

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

— *Preliminary Report on the February 8, 2011 NCVHS Workshop* —

by Susan Baird Kanaan

Executive Summary

The National Committee on Vital and Health Statistics (NCVHS) hosted a workshop in Washington, DC, on February 8 to learn from innovative communities about their experiences using multiple data sources to improve local health. NCVHS is a statutory advisory committee on health information policy to the Secretary of Health and Human Services. Its workshop showcased a diverse group of exemplars from every region of the country, including four large, multifaceted public health programs; four focused community health initiatives; and three health information exchanges (HIEs). The Committee learned that an exciting national trend is gaining momentum as leading-edge communities pioneer new ways to link local policy and program planning to data gathering and analysis.

The workshop brought to light a clear opportunity to strengthen communities' data and analytic capacities and help them connect with each other and with external resources. The presenters called for more granular data on neighborhoods, sub-populations, environmental factors, and resources, as well as stronger capacities to analyze and use data. Ideas took shape for a set of standardized community health indicators and a national infrastructure to support local efforts and help align local, state, and federal activities.

This report describes illustrative projects in the eleven communities, summarizes their common success factors and challenges, and outlines the Committee's preliminary findings about how the federal government can strengthen and harness the growing energy of community health movements. NCVHS will host a follow-up workshop on May 12 to delve further into privacy issues associated with local data use, in hopes of identifying guidelines and best practices to facilitate safe and effective data use.

Introduction

Across the United States, an exciting national trend is gaining momentum as leading-edge communities pioneer innovative solutions to local health concerns. These initiatives are significant for the range of partners involved and the comprehensiveness and evidence base of the strategies being used. Health professionals, community activists, research scientists, and members of local government are crafting shared visions of community health, and leveraging multiple data sources and a range of public health and community organizing skills to work toward them. In short, these learning communities are using data to drive policy, planning, and change for better community health.

While communities have always worked for local health improvement, something new is afoot. It is enabled by the growing power of data and information tools and by novel forms of support from community networks, academia, the federal government, and other sources.

The Committee hosted a workshop on February 8 in Washington, DC, to learn from some of these innovative communities about their experiences using local, state, and national data to improve local health. The NCVHS Subcommittees on Population Health and Privacy, Confidentiality and Security are coordinating this Community Health Information Project. Members are interested in the challenges the exemplar communities are encountering, the benefits they are achieving, and the lessons and models that might be useful to others. The Committee hopes to use its findings to help identify new ways for the federal government to support local endeavors.

The workshop brought to light a clear opportunity to strengthen communities' data and analytic capacities and help them connect with each other and with external resources. NCVHS believes that with support of this kind, local efforts like the ones showcased at the workshop could become a powerful engine for population health improvement on a national scale.

The Communities and Their Activities

Using an informal nomination process, the Committee found exemplars in every region of the country. It selected eleven communities, most of them counties, that are diverse in size, resources, programmatic focus, leadership, and type of participation. The exemplars are located in (or comprise) nine states in four regions. The program summaries on pages 5-8 illustrate the kind of health improvement activities they are conducting; the names of the presenters and their organizations are listed in the appendix.

The Committee chose to include four large, multifaceted public health programs; four focused community health initiatives; and three health information exchanges (HIEs). Besides facilitating information sharing to enhance health care, the selected HIEs are laying the groundwork for

information sharing that will enable the kind of population health management being modeled by the other communities. These three groupings provided the structure for the day-long workshop:

Panel 1: Multi-faceted Public Health Programs

- King County, Washington
- Olmsted County, Minnesota
- Sonoma County, California
- State of South Carolina

Panel 2: Focused Community Health Initiatives

- Boone County, Missouri
- Denver, Colorado
- Mahoning Valley, Ohio
- South Los Angeles, California

Panel 3: Health Information Exchanges

- Grand Junction, Colorado
- Bronx, New York RHIO
- Indiana Health Information Exchange (IHIE)

The local actors in these communities come from public health departments, community-based organizations, health care providers, health information exchanges, and government agencies as well as academic and scientific institutions and foundations. The organizational base of the leaders varies. Six of the eleven community initiatives are led by health department staff, who are well positioned to mobilize broad-based efforts. Five initiatives are led by non-governmental organizations, and one (IHIE) is a hybrid of the two. All have the support of their state health departments, and some also have federal agency partners. Many presenters stressed the central role of local coalitions and the importance of having the necessary time and resources to build and sustain them. Significantly, five of the communities are also part of larger, regional or national networks that provide technical assistance, data services, and other forms of support. The list of presenters in the Appendix shows the range of organizations involved.

