—DRAFT—

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

A Report of the

National Committee on Vital and Health Statistics

by Susan Baird Kanaan

The National Committee on Vital and Health Statistics (NCVHS) serves as the statutory [42 U.S.C. 242k(k)] public advisory body to the Secretary of Health and Human Services in the area of health data and statistics. In that capacity, the Committee provides advice and assistance to the Department and serves as a forum for interaction with interested private sector groups on a variety of key health data issues. The Committee is composed of 18 individuals from the private sector who have distinguished themselves in the fields of health statistics, electronic interchange of health care information, privacy and security of electronic information, population-based public health, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Sixteen of the members are appointed by the Secretary of HHS for terms of four years each, with about four new members being appointed each year. Two additional members are selected by Congress.

Membership

Justine M.Carr, M.D., Chair
John J. Burke, M.B.A, MSPharm.
Raj Chanderraj, M.D., F.A.C.C.
Bruce B. Cohen, Ph.D.
Leslie Pickering Francis, J.D., Ph.D.
Larry A. Green, M.D.
Mark C. Hornbrook, Ph.D.
Linda L. Kloss, M.A., RHIA, CAE, FAHIMA
Vickie M. Mays, Ph.D., M.S.P.H.
Blackford Middleton, M.D., M.P.H., MSc
Sallie Milam, J.D., CIPP/G
Len Nichols, Ph.D.
William J. Scanlon, Ph.D.
W. Ob Soonthornsima
Walter G. Suarez, M.D., M.P.H.
Paul C. Tang, M.D.
James M. Walker, M.D., FACP*
Judith Warren, Ph.D., RN

HHS Executive Staff Director

James Scanlon
Deputy Assistant Secretary, Office of Science and Data Policy
Office of the Assistant Secretary for Planning and Evaluation, DHHS

Executive Secretary

Marjorie S. Greenberg, M.A.
Chief, Classifications and Public Health Data Standards Staff, Office of the Director
National Center for Health Statistics, CDC

www.ncvhs.hhs.gov

Contents

Executive Summary

Local communities have expanding opportunities to develop data-driven policy and programs, thanks to health information technology and new investments in local data use; and local data are becoming a powerful tool for collaboratively carrying out initiatives to improve community health and quality of life. The National Committee on Vital and Health Statistics (NCVHS) has examined how communities can become *learning systems for health* and what resources exist and are needed to help them. Its Community Health Information Project is a response to the upsurge of leading-edge community health initiatives, juxtaposed against the reality that many communities have difficulty taking advantage of the new opportunities.

The Committee's interest in community-based health activities was sparked primarily by two initiatives of the Department of Health and Human Services (HHS), the Community Health Data Initiative and the Learning Health System project. NCVHS views communities as important learning systems for health, or potential ones, and it sought to learn what experiences communities were having and what issues they were encountering in using local data to improve local health and how they could be supported. Consistent with the NCVHS population health mission, the Committee wanted to look at these questions broadly, encompassing the social determinants of health as well as health care, and privacy and confidentiality priorities as well as other significant data issues.

The project and report focus on geographic communities because the place where people live not only has a large impact on their health and well-being, but also is where they can have an impact on many of the determinants of their health. NCVHS talked with leaders from 14 communities around the country at workshops in February and May, 2011, sponsored by the subcommittees on Population Health and on Privacy, Confidentiality and Security. These local coalitions and others like them are devising strikingly creative ways to link policy and program planning directly to data gathering and analysis in their communities. The workshop discussions highlighted common success factors and challenges among these community health initiatives.

The Committee has come to believe that getting usable data into the hands of communities and ensuring that they have the tools and capacities to use them could move the nation a long distance toward realizing the public benefits of the informatics revolution. Communities need many types of data, including data drawn from health records, environmental and resource measures, vital statistics, and a myriad of surveys of community attitudes and behaviors, as well as qualitative data on the experiences and opinions of local citizens. The Federal government has a critical role to play in helping local efforts succeed; and it is likely that a targeted investment could generate large efficiencies, given the local ingenuity and resourcefulness so amply illustrated by the communities profiled here.

This report presents a vision for strengthening local data, capacities, and uses, with specific suggestions for ways to increase the momentum toward better local health. The initial sections present the Committee's findings about local data access and use and the information-related issues communities are facing as they try to leverage their data to improve local health. The final sections look to the future, with comments on how the Federal government and others can support and sustain local efforts. The time has come to recognize communities as significant actors and

data users, and to elevate systematic support for local initiatives to the position of a major national policy goal.

Learning from Local Solutions

NCVHS learned from the representatives of selected communities about their local activities in three key and interdependent areas—collaboration, data collection and use, and trust-building.

Identifying Priorities and Building Partnerships and Collaboration

The importance of collaboration and partnerships is a major theme and finding that weaves through this report. Local projects need strong community organizing skills as well as good population health data to enlist a range of partners in crafting a common vision for their communities' health and sharing the work to achieve it. Such coalitions often extend well beyond the boundaries of the public health department and include community activists and leaders, health professionals and health care institutions, research scientists and other academics, members of local government, and other partners. The workshop participants stressed that clear and compelling local data play a key role in their ability to engage community members and leaders and reach agreement on common priorities. As this report illustrates, many leading-edge communities also participate in regional or national partnerships among communities.

Developing Data around a Broad Definition of Health

The central message of this report is the importance of connecting people to data to enable local problem-solving. Just as the actors and decision-makers need to be broad-based, the data on which they base their actions must be broad enough to inform action on the many determinants of health. Local activities involving data include the following:

- Leveraging and linking multiple data sources on health and its determinants;
- Linking clinical and population health data and exploring novel forms of data and data linkages;
- Generating local data;
- Innovatively displaying and disseminating data;
- Mobilizing for information-driven action and evaluation; and
- Collaborating with external experts in town-gown partnerships and in other ways.

