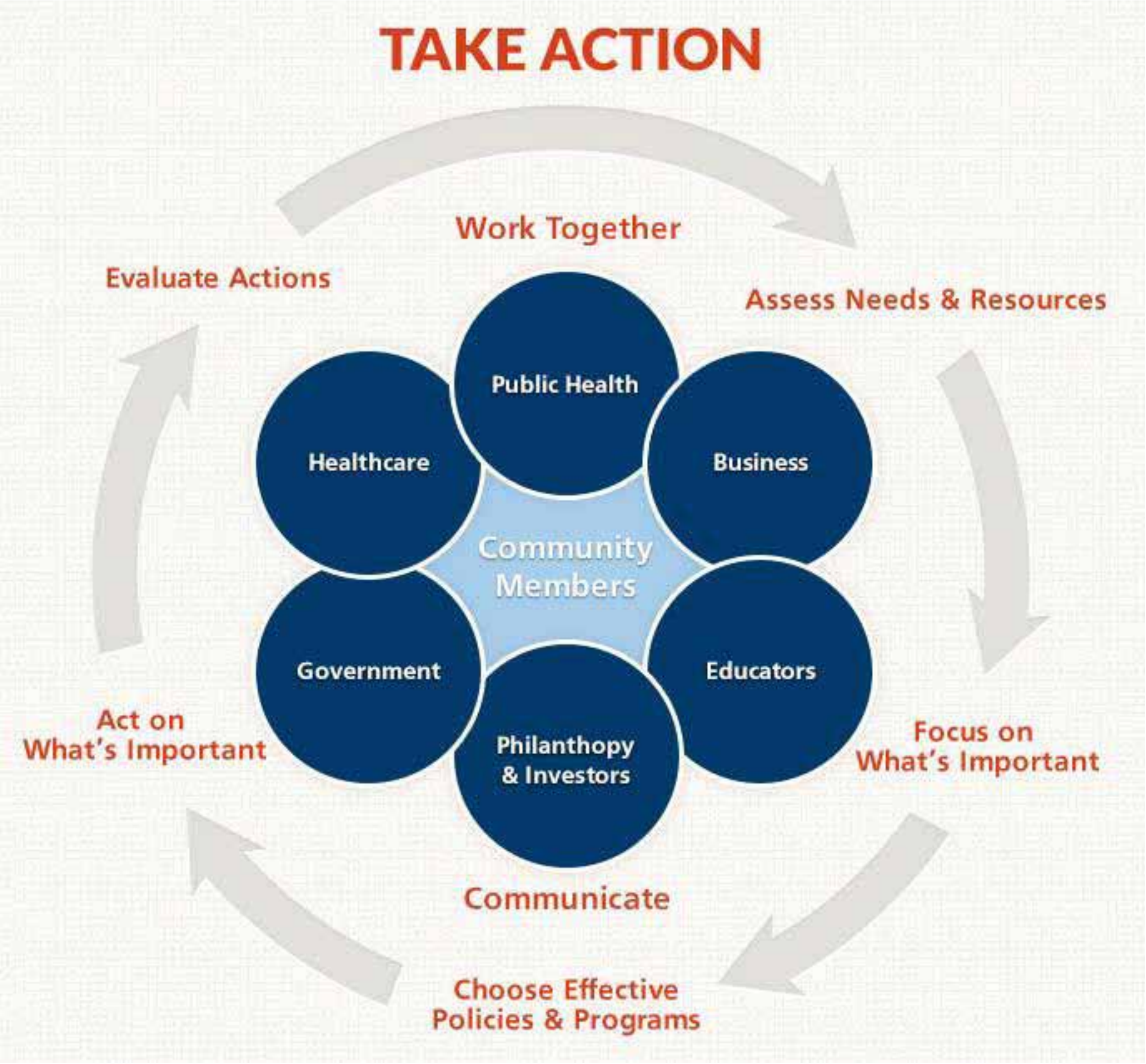
Time	Topic	Moderator
9:00 – 9:10am	**Review work plan for Day 2**	Bruce Cohen, Co-Chair, Population Health Leslie Francis, Co-chair, Privacy, Confidentiality & Security
9:10 – 10:10am	**Panel 3: Using Data to Promote Community Driven Change Needs** • Carladenise Edwards, PhD *Senior eHealth Advisor* *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	**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: Rm 1406 Yellow group: Aud A/B Red group: Rm 1404
11:20am	**Lunch**	
12:30 – 1:00pm	**Report of Small Group Discussion 3**	Vickie Mays, Population Health and Privacy, Confidentiality & Security