Taken together, their approaches reflect a broad definition of health, and grounding in the principles of prevention and eliminating health disparities. Their focal issues cross a spectrum from changing social and environmental health determinants to promoting healthy behaviors to improving health care access, quality, and coordination.

Building coalitions and drawing on a wide range of data are mutually reinforcing activities that happen fairly naturally at the local level, given a broad-enough understanding of health and its determinants. Together, these elements can be as transformative for traditional public health

practices as they are for health care. Communities are likely to focus on determinants that are amenable to change through local action. The current national attention to obesity as an underlying cause of prevalent chronic diseases is a good example. Several of the exemplar communities are tackling the high chronic disease rates in their areas by improving access to healthy food and exercise opportunities, particularly in neighborhoods and population groups with disproportionately high rates of disease.

For all the variety among the communities and local conditions, there are many common elements in their approaches to improving local health. Local leaders provide opportunities for collaboration and coalition-building, engaging community members and organizations and partnering with related sectors such as transportation and housing. The coalitions gather and link data, in many cases augmenting established sources by conducting their own local research with the participation of community members. The partners use the data to analyze major health issues, set priorities, and develop policies and programs. They create communication and data visualization tools to inform and educate stakeholders and influence decision-makers. Finally, they monitor progress, evaluate results, and modify the foregoing components as needed. Among these steps, there are many possible entry points and feedback loops.

Key Success Factors

To summarize, the workshop highlighted these common success factors among the exemplars:

- A galvanizing health concern;
- A comprehensive understanding of health;
- Strong local leadership;
- A collaborative local culture, and trust;
- Political will and governmental commitment to data collection and analysis;
- Comprehensive data to enable consensus around priorities and to mobilize action;
- Effective analytic capacities and data visualization tools; and
- Organizational and technical support by expert partners, funders, and others.

The following sketches describe representative activities in each of the eleven communities. The sketches are followed by the Committee's observations and preliminary findings from the workshop.

Panel 1: Multi-faceted Public Health Programs

King County, WA: *Multiple data audiences and partners*

Washington's large local health department, Public Health Seattle King County, is fortunate to have strong support from its Board of Health for epidemiology and evidence-based evaluation. Dr. Marguerite Ro, the department's Chief of Assessment, Policy Development and Evaluation, observes that shrinking budgets only heighten the need to capture and understand what is happening at granular levels (e.g., in health planning areas) in terms of population health and the broader health determinants, to enable the most cost-effective decision-making. She told NCVHS about King County's biennial Communities Count project, which draws from several data sets to create web-based reports on social and health indicators including food, housing, income, health care, violence, tobacco use, social cohesion, and morbidity and mortality. The County's commitment to "data democratization" translates into an aggressive program of health data dissemination to its partners. The partners include local government, the human services sector, the land use and planning sector, and criminal justice, in addition to the more "usual suspects" such as the Board of Health, education sector, community based health centers, and the health and hospital systems.

Olmstead County, MN: *Schools, physicians, public health department and families join forces to reduce the impact of childhood asthma*

State law requires all Minnesota counties to conduct a Community Health Needs Assessment every five years, using a standardized framework. The resulting data inform local public health priority-setting and program development. For Olmsted County, one priority involves reducing the impact of childhood asthma and improving early identification in school and early medical treatment. Public Health Director Mary Wellik told NCVHS about the longstanding partnership between the health department and the local school system. The partners have now joined the Mayo Clinic, health care providers, and family members in a demonstration project—the focus of a Beacon project—to ensure that kids with asthma are getting the best care and living healthy lifestyles. Physicians' asthma action plans will be made available to the health department, parents, and schools, which in turn will report to providers as needed on children's health status. The health department and school district have worked out a joint HIPAA-FERPA¹ consent form to facilitate the process and standardize privacy protection procedures.