Building Trust

The stories of the featured communities show the importance of embedding necessary legal and regulatory protections in a relational fabric of trust. The protections help create the conditions for what might be called earned trust; they are necessary, but not sufficient. NCVHS learned that promoting trust takes time and requires a multi-faceted, layered approach. This approach involves not just technological mechanisms and data stewardship but also community education and engagement, transparency, and governance. The approach, which is modeled by several community initiatives featured in this report, includes:

- Educating community members and leaders about data use and benefits;
- Involving community members in decisions about data use;

- Building cooperation and trust among organizations and agencies that are data sources; and

- Fostering a sense of ownership and control through governance mechanisms.

The workshop highlighted among the featured communities these ten common, interconnected success factors:

1. A galvanizing health concern
2. A comprehensive understanding of health and community health
3. A collaborative culture; social capital
4. Trust, achieved through regulatory protection, governance, and community engagement
5. Access to data on local health and its determinants, plus analytic capacities
6. Data display and dissemination capacities
7. Functioning coalitions, community engagement, and agreement about priorities
8. Organizational and technical support
9. Political and financial support
10. Processes and systems to translate information and priorities into action, evaluate results, and modify as needed

Together, these factors can enable communities to function as learning systems in which people, actions, results, and knowledge are dynamically connected in the work to improve local health.

Needs, Issues and Gaps

Besides identifying the success factors outlined in the previous section, NCVHS received first-hand information from the community leaders about the gaps and challenges they confront related to data and trust. This section summarizes the major challenges, and offers an idea for a sustaining infrastructure to help communities meet them.

Data issues

Communities need access to relevant data; methods and skills to analyze the data and address local priorities and needs; and tools to make the data analysis usable and useful. The Committee has identified several areas in which community data and analytic assets need strengthening. In particular, the workshop participants stressed their need for more granular data across the board and for better analytic capacity to make appropriate use of the data. They discussed the possibility that a short list of standardized community health indicators, encompassing both health measures and social determinants of health, might facilitate local efforts and enable useful comparisons and monitoring.

Attention must be paid to the quality of local data in terms of integrity, accuracy, timeliness, and completeness, as well as to educating community members so they can draw appropriate conclusions from local data. The growing interest in linking and using data from heterogeneous sources, together with the growing power and availability of data, raise a host of challenges associated with aggregation, scale, data quality, and integrating data on the social determinants of health into community health policy and practice.

Stewardship + privacy protection + engagement + governance = Trust

Trust is the climate that enables the cooperative use of data for presumed public benefit by providing necessary protections and cultivating an engaged and informed citizenry. Trust takes time and effort to build, and can be jeopardized by actual, perceived, or feared abuses of information, any one of which can result in the loss of important population health data and undermine health improvement efforts. Different sub-communities and stakeholders have different interests and concerns related to trust that must be addressed. For their part, data stewards controlling potentially useful data can resort to a "lock-box mentality" for fear of violating a privacy law when privacy guidelines are not clear. As the data available for local use become more granular and linkable across diverse data sources, the need for protections and trust becomes more acute and complex. Significantly, an expert workshop participant reported his findings that technical protections such as de-identification are inadequate to assure the public that health data are being used appropriately and that privacy and confidentiality are protected.

All of these factors affect community health efforts and point to the need for a well-defined and clearly-understood privacy and security framework to guide local data use. They also reinforce the importance of integrating health data stewardship into community health practices—a topic on which NCVHS has issued a series of reports and recommendations. The Committee plans further work on trust, privacy, and data stewardship in a community health context.

Needed: An infrastructure to provide support, facilitate shared learning, and create economies of scale

The NCVHS Community Health Information Project has shed light on the need for a new kind of infrastructure to support, connect, and inform vanguard community health initiatives and enable others to follow their lead. A publicly or jointly supported infrastructure of standardized data, measures, and tools would greatly enable and empower communities to use data to improve local health. Providing this kind of support is an appropriate role for the Federal government. The following are important components of such an infrastructure:

- A privacy and security framework to guide communities in using local data;
- A standardized set of community health indicators;
- Training and technical assistance to improve data access, management, and analysis methods and competencies;
- Better data visualization tools and skills;
- Support and/or external facilitation to strengthen local financial and human resources, including those for coalition development;
- Support for public health departments to take advantage of Meaningful Use criteria as they evolve;
- Guidance on achieving data-informed improvement through effective leadership for change; and
- Mechanisms to enable communities to share knowledge and information and stay abreast of Federal and state resources and activities

Envisioning a Federal Role

The Federal government can do much to both seed and harness the energy of community health movements. Communities must be recognized as significant actors and data users, and support for local initiatives must be elevated to the position of a major national policy goal. It is critically important to strengthen the public health information infrastructure so it parallels the clinical information infrastructure and can fully interact with it. In an era of growing need and shrinking resources, Federal and local activities must be closely aligned so the work at all levels is mutually supportive and cost-effective. And local communities can and must play central roles in bringing about these improvements.

Conclusion and Future Directions

In conclusion, we want to emphasize as most urgent the need for a community-oriented infrastructure with the elements outlined above, including privacy and security guidance to help community leaders protect individuals and preserve trust as they work to improve local health. The environment for local health efforts is moving rapidly, and foundations, state and local governments, and Federal agencies are already doing significant work to enhance local efforts. This project has highlighted areas in the NCVHS health information policy purview where research and/or theoretical work could strengthen the data sources, structures, and uses available to communities. The Committee will continue to work with the Department and others to address these needs.