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	**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: Rm 1406 Yellow group: Aud A/B Red group: Rm 1404
3:15	**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

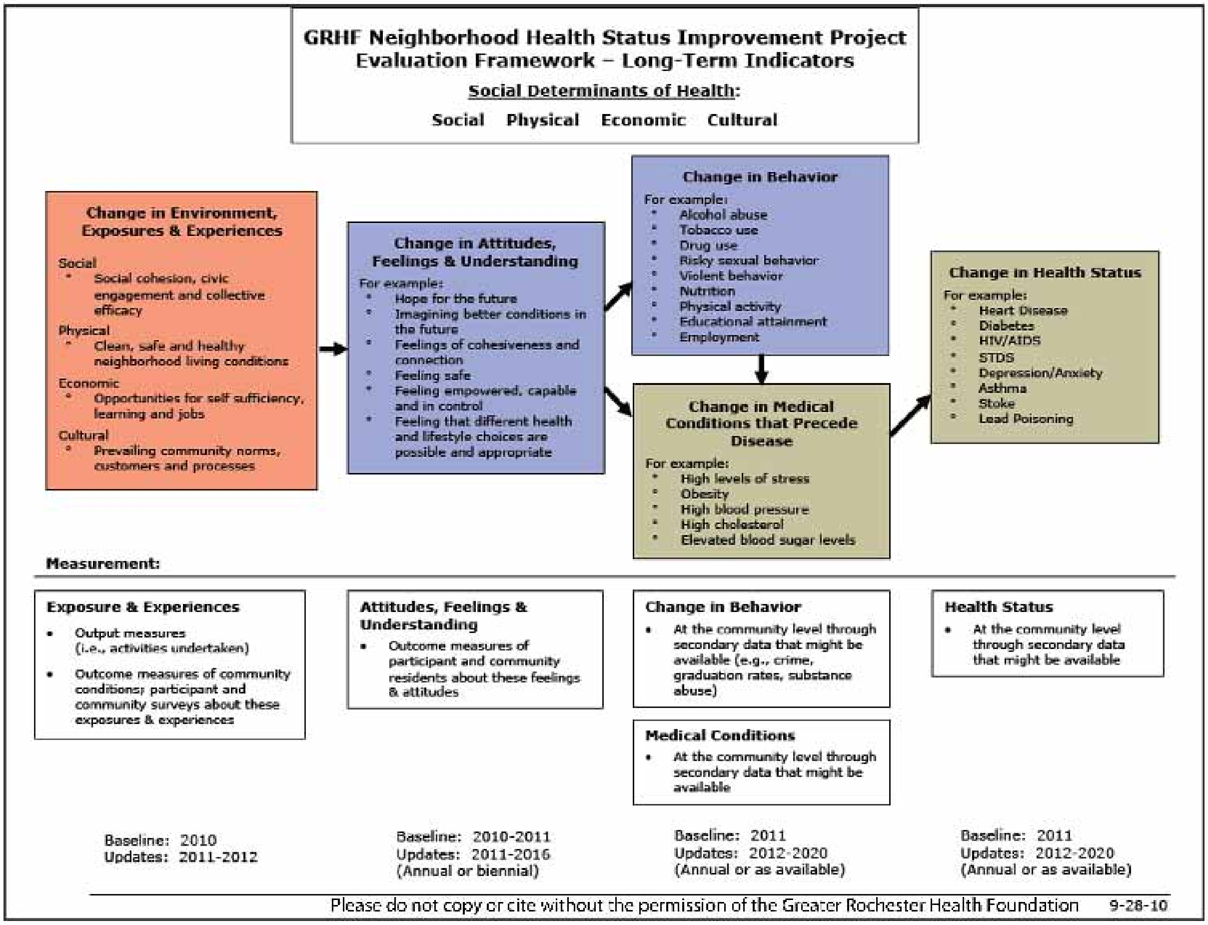
Time	Topic	Moderator
9:00 – 11:45 am	**Review and refine options for potential Committee action.** **Draft a specific plan and timetable for carrying out the work.**	Leslie Francis, Co-chair, Privacy, Confidentiality & Security Sallie Milam, Co-chair, Population Health
11:45 – 12 noon	**Public Comments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