Sonoma County, CA: *Dynamic website informs action by multiple coalitions*

Sonoma County, California's *Healthy Sonoma* website provides user-friendly access to information on local health, health determinants, and community programs. The data visualization tools in the website, which links all the county's community health projects together, are recognized as a national model. Sonoma County launched the site in 2009 as a platform for data-based planning and community action. Healthy Sonoma now enables multiple local coalitions to work on health-related issues such as food, fitness, chronic disease, primary care access and the social determinants of health, in close alignment with Health Action, a countywide multi-stakeholder initiative to improve community health and the local health care system. One such coalition, the prevention-oriented Sonoma Upstream initiative, grew out of strategic planning and analysis that showed the human and material cost of unmet needs in terms of "downstream" effects such as incarceration, addiction, and abuse. The coalition aligns efforts across law enforcement, health, human services, and economic development sectors to intervene further "upstream" using a portfolio of evidence-based strategies and a suite of indicators for tracking progress. The *Healthy Sonoma* website was created and is maintained (with ongoing input from the Sonoma County Health Department) by the Healthy Communities Institute, which is affiliated with the University of California, Berkeley. The Institute provides timely, customized community health data, best practices, and collaboration and engagement tools for several northern Californian counties. Sonoma County's Health Officer, Mary Maddux-Gonzalez, MD, MPH, talked with NCVHS about the benefits of having expert external support of this kind—especially for smaller communities with more limited staffs.

¹ Health Information Portability and Affordability Act (HIPAA); Family Educational Rights and Privacy Act (FERPA).

State of South Carolina: *Childcare Data Bridge powers an initiative to improve childcare*

In South Carolina, the Office of Research and Statistics (ORS) of the State's Budget and Control Board warehouses administrative data from a wide range of public agencies and makes integrated data available for analysis and to inform program development and evaluation. The Childcare Data Bridge, for example, links longitudinal Social Services data on childcare facilities with data on child health and welfare outcomes (some provided by parents) to monitor childcare quality and reward quality improvements. This is one of many initiatives made possible by strong partnerships between the State's health and education institutions, working jointly to understand and enhance the mutual impact of education and health at all levels of development. ORS Director David Patterson, Ph.D., told NCVHS that the combination of rich data, useful data tools, and trust in the ORS as a neutral source all play a part in enabling a growing range of publicly beneficial data uses by the agency's partners

Panel 2: Focused Community Health Initiatives**Boone County, MO: *Community Issues Management tool spurs collaboration, research, and action***

The public health Department in Boone County, Missouri, uses the Community Issues Management (CIM) tool as the "leading edge" of its work. CIM leverages multiple data sets to provide a platform for local mapping and reporting. Community workgroups use it to plan and carry out targeted projects and work for policy change in areas such as alternative transportation, incentives for housing, community gardens, and grocery store locations. Stephanie Browning, the Administrator of the county's health department, told NCVHS that comprehensive approaches of this kind help her to educate colleagues in other public agencies about the relevance of their work to community health. Besides helping issue-oriented workgroups get started and training them to use CIM, the health department and other government agencies use it for emergency preparedness planning. CIM was created by the University of Missouri's Center for Applied Research in Environmental Systems, based just blocks from her department's headquarters. Boone County is one of 15 U.S. communities in the CIM Collaborative that are working together to refine the tool, with technical assistance from the University.