1. Introduction

Health is a community affair.[1]

In recent years, striking new solutions have emerged that are strengthening communities' ability to improve local health and well-being. Health information technology is elevating the role data can play in local priority-setting, planning, program development, and evaluation. As a result, communities have new and growing opportunities to develop data-driven policy and programs, and data have become an effective tool for organizing people to work together on setting priorities and carrying out initiatives. Communities have access to more usable data on local health and its determinants, and to dazzling ways to display and disseminate information to stakeholders. Health information exchanges are making it possible to extract clinical data from electronic health records for community uses. In addition, the growing recognition of the role of the social determinants of health is energizing local action across a broad range of factors that influence community health. This perspective is stimulating the engagement of citizens, community-based organizations, and local government around a host of interrelated local issues with the goal of improving population health.

The NCVHS Community Health Information Project is an effort to identify how communities can become *learning systems for health* and what resources exist and are needed to help them. The project is a response to the upsurge of innovative community health initiatives and public and private sector investments in local data use, juxtaposed against the reality that most U.S. communities face daunting challenges in taking advantage of the opportunities. In recent months, NCVHS talked with community leaders from around the country and identified common success factors and challenges among leading-edge local health initiatives. This report tells the story of bottom-up solutions, tailored to local needs and powered by local talent. It describes what communities are accomplishing despite limited resources, and what they say they need to do more.

The Committee has come to believe that getting usable data into the hands of communities and ensuring that they have the tools and capacities to use them could move the nation a long distance toward realizing the public benefits of the informatics revolution. Not just leading-edge communities but all U.S. communities need to operate in a national policy environment that supports local data collection and use. They also need the support of an infrastructure with adequate local data and analytic capacities and an overarching privacy and security framework. NCVHS believes that if undergirded and connected by such an infrastructure, local health initiatives could become a powerful engine for population health improvement on a national scale.

The Federal government has a critical role to play in helping local efforts succeed; and the Committee believes that a relatively small but strategic investment along these lines could generate large efficiencies. Government is already investing in community health work—for example, in the

---

[1] National Commission on Community Health Services , *Health Is a Community Affair*, 1966 (called the Folsom Report after its Chair). See also Dean W. Roberts, MD, "Health is a Community Affair: Preview of the Final Report of the National Commission on Community Health Services," *Journal of the American Medical Association*, April 25, 1996, Vol 196, No. 4.

HHS Community Health Data Initiative. As the Federal advisory committee on health information policy, NCVHS is interested in what else HHS and other agencies can do to help more and more communities make the fullest and safest use of local data to improve local health.

This is a critical time for such an investment. Communities are facing greater human need and more limited resources than they have seen in many decades, and struggling with persistent health disparities among segments of their populations and severe resource constraints in their public agencies. This confluence of pressures makes it difficult to seize new opportunities and follow the lead of the innovators; and even the innovators find it challenging to sustain what they have built.

This report draws lessons from a group of leading-edge local projects (see page 9) and presents a vision for strengthening local data and capacities, with specific suggestions for ways to increase the momentum toward better local health. Sections 2 and 3 present the Committee's findings about local data access and use and the information-related issues communities are facing as they try to improve local health. Sections 4 and 5 look to the future, with comments on how the Federal government could support and sustain local efforts and what kinds of work are needed to inform infrastructure development. The time has come to recognize communities as significant actors and data users, and to elevate support for local initiatives to the position of a major national policy goal.

The NCVHS Community Health Information Project has deep roots in the Committee's population health mission and the vision statements and policy recommendations it has promulgated over its 61-year history. From 1991 to 1996, the NCVHS Subcommittee on State and Community Health Statistics focused primarily on community health assessment and the role of state health statistics agencies in facilitating it. It issued a report in 1993, and a letter and recommendations to the Secretary in 1997 calling for Federal action to strengthen state centers and improve local data access. The present report is a direct descendent of those reports, and of more recent ones that outline the Committee's visions for the National Health Information Infrastructure, 21st century health statistics, data stewardship, and enhanced information capacities for health. Past NCVHS recommendations on privacy, population health, and eliminating health disparities and ongoing NCVHS work on quality and standards also inform this project.[2]

What Do We Mean by *Community*, and What Is a *Learning System for Health*?

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. This sense is sometimes combined with recognition of mutual responsibility. The present NCVHS project and report focus on *geographic* communities, in which members are connected through the place where they live. A geographic community has resources, leaders, and governmental and grass-roots organizations capable of joining forces around common concerns about health and other matters. The choice of this geographic frame stems from the principle that *place*

---

[2] NCVHS Letter to the Secretary with Recommendations on Community Health Assessment (July 2, 1997). http://www.ncvhs.hhs.gov/commrec1.htm

The bibliography at the end of this report lists the most relevant NCVHS reports. All NCVHS reports, letters, and meeting summaries are posted on its website, http://www.ncvhs.hhs.gov/.

matters—that is, the place where people live has a large impact on their health and well-being. This is a motto of the community health movement, and the focus of an informative 2007 report from PolicyLink and the California Endowment.[3]

Of course, geographic communities are not homogeneous; each is composed of many subcommunities, neighborhoods, sectors, interests, and levels of need and capacity. Indeed, the disparities among different neighborhoods and population segments are a major focus of many community health endeavors. In addition, geographic and virtual communities are not mutually exclusive. As the communities profiled in this report illustrate, geographic communities participate in and/or encompass many forms of virtual communities; and many local communities use social media to help residents stay connected and informed.

The communities featured in the present NCVHS report are of varied sizes and represent different jurisdictions—cities and towns; targeted neighborhoods; sub-populations, such as children with asthma, dispersed across a larger area; counties; groups of counties. (NCVHS also examined statewide activities in Indiana and South Carolina that function as important community supports.)

This report identifies a set of factors that successful community health improvement efforts seem to have in common: trust, collaboration, access to useful data, agreement on priorities, support of many kinds, and mechanisms for translating information into action and evaluating the results. All are grounded in a broad understanding of health and its determinants. Together, these factors enable communities to engage in data-driven action and knowledge management around local priorities. And they are core features of a *learning system for health*.