APPENDIX 2



Source: County Health Rankings

APPENDIX 3



GRHF Neighborhood Health Status Improvement Project
Evaluation Framework – Long-Term Indicators

Social Determinants of Health:

Social Physical Economic Cultural

Change in Environment, Exposures & Experiences

Social
- Social cohesion, civic engagement and collective efficacy

Physical
- Clean, safe and healthy neighborhood living conditions

Economic
- Opportunities for self sufficiency, learning and jobs

Cultural
- Prevailing community norms, customers and processes

Change in Attitudes, Feelings & Understanding

For example:
- Hope for the future
- Imagining better conditions in the future
- Feelings of cohesiveness and connection
- Feeling safe
- Feeling empowered, capable and in control
- Feeling that different health and lifestyle choices are possible and appropriate

Change in Behavior

For example:
- Alcohol abuse
- Tobacco use
- Drug use
- Risky sexual behavior
- Violent behavior
- Nutrition
- Physical activity
- Educational attainment
- Employment

Change in Medical Conditions that Precede Disease

For example:
- High levels of stress
- Obesity
- High blood pressure
- High cholesterol
- Elevated blood sugar levels

Change in Health Status

For example:
- Heart Disease
- Diabetes
- HIV/AIDS
- STDS
- Depression/Anxiety
- Asthma
- Stoke
- Lead Poisoning

Measurement:

Exposure & Experiences
- Output measures (i.e., activities undertaken)
- Outcome measures of community conditions; participant and community surveys about these exposures & experiences

Baseline: 2010
Updates: 2011-2012

Attitudes, Feelings & Understanding
- Outcome measures of participant and community residents about these feelings & attitudes

Baseline: 2010-2011
Updates: 2011-2016
(Annual or biennial)

Change in Behavior
- At the community level through secondary data that might be available (e.g., crime, graduation rates, substance abuse)

Medical Conditions
- At the community level through secondary data that might be available

Baseline: 2011
Updates: 2012-2020
(Annual or as available)

Health Status
- At the community level through secondary data that might be available

Baseline: 2011
Updates: 2012-2020
(Annual or as available)

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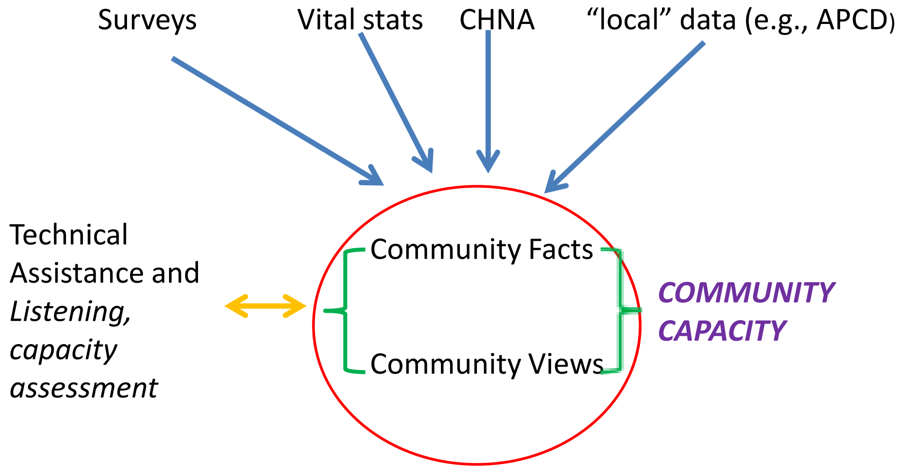
Source: Greater Rochester Health Foundation

APPENDIX 4

Turning Local Health Information Into Action



Surveys

Vital stats

CHNA

“local” data (e.g., APCD)

Technical
Assistance and
Listening,
capacity
assessment

Community Facts

Community Views

COMMUNITY CAPACITY

Source: Len M. Nichols, George Mason University, and discussion with the full committee.