Denver, CO: *"Community priorities drive what we do."*

In the five Denver neighborhoods that comprise the organization 2040 Partners for Health, local citizens not only conduct participatory research but decide how data on their community will be used. *Taking Neighborhood Health to Heart (TNH2H)* began in 2007 as a community-based research project of the University of Colorado's Department of Family Medicine. It grew into an ongoing initiative to improve cardiovascular health and study the influence of health care access and the built environment on health in these predominantly low-income neighborhoods. Community members helped design and conduct the study and guide the interpretation of the results. The original study was recently extended to look at childhood obesity, and included a survey guided by a youth advisory group. The community-based Data Review and Dissemination (D-RAD) group ensures that data are used in beneficial ways that do not stigmatize community residents. It also reviews the program's extensive bilingual resource materials to make sure they contain clear, useful information. These programs, which operate in tandem, emphasize local participation and engagement. The three Denver presenters at the NCVHS workshop—a community leader, the TNH2H research director, and Denver 2040's executive director—all stress that their community-based approach is what transforms *community involvement* into *community ownership*.

Mahoning Valley, OH: *Survey data inform a campaign to increase CHIP enrollment*

The Covering Kids and Families Coalition in the Mahoning Valley, Ohio, has a campaign to enroll all eligible children in the state's Children's Health Insurance Program (CHIP). The partners include United Way, the Easter Seals Society, public health officials, local foundations, the Medicaid agency, and other organizations. County Health Commissioner Matthew Stefanak told NCVHS that local leaders mounted the campaign after comparative data from the 2004 statewide Ohio Family Health Survey (OFHS) showed that local CHIP enrollment efforts had produced good results for their area compared to other metropolitan counties—despite having the highest rate of families with children below 200 percent of poverty. The survey also showed, however, that pockets of unenrolled kids remained; so the Coalition created additional outreach programs to inform, screen, and enroll these children. One form of outreach involves providing CHIP information to families in the kindergarten readiness summer program held in many school districts in Mahoning and Trumbull counties. The Coalition will use OFHS data to track the results of these intensified efforts.

South Los Angeles, CA: *Influencing land use policies to improve health determinants and reduce disparities*

The goal of the Community Health Council's REACH (Racial and Ethnic Approaches to Community Health) initiative in South Los Angeles is to reduce the disproportionately high diabetes and cardiovascular disease rates and severity among local African American residents. The major focus is changing the environment to support people's healthful choices related to food and exercise. Gwendolyn Flynn, the Council's Community Health and Education Policy Director, told NCVHS that the initiative engages a wide range of stakeholder organizations in local research and advocacy. Drawing on data on health determinants, health indicators, community food resources and physical activity venues, these community activists are working with members of local government to influence urban design and land use management policies. This has already resulted in policies that limit stand-alone fast food outlets in South LA and policy recommendations that increase residents' access to healthy food and activity venues such as parks, bike lanes, and walkable areas. The local initiative, which is affiliated with the Centers for Disease Control's national REACH initiative, has influenced the South Los Angeles General Plan and led to the development of two new full-service supermarkets in the area.

Panel 3: Health Information Exchanges**Grand Junction, CO: *Collaborative culture lays groundwork for a Beacon project with population health improvement goals***

Health care providers and a health plan in this large, partly-rural and partly-urban area of western Colorado have been building a non-profit health information exchange for several years. In 2009, they launched a joint effort to improve health care technology, efficiency, payment, and quality for all area residents, both insured and uninsured. Patrick Gordon, Director of the local Beacon Consortium, told NCVHS that the HIE's sustainability and its meaningful use goals created the conditions for recognition as a Beacon project in 2010. He noted the importance of leveraging local leadership and respecting the autonomy of each of the area's seven counties. He also stressed the benefits of working through methodological and interoperability issues to align local efforts with national incentives and quality frameworks. The Grand Junction Beacon Consortium is developing an infrastructure to support population health management. It is already successfully exchanging data among physicians, health departments, hospitals, and the community mental health system.