In a learning system, people, actions, results, and knowledge are connected in continuous feedback loops that enable improvement and change—learning—over time. Health information technology is making it increasingly possible for communities to become dynamic learning systems that are working to improve local health. When it comes to population health, the local community may well be the quintessential learning system, because it can deploy all of the success factors named above. In addition, health is affected by multiple determinants—economic status, education, transportation, physical activity, food quality, environmental quality, and more; and community initiatives can mobilize a range of actors to address many determinants, as the examples in this report illustrate.[4] In short, the local community is precisely the context in which trust and engagement in efforts to improve the quality of life can be nurtured.

The Institute of Medicine's Roundtable on Value and Science-Driven Healthcare recently completed a two-year study of what it called the "learning health system," generating eleven

---

[3] PolicyLink & California Endowment, "Why Place Matters: Building a Movement for Healthy Communities." 2007.

[4] See footnote 1 on the Folsom Report. This landmark 1966 report envisioned what it called a *community of solution*, defined as "a geographic area within which health problems can be defined and dealt with." The insights and approaches of the Folsom Report resonate throughout the present report. Many aspects of the Folsom Report's vision are being realized as more and more communities across the U.S. work for local health, enabled by new information technologies.

reports.[5] A vision of the health care system as a learning system is a useful frame for fostering quality improvement, the major focus of the IOM study. As critical as it is to health, though, the health care delivery system's impact as a change agent is limited. In this paper, NCVHS proposes a broader perspective on the learning health system, with health care playing a critical part within it. Health care is directed at individuals and families; and even the important role of the patient in health improvement is similarly limited unless it connects to larger efforts. Health is won or lost in the community more often than in the clinic. To have maximum impact on patients' health, health care providers and institutions need to be part of the learning systems in the communities where they reside. By doing so, they can accomplish the kind of primary, "upstream" prevention and chronic illness management that otherwise are beyond their reach.

2. Learning from Local Solutions

This is a joint project of the NCVHS Subcommittees on Population Health and on Privacy, Confidentiality, and Security. They identified 14 leading-edge community projects in eleven states and four U.S. regions, and invited the leaders to participate in workshops in Washington, D.C., in February and May, 2011. To provide a broad context for the Committee's explorations, the first workshop examined the communities' general experiences using multiple data sources to improve local health. The second workshop focused in on privacy and trust issues related to data. The 14 communities are shown below, and profiled in Appendix 1.[6]

Figure 1. Locations of Featured Communities

---

[5]http://www.iom.edu/Reports/2011/~/media/Files/Activity%20Files/Quality/VSRT/Core%20Documents/LearningHealthSystem.pdf

[6] Presenter lists, slides or written testimony, and summaries of both workshops can be found on the NCVHS website, http://www.ncvhs.hhs.gov/

The local actors and leaders in these projects come from public health departments (primarily county-level), community-based organizations, health care institutions, health information exchanges, and government agencies as well as academic and scientific institutions and foundations. All have the support of their state health departments, and some have Federal agency partners, as well.

These coalitions and ones like them around the U.S. are devising strikingly creative ways to link policy and program planning directly to data gathering and analysis in their communities. Despite limitations in funding, available data, and local capacities, they are using local data to drive policy, planning, and change for better community health. Their approaches and targets are diverse, with focal issues that cross a spectrum from changing social and environmental conditions to promoting healthy behaviors to improving health care access, quality, and coordination. The case descriptions at the end of this report illustrate the unique combinations of stakeholders, priorities, and data-based strategies being crafted in communities across the country.

This section presents what NCVHS learned from its informants about community health activities in three key and interdependent areas—coalition-building, data collection and use, and trust-building—followed by a summary of common success factors. Section 3 outlines major gaps and challenges in these same areas, and offers an idea for a sustaining infrastructure to help communities fill the gaps and meet the challenges. Section 4 discusses the potential Federal role in meeting these needs.

Identifying Priorities and Building Partnerships and Collaboration

To enlist a range of partners in crafting a common vision for their community's health and sharing in the work to bring it about, local projects need strong community organizing skills as well as good population health data; and both depend on trust. Such coalitions often extend well beyond the boundaries of the public health department and include community activists and leaders, health professionals and health care institutions, research scientists and academics, members of local government, and other partners. The workshop presenters stressed the need for adequate time and resources to build and sustain these partnerships—both hard to come by in typical funding cycles.

Involving citizens and community groups; generating new partnerships

The stories of citizen engagement were among the most exciting ones NCVHS heard during the workshops, as community leaders described their activities to engage citizens; recruit community organizations such as churches, schools, and health care institutions; and stimulate the creation of new partnerships around targeted health objectives such as reducing teen pregnancy or improving neighborhood walkability. Coalition-building involves bringing major stakeholder organizations to the table where decisions are to be made about priorities and the uses of information and resources. Educating citizens and community leaders about the benefits and mechanics of data use and involving them in decision-making are key strategies in creating trust around local data use.

Virtually all of the 14 projects profiled in this report illustrate collaborative local work. In Olmsted County, Minnesota, for example, the Health Department and the local school system, longstanding partners, are working together in a Beacon Project to reduce the impact of childhood asthma.[7] In Mahoning Valley, Ohio, the public health department is collaborating with United Way and Easter Seals, among other organizations, in a campaign to increase enrollment in the Children's Health Insurance Program. The policy director of King County, Washington's health department speaks of its community partners as members of the "data audience." The South Carolina project illustrates how having a neutral convener—in this case, the state's data agency—can promote trust.

As will be seen repeatedly in this report, participation in wider, regional or national networks is another form and level of collaboration that helps communities function more effectively and make the best use of limited resources. Many community coalitions participate in regional or national networks that provide technical assistance, data services, program ideas, and other forms of support. Examples include the Centers for Disease Control's Racial and Ethnic Approaches to Community Health (REACH) Initiative (South Los Angeles), the CIM (Community Issues Management) Coalition (Boone County, Missouri), and Minnesota's network of county health departments (Olmsted County).

Political scientist Sidney Tarrow of Cornell University has identified four elements that are necessary to maintain a coalition of individuals or organizations: Members must frame the issue that brings them together with a common interest; they must trust each other and believe that their peers have a credible commitment to the common issue(s) and/or goal(s); the coalition must have mechanisms to manage differences in language, orientation, tactics, culture, ideology, etc. between and among the members; and members must share incentives to participate and, consequently, benefits.[8] Accordingly, the theme of collaboration is implicit in the following discussions of local data capacities and trust.

The key role of data

Many community representatives stressed that local data are a key tool in recruiting partners and enabling them to reach consensus on priorities. The principle that "what gets measured gets managed" applies; data—especially actionable data—can be persuasive about the magnitude of particular problems and helpful in identifying the most pressing ones. Presenters described using data strategically to recruit political allies, such as in South Los Angeles, where members of local government are working with local activists to reduce obesity rates by changing urban design and land use management policies.

---

[7] The Beacon Community Cooperative Agreement Program, administered by the HHS Office of the National Coordinator, provides funding to 17 selected communities throughout the United States that have made inroads in the development of secure, private, and accurate systems of electronic health record (EHR) adoption and health information exchange.
http://healthit.hhs.gov/portal/server.pt?open=512&objID=1805&parentname=CommunityPage&parentid=2&mode=2&cached=true

[8] http://en.wikipedia.org/wiki/Coalition [will try to substitute a better reference]

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

The goal of the Community Health Council's REACH Initiative in South Los Angeles is to reduce the disproportionately high diabetes and cardiovascular disease rates and severity among African American residents. The major focus is changing the environment to support people's healthful choices related to food and exercise. 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 Los Angeles, 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 also influenced the South Los Angeles General Plan and led to the development of two new full-service supermarkets in the area.

Developing Data around a Broad Definition of Health

Leveraging and linking multiple data sources on health and determinants

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-based understanding of health and its determinants. Together, these elements can be as transformative for traditional public health practices as they are for health care.

The demand for local data is large and growing as community health initiatives recognize the need to link, analyze, and communicate about data from multiple sources. NCVHS learned that 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 health records). To understand and have an impact on social determinants of health, 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. The presenters also stressed the importance of qualitative data, which tell the compelling stories of local health problems and solutions and help establish priorities and directions for local planning and intervention development.

Focusing on population health and prevention makes it essential to look beyond medical factors to local determinants such as food, physical activity, public safety, land use, and socioeconomic factors, and to join forces to work on these multiple fronts.[9] Data tools can enable local citizens and leaders to identify the key health issues affecting their communities and address them by changing the underlying policies and social and environmental determinants. Communities are likely to focus on determinants that are amenable to change through local action, as can be seen in the current national attention to obesity as an underlying cause of prevalent chronic diseases such as diabetes. Several of the communities featured in the NCVHS workshops are tackling the high rates of chronic disease in their areas by improving access to healthy food and exercise opportunities, particularly in neighborhoods and population groups with disproportionately high prevalence of chronic disease. Examples include South Los Angeles (described above), Boone County's use of Community Issues Mapping (CIM), and Sonoma County's I-Walk initiative.

Examples of wide-ranging community health metrics

"Changing what we measure can lead to new directions in how we act."
—H. Koh, MD, MPH, Assistant Secretary for Health[10]

Housing (e.g., home mortgage loans)	Immunization rates
Unemployment index	Health insurance coverage
Poverty index	Life expectancy
Gender equity (e.g., duration of paid maternal leave)	Child welfare
Education (e.g., high school graduation rates)	Elder welfare
Crime, incarceration, justice	Unwed teen birthrate
Environmental health/potential exposures	Distribution of Body Mass Index
Family and social support	Firearm-related injuries
Food quality, hunger (e.g., food stamps enrollment)	ED visits for interpersonal violence
Community safety	Tobacco sales
Built environment (e.g., walkability)	Drug overdose deaths

Better local-level data and technology would be beneficial in different ways for different stakeholders. To cite a few examples, a local health department needs to track and monitor local health, disseminate information to the public, and communicate with other local government agencies. Its technology needs could encompass online restaurant inspection data, reverse-911 capacity to reach the public, quick links with public safety and school department, local health data bases for community knowledge and grant applications, GIS to map rabid bats, guides to open space and department programs, and extensive emergency response capabilities, among other sources. Community-based organizations and agencies need data for grant writing, to follow clients

---

[9] The 2002 NCVHS report *Shaping a Health Statistics Vision for the 21st Century* offers a detailed schematic of the Influences on the Population's Health (page 9 of that report). Many schemas and models of health determinants from different sources could be cited. As one example, the California Endowment report *Place Matters* (referenced above) groups determinants into four "environments"—social, economic, physical, and service.

[10] "The Ultimate Measures in Health," *Public Health Reports Supplement 3,* Vol.126, Issue 9 (2011), p.15.

and engage in outreach, and to develop and evaluate programs. Grass-roots advocates and activists need data to assess the outcomes of policies and programs and understand disparities in well-being within the community. Local residents need information about bus routes, clinic hours, walking trails, public safety issues, farmers' markets, and much more. Clinicians and communities need community-based data such as home blood pressures, linked to clinical records, to attain important health goals and locate where disparities exist that could be addressed by joint action.

Linking clinical and population health data

As health information exchanges (HIEs) form around the U.S., early examples are emerging of ways to enhance the synergies between the uses of clinical and public health information to improve community health. Local and state-level HIEs are playing critical roles in making two-way connections between public health and clinical domains, and these synergies are broadening the conception of both domains. If more HIEs follow the lead of the ones featured in this report and make population health an explicit part of their missions, they could become a significant force for population health improvement.