Bronx, New York RHIO: *Partnerships to improve care transitions and reduce re-hospitalization*

With participants representing 85 percent of health care in this New York City borough, the Bronx Regional Health Information Organization (RHIO) is well positioned for its initiative to reduce hospital readmissions and support patient-centered medical homes. Its members include home care agencies, long-term care facilities, and a large private social service agency as well as hospitals, community clinics, and independent clinicians. The RHIO's Nance Shatzkin told NCVHS that its primary mission is to make data available to physicians at the point of care. Its Registration Alerts subscription service notifies physicians when identified patients are admitted to a local emergency department or hospital. In collaboration with three local hospitals and two health plans these alerts are part of an evidence-based program to reduce hospital readmissions, by offering extra services to targeted patients in the hospital and after discharge.

Indiana Health Information Exchange (IHIE): *Implementing a population-based approach to health care quality improvement*

The Indiana Health Information Exchange (IHIE) is the nation's largest health information exchange. Its Quality Health First Program analyzes and assembles the data IHIE manages to improve health care in ways that meet the state's population health goals. The program assesses and monitors quality improvements in cancer and diabetes screening and heart disease care for all patients of participating physicians. Payors participate in the program and provide bonus payments directly to physicians based on improvements in patient health. State Health Commissioner Gregory Larkin, M.D., told NCVHS that the initiative has already led to measurable improvements in health outcomes. The State Health Department is working toward population health improvement with IHIE. For example, the statewide immunization database, CHIRP, will be incorporated into the IHIE and other health information exchanges in the state. This will make it possible to monitor physicians' immunization rates and potentially incentivize improvements.

Observations and Preliminary Findings

As intended, the NCVHS workshop provided insight into the experiences of leading-edge communities as they leverage a range of data sources to inform local action. By bringing together local and national perspectives, the meeting showed the positive feedback loops that are possible between the rising tide of local initiatives and federal policy. These topics are summarized in the following sections.

Data Issues

As noted, a major factor underlying community health initiatives is the ability to link and analyze data from multiple sources and communicate the findings persuasively. The demand for local data is large and growing. Without exception, the exemplar communities want, and are using, comprehensive data to inform their broad understanding of health, establish credibility, and mobilize action. This involves leveraging data from both "off-the-shelf" and "home-grown" sources that include state and national surveys, public health surveillance data, government program data, local surveys, and clinical data (administrative and/or derived from electronic medical records). Many communities are also making creative use of contextual and environmental data from sources such as GIS maps showing land use for grocery stores, farmers' markets, and recreation areas as well as data on economic factors, transportation, housing, environmental hazards, and more. In addition, the panelists stressed the importance of qualitative data, to tell the compelling stories about local health problems and solutions.

Together, these data tools are enabling community leaders to show and address the key health issues affecting their citizens and the underlying policies and social and environmental factors that influence them. These activities are increasing the synergies between health care and public health, and broadening the conception of both domains.

The workshop presenters shone a bright and persistent light on the data gaps that limit their ability to make informed decisions and influence decision-makers. They called not only for more

granular data on neighborhoods, sub-populations, environmental factors, and resources, but also for stronger capacities to analyze and use data. A few of the exemplars have strong internal analytic capacities; others outsource analysis and data display functions to external experts, as intermediaries emerge to play these roles. Virtually all of the community representatives say they need stronger capacities in informatics and epidemiology to make fuller use of available data. Several also noted their need for better ways to display and disseminate data, to improve their ability to engage collaborative partners and influence policy makers.

The workshop highlighted the potential tension between the population health benefits of data linkages and more granular data, on the one hand, and the risks of re-identification and compromising privacy, on the other. Some presenters described the local solutions they had worked out for obtaining consents and protecting privacy; others told of their struggles with perceived barriers to data use. NCVHS will host a follow-up workshop on May 12 to explore community-level privacy issues, with the aim of identifying guidelines and best practices to enable safe data use at the levels communities need to target their interventions and monitor impacts.

Potential Synergies and Economies of Scale

A national perspective affords opportunities to find economies of scale by supporting many communities at once, as well as a chance to identify best practices, models, and resources that have broad applicability. Several such opportunities became apparent at the workshop, related to clinical-public health synergies; standardized community health indicators; a national infrastructure to support local work; and other forms of support.

Perhaps most importantly, the workshop highlighted ways to enhance the synergies between clinical and public health information uses for community health improvement, as well as the critical importance of doing so. In general, stronger bridges are needed between public health and clinical information systems in order to address issues of concern to both, such as care transitions and immunizations. Public health has information that clinicians can use; and clinical information systems can provide useful information in response to targeted queries from public health. The participants stressed the opportunity afforded by the inclusion of public health in the government's Meaningful Use criteria, along with the fact that local public health departments need help to take advantage of it. In general, they pointed out that local health departments need to build capacity to make better use of health information technology.

A set of standardized community health indicators was an efficiency that attracted considerable interest. The workshop participants discussed the potential benefits of having a standardized tool for assessing local health and comparing one's community with others over time. The

experience of Olmsted County, Minnesota, shows the merits of this approach to community health assessment, which Minnesota law requires of all of its counties and helps to facilitate.

Building a Strong Infrastructure

To review, the workshop highlighted questions about how to strengthen local capacities, improve the data informing local work, protect individual privacy, and balance local autonomy and uniqueness with the benefits of standardization.

The benefits of bringing together national and local perspectives were especially evident when the discussion turned to problem-solving. The presentations and discussions stimulated thinking about a new infrastructure that would support, connect, and inform vanguard community health initiatives and enable others to follow their lead. Besides reinforcing local efforts and helping new communities get started, such an infrastructure could strengthen the alignment of local, state, and federal population health activities. The workshop highlighted the following as important components:

- A standardized set of community health indicators;
- Training and technical assistance to improve analytic and data management capacities;
- Support and/or external facilitation to strengthen local financial and human resources;
- Better data visualization tools and skills;
- Support for public health departments to take advantage of Meaningful Use criteria; and
- Mechanisms for sharing with other communities and staying abreast of federal and state resources and activities—e.g., a clearinghouse.

Town-Gown Partnerships to Improve Local Health

One of the strongest take-home messages from workshop participants concerned their need for stronger analytic capacities, on staff and/or through expert assistance. The majority of the featured communities have worked with local academic or research institutions to achieve what they've accomplished so far, illustrating a successful model for strengthening local capacity in an era of diminishing government workers. Of the 11, the following communities have partnerships with local institutions that assist with research, analysis, program development, and/or data management:

- Boone County, MO: University of MO Center for Applied Research in Environmental Systems
- Denver 2040: University of Colorado Department of Family Medicine
- Indiana Health Information Exchange: Regenstrief Institute
- Mahoning Valley, OH: Health Policy Institute of Ohio
- Olmsted County, MN: Mayo Clinic College of Medicine Department of Bioethics
- Sonoma County, CA: Healthy Communities Institute, University of California, Berkeley
- South Los Angeles, CA: University of Southern California

See the summaries of Sonoma and Boone Counties above for examples. It should be noted that in some areas, these local or regional assets are augmented by the technical assistance and other forms of support received from the HHS Beacon project, the Community Health Data Initiative, and other national programs.

Implications for a Possible Federal Role

As noted, the Committee's purpose in hosting its February and May workshops is to identify ways for the federal government to encourage community-based health initiatives. In an era of growing need and shrinking resources, federal and local activities must be aligned so the work at all levels is mutually supportive and cost-effective. The growing federal interest in local activities and new federal initiatives and "data liberation" mechanisms to support them are positive developments. Close familiarity with activities on the ground in local communities will be critical to the effectiveness of these interventions.

The Committee began to envision ways in which federal government could both seed and harness the growing energy of community health movements. At the most fundamental level, the national health information policy discussion should be expanded to recognize communities as significant data users and make supporting local initiatives a major policy goal. The public health information infrastructure needs to be strengthened so it more closely parallels the clinical information infrastructure and can more fully interact with it. The Committee believes this will require a national effort on a par with the investment in EHR adoption and health information exchange. The present NCVHS project demonstrates the pivotal role that local communities can and must play in bringing about these improvements.