The February NCVHS workshop featured three information exchanges that are pointing the way forward. Grand Junction, Colorado, is developing the region's HIE infrastructure explicitly to support population health management; and it is already exchanging data among physicians, health departments, hospitals, and the community mental health system. The Indiana HIE is working with the State Health Department on population health improvement projects, including incorporating the state's immunization database to make it possible to monitor physicians' immunization rates and incentivize improvements. The Bronx Regional Health Information Organization is piloting a service to reduce hospital readmissions by notifying physicians when their at-risk patients are admitted to a local emergency department or hospital.

Generating local data

Many communities are developing ways to produce and compile data locally to augment secondary sources such as state and Federal surveys. 2040 Partners for Health, an initiative in five Denver neighborhoods, provides an outstanding example of "home-grown" data generation of this kind. Local leaders and community members collaborated on research led by the University of Colorado's Department of Family Medicine in this project to conduct community-based participatory research and generate actionable data. The Denver partners have devised trust and governance mechanisms for using the data (described in Section 3, below) that are another critical component of this initiative and a model for other communities. In California, Sonoma County's Health Action coalition conducted an inventory of county health care providers as part of a study of access issues and posted the data on a county website, described below. Boone County, Missouri, uses a tool called Community Issues Management (CIM) as a platform for local reporting, planning, and citizen engagement.

Community health assessments are another useful tool for identifying local health priorities, developing targeted interventions, and monitoring progress. Several states (notably, California, Ohio, Minnesota, Wisconsin, and Connecticut) are helping communities develop standardized indicators. Minnesota requires all of its counties to conduct community health needs assessments every five years. The new (2010) Federal requirement that non-profit hospitals must document

public benefit in terms of specific community health needs is likely to increase the use of this type of assessment across the U.S.[11]

All of these factors—local surveys, community health needs assessments, state mandates, and new Federal requirements—contribute to the likelihood that local health data will become an increasingly important tool in improving community health.

Innovatively displaying and disseminating data: dashboards and more

The central theme of this report is the importance of connecting people to data to enable local problem-solving. Many people want to see how their communities are doing in health and quality of life, and to track progress and be able to compare their own status to local objectives and other communities. Once again, health information technology is making much possible. Many leaders now regard sophisticated information display and dissemination tools as an essential part of building learning environments in their communities.

Sonoma County: 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 website, which links all the county's community health projects together, is recognized as a national model. *Healthy Sonoma* 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 county's Health Officer talked with NCVHS about the benefits of having expert external support of this kind—especially for smaller communities with more limited staffs, such as Sonoma County.

At its February workshop, NCVHS learned about a leading-edge example of data display, the *HealthySonoma* website of Sonoma County, California.[12] The website links all of the county's community health projects together and provides a platform for planning and action. Regularly-updated data drawn from national, state, and local sources are displayed on user-friendly dashboards. Healthy Sonoma is one of more than 30 "healthy community" websites customized

---

[11] The ACA stipulates that IRS Section 6033 (b) require tax-exempt hospitals to report in their annual Form 990 how the organization is addressing the needs identified in each community health needs assessment. At the request of the IRS, the CDC Policy Office is leading an interagency project on community health needs assessment, spurred by the ACA's community benefit clause.

[12] http://www.healthysonoma.org/

and maintained by Healthy Communities Institute (HCI) for communities across the U.S.[13] These sites graphically illustrate the range of components and feedback loops involved in a community-based learning system for health: data collection and analysis, display and dissemination, community organizing, priority setting, program and intervention planning, implementation, and evaluation—and around again and again, all combined with sharing and networking with other communities. The founder and director of HCI has called this lively process "informed democracy."[14] Another HCI community provides a good model of the innovative use of social networking tools to promote community health: Northeast Florida Counts, a seven-county initiative, uses Facebook, Twitter, and Quick Response (QR) codes to invite and connect people to its HCI website.[15]

Mobilizing for information-driven action and evaluation

For many communities, learning to base program design, implementation, and evaluation on data and information is a work in progress. Some of the projects featured in the February workshop were young enough still to be in the data-gathering stage, and presenters said their communities had not yet moved fully into the implementation stage. The Federal government and other entities are actively facilitating the translation of knowledge into practice in the clinical arena; local communities need the same kind of support, along with opportunities to share learnings with other communities. The HCI database of some 1700 "Promising Practices," complete with contact information, is an example of a useful tool for guiding implementation. The Institute ranks the practices submitted by member communities as either "evidence-based," "effective," or "good ideas." The database can be accessed free of charge from any HCI community site including those referenced below.

Town-gown partnerships to improve local health

One of the strongest take-home messages from the February workshop participants concerned their communities' need for stronger analytic capacities, both on their own staff and through external expert assistance. Several of the communities work with local academic or research institutions that help with research, analysis, program development, and/or data management. (See the case descriptions in the appendix for examples, including Boone County, Missouri, and Mahoning Valley, Ohio.) This illustrates a road-tested model for strengthening local capacity in an era of diminishing government resources. Some communities augment local or regional assets with technical assistance and other forms of support from entities such as the HHS Community Health Data Initiative, the Robert Wood Johnson Foundation, the California Endowment, and the HHS Beacon Community project. Both Grand Junction, Colorado, and Olmsted County, Minnesota, are Beacon Communities. In addition, state health surveys such as the California Health Interview Survey provide local data, often along with technical support for analysis. State universities often conduct these surveys and provide the analytic support.

---

[13] http://healthycommunitiesinstitute.com/

[14] Presentation to Mendocino County Health and Human Services Advisory Board, June 22, 2011.

[15] www.nefloridacounts.org

Building Trust

All community members, including health care and public health workers and researchers, must be able to depend on legal and regulatory privacy protections that guard personal health information. The protections are the first line of defense in assuring community members that their personal and community-level data are adequately protected and appropriately used. As discussed below, further efforts and leadership are needed to define a privacy and security framework to guide the innovative uses of local data emerging in communities across the country.

The May, 2011 NCVHS workshop focused on privacy and confidentiality issues in the use of individual and aggregate data for community health. It featured illustrative local initiatives, the research findings and analysis of two scholars, and advice from a national data organization. The community stories illustrated the fact that legal and regulatory protections must be embedded in a broader, relational fabric of trust, based on respect. The protections help create the conditions for what might be called *earned* trust. NCVHS learned that promoting trust takes time and requires a multi-faceted, "layered" approach involving not just technological mechanisms and data stewardship but also community education and engagement, transparency, and governance. This section describes community initiatives that illustrate elements of this layered approach. The more challenging and unresolved aspects of privacy and trust are discussed in Section 3, below.

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 help 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 to 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 community-based Data Review and Dissemination (D-RAD) group ensures that data are used in beneficial ways and do not stigmatize community residents. D-RAD also reviews the program's extensive bilingual resource materials to make sure they contain clear, useful information. The data and community organizing provide the foundation for a range of community-driven efforts to improve community health and its determinants. These programs, which operate in tandem, emphasize local participation and engagement. The Denver presenters stressed that their community-based approach is what transforms *community engagement* into *community ownership*.

Educating community members and leaders about data uses and benefits

Research shows that community members want to know in advance about the potential uses of their data and data about their communities, and they want to be asked for permission to use the data and/or to participate in decisions about data uses. NCVHS learned that educating and engaging community members around the intended purposes of data use can have a significant positive impact on public confidence.

Dr. Jeffrey Botkin of the University of Utah reported on a research project in the Intermountain Area to engage members of the public with the ethical, policy, and personal issues associated with research using biobanked tissue samples. His project compared different forms of public outreach and used a video to educate people on the risks and benefits of research with tissue samples. The study found that educating the public increased their support for authorized sample use for research. This raises the possibility that with strong protections and better information and transparency about data uses, more people can come to see the use of personal and community health data for public good as appropriate and beneficial.

Involving community members in decisions about data use and more

Involving community members in data use decisions can promote not only trust but a sense of agency, a key ingredient in both health self-management and the full expression of citizenship. The more disenfranchised community members feel, the more important it is to involve them in decisions. There are many models of community engagement. One possibility is direct participation in planning data acquisition and use; another is the use of focus groups or polling data to ascertain community preferences. Another is reliance on community leaders such as a city council for agreement on uses of data from the community. Some call this "community consent."[16] Still another approach is to build long-term relationships with community members so they trust that data will be used in acceptable ways.

Community engagement itself can be an effective form of governance, as the Denver-based 2040 Partners for Health demonstrates (see sidebar above). This initiative not only engages local residents in research; its community-based Data Review and Dissemination (D-RAD) group makes the decisions about what data will be used, and how. The Denver activities provide a model of the layered approaches to building trust described above, including community engagement and education, transparency, and governance of data use.

Trust-building among organizations and agencies that are data sources

Data silos are widely recognized as a major barrier to effective sharing of useful information. These silos can be the result not just of interoperability problems and/or bureaucratic constraints but also of differences in ways of doing business, turf issues, and a lack of trust among data sources. Communities must find ways to overcome all of these barriers.

In Mendocino County, California, for example, an ad-hoc group of public and private service providers came together to address the issue of "frequent flyers" in the region who were responsible for a disproportionate part of their agencies' expenses. The group's members spent many months developing trust among themselves before they were able to lower their turf barriers and begin to pool data and develop comprehensive, cooperative solutions. Once high-risk individuals are identified, the project secures their consent to use their personal data to devise comprehensive case management plans. The fledgling initiative recently was awarded a grant to expand its case management and service coordination work. Its collaborative approach to problem-

---

[16] [Add reference per Leslie Francis]

solving was cited as a major reason for awarding the grant, and it is seen locally as a model for work on other issues.

Governance fosters a sense of ownership and control

There are at least two forms of governance, community engagement and oversight. The Denver initiative described above is a robust example of governance through community engagement in policy development. Oversight mechanisms can provide a measure of simultaneous monitoring and guidance. Of course, communities that approach governance using a community engagement or community consent model must also ensure basic privacy and security protections, to protect individual identities.

Summary: Success Factors

Every community is unique, and communities are working out locally-achievable solutions tailored to local conditions. Still, NCVHS has identified common elements among local approaches that may be instructive to other communities. To summarize, the workshop highlighted among the featured communities these ten common, interconnected success factors:

1. A galvanizing health concern
2. A comprehensive understanding of health and community health
3. A collaborative culture; social capital
4. Trust, achieved through regulatory protection, governance, and community engagement
5. Access to data on local health and its determinants, plus analytic capacities
6. Data display and dissemination capacities
7. Functioning coalitions, community engagement, and agreement about priorities
8. Organizational and technical support
9. Political and financial support
10. Processes and systems to translate information and priorities into action, evaluate results, and modify as needed

Together, these factors can enable communities to function as learning systems in which people, actions, results, and knowledge are dynamically connected in the work to improve local health. Stepping back from particularities, the following picture of communities as learning systems emerges: Local leaders create opportunities for collaboration and coalition-building, engaging community members and organizations and partnering with public health, health care, and related sectors such as transportation and housing. The partners draw on multiple data sources, perhaps augmenting established ones by conducting their own local research with the participation of community members. They assure privacy and build trust through a web of interrelated practices and protections. They use the data to analyze major health issues, agree on priorities, enlist additional partners, and develop policies and programs; and 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.

[place-holder for possible "Community as a Learning System" graphic]

3. Needs, Issues and Gaps

Miles to Go

While the previous section focused on the promising strategies gleaned from the community presenters, this section highlights common challenges and priorities for future action.