As examples, the Department could help build bridges between clinical and public health data systems. It could help identify and encourage the adoption of standardized community health indicators. It could help communities gain access to more granular data, with proper privacy protections, along with data on environmental and resource factors. Through existing initiatives such as regional extension centers, federal government could provide training, technical assistance, mentoring, and technology solutions to local communities, working with many at once to realize economies of scale.

The community representatives at the NCVHS workshop welcomed information about the new HHS Community Health Data Initiative, which many regard as a promising resource. HHS Chief Technology Officer Todd Park invited them all to attend the second Community Health Data Users Forum, which HHS and the Institute of Medicine will host on June 9, 2011.

NCVHS Next Steps

The National Committee on Vital and Health Statistics plans the following near-term steps to support these priorities as it explores further ways to contribute to policies that strengthen local efforts:

- May 12 workshop on privacy and confidentiality
- Report(s) with findings from the February 8 and May 12 NCVHS workshops
- Participation in the June 9 Community Health Data Users Forum

Appendix 1. February 8, 2011 Workshop Speakers

Stephanie Browning

Administrator
Columbia/Boone County Health Department
Columbia, MO
<http://www.cim-network.org/>

Gwendolyn Flynn

Community Health and Education Policy Director
Community Health Councils
South Los Angeles, CA
www.CHC-inc.org

Patrick Gordon, M.P.A.

Director
Colorado Beacon Consortium
Grand Junction, CO
<http://www.coloradobeaconconsortium.org/>

Greg Larkin, M.D.

State Health Commissioner
Indianapolis, IN
(representing Indiana Health Information Exchange)
<http://www.ihie.com/>

Mary Maddux-Gonzalez, M.D.

Health Officer and Public Health Division Director
Sonoma County Department of Health Services
Santa Rosa, CA
www.healthysonoma.org

Debbi Main, Ph.D.

Professor and Chair
Department of Health and Behavioral Sciences
University of Colorado Denver, CO
<http://www.ucdenver.edu/academics/colleges/CLAS/Departments/hbsc/Pages/HealthBehavioralSciences.aspx>

Janet Meredith, B.A., M.B.A.

Executive Director
2040 Partners for Health
Denver, CO
<http://www.2040partnersforhealth.org/>

David Patterson, Ph.D.

Chief, Health and Demographics
SC Budget and Control Board Office of Research and Statistics
Columbia, SC
www.schiex.org (HIE information)
<http://ors.sc.gov/hd/default.php> (data warehouse and general information)

Marguerite Ro, Dr.P.H.

Chief, Assessment, Policy Development, and Evaluation
King County Public Health Department
Seattle, WA

<http://www.kingcounty.gov/healthservices/health/data.aspx>

Nance Shatzkin

Shatzkin Systems, Inc.
Bronx RHIO
Bronx, NY

bronxrhio.org

Matthew Stefanak, M.P.H.

Mahoning County Health Commissioner
Youngstown, Ohio

<http://www.mahoninghealth.org/>

Tracey Stewart

Economic Self-Sufficiency Project Coordinator
Colorado Center on Law and Policy
(2040 Partners for Health)
Denver CO

Mary Wellik

Public Health Director
Olmsted County Public Health Services
Rochester, MN

<http://www.co.olmsted.mn.us/ocphs/Pages/default.aspx>

Appendix 2. National Committee on Vital and Health Statistics

Justine Carr, M.D., Chair

Marjorie S. Greenberg, NCHS, Executive Secretary

Jim Scanlon, ASPE, Executive Staff Director

Subcommittee on Population Health

Larry A. Green, M.D., Co-Chair

Sallie Milam, J.D., Co-Chair

Mark C. Hornbrook, Ph.D.

Garland Land, M.P.H.

Blackford Middleton, M.D., M.P.H.

Donald M. Steinwachs, Ph.D.

Walter G. Suarez, M.D., M.P.H.

Nancy Breen, Ph.D., NCI, NIH, Staff

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J. Marc Overhage, M.D., Ph.D., Co-Chair

Sallie Milam, J.D.

Walter G. Suarez, M.D., M.P.H.

Paul C. Tang, M.D.

Maya Bernstein, J.D., ASPE, Lead Staff