In July, 1997, NCVHS sent the Secretary recommendations on community health assessment that prefigure many of the issues addressed in the present report. The recommendations were based on three years of hearings that highlighted the problems facing communities as they tried to use local data to improve community health. The problems included a lack of quantitative expertise and equipment among local public health staff; limited budgets; a scarcity of good local data and the inability to disaggregate national and state data; inadequate privacy and confidentiality protections; standardization issues that made locally-generated data difficult to share and impossible to compare with other jurisdictions; and data stewardship/control issues and a lack of trust.[17] Developments in the ensuing 14 years have gone some distance toward creating a tipping point favoring community health; but many of the same obstacles still remain. As NCVHS heard from its informants, local health departments still lack staff with quantitative and analytic expertise and need better local data; and to make matters worse, many are losing support through federal and state budget cuts that may in real terms put them behind where they were in the mid-1990s.

The Executive Director of the National Association of Health Data Organizations (NAHDO) presented a contemporary perspective on the challenges of accessing and using multi-source data at the May 2011 NCVHS workshop. After outlining the barriers related to data gaps, interoperability, and reliable ways to match patients to their medical records, she stressed the need for standards for the collection of identifiable, granular data in uniform formats; for release practices; and for identifiers for patients and providers. She offered eight NAHDO recommendations, and called on NCVHS to lead a national discussion about privacy and confidentiality issues aimed at bringing about greater cooperation in maximizing the utility of local data.[18]

Data Issues

More granular data across the board, and better analytic capacity

The February workshop brought to light a clear opportunity to strengthen local data and analytic capacities and help communities connect with each other and with external resources. In short, communities need access to relevant data, analytic capabilities to analyze the data and address local priorities and needs, and tools to make the data analysis usable and useful.

The authors of a paper for the 2011 World Health Organization's World Conference on Social Determinants of Health put it this way: "Presented wisely, used effectively, directed to the right audience, within the context of the social determinants of health, data can persuade, elicit interest, help inform, engage, advocate, and initiate action. Existing data framed in a manner that speaks to

---

[17] See footnote 2.

[18] The NAHDO recommendations are presented in Appendix 2.

community needs and issues and that the people can connect with . . . are much more likely to resonate across the political spectrum."[19]

The community presenters at the NCVHS workshops stressed that data gaps limit their ability to make informed decisions, design and evaluate effective programs, and influence decision-makers. In particular, they need more granular data on neighborhoods, sub-populations, environmental factors, and resources, as well as stronger capacities to analyze and use data. Some communities have strong internal analytic capacities; others outsource analysis and data display functions to external experts, as intermediaries emerge to play these roles. Still, virtually all of the informants said they need stronger capacities in informatics and epidemiology to make full use of available data, along with better ways to display and disseminate data. One area for future exploration is how the nation's data experts can be made more available to communities to help them develop data-based policies and programs.

The potential uses of clinical data to understand and advance community health is a relatively new area of exploration. Public health has information that clinicians can use; and clinical information systems can provide useful information to public health in response to targeted queries. Stronger bridges are needed between public health and clinical information systems to realize this potential, so that together they can address issues of common concern such as care transitions, immunizations, and over- and under-used medical services. The building-blocks for such a bridge between public health and clinical data include, first, a reliable flow of clinical data to and from public health for surveillance and tracking; second, a way for public health to benefit from access to clinical data on population cohorts in response to targeted queries; and third, creation of multipurpose data bases such as the all-payer claims data base, to permit analysis of paid claims by complete episodes of care. The work under way by states and NAHDO to create all-payer claims databases offers the prospect of a complementary data source that will be useful for local population health endeavors.

Most of the nation's 3,000 county health departments need to develop stronger technological and analytic capacities to gain access to useful data that health information technology is making available. New Federal requirements on Meaningful Use, if taken to their full potential in Stage 3, could increase the opportunities for synergy between public health and clinical domains. However, the workshop participants made it clear that local public health departments would need help to be able to take advantage of such an opportunity.[20]

Standardized community health indicators: part of the solution?

At the February workshop, participants discussed the potential benefits of having a standardized set of community health indicators for assessing local health and comparing their communities with

---

[19] Novilla L, Barnes M, et al., "How can we get the social determinants of health message on the public policy and public health agenda? For WHO World Conference on Social Determinants of Health, Rio de Janeiro, Brazil, 19-21 October 2011.

[20] The Health Information Technology for Economic and Clinical Health (HITECH) Act's Meaningful Use criteria incentivize providers to collect standardized data in electronic health records (including demographic data), and enable the transmission of relevant clinical data to public health departments. http://healthit.hhs.gov/portal/server.pt?open=512&objID=2996&mode=2

others over time. The ideal form of such an instrument may be both short and broad, with information on key determinants as well as health status indicators. Communities also need the flexibility to be able to select indicators that are relevant to the local setting. The Leading Health Indicators for Healthy People 2020, which were developed by HHS based on recommendations from the Institute of Medicine in a March 15, 2011 Letter Report, are likely to be a useful resource for identifying local indicators.[21]

In an example from the United Kingdom, charts from the London Health Observatory show key indicators for monitoring health and social inequalities for all local authorities. The four local-level indicators are life expectancy at birth; children reaching a good level of development at age five; young people not in employment, education or training; and percentage of people in households receiving means-tested benefits. An index shows the level of social inequalities using three indicators: life expectancy at birth; disability-free life expectancy at birth, and percentage of people in households receiving means-tested benefits.[22]

In their community needs assessments, some communities integrate qualitative data acquired from focus groups, key informant interviews, and other sources with quantitative information to help establish priorities and directions for local planning and develop workable interventions. Qualitative information of this kind can be a rich source, especially if communities have access to support and resources to help them understand how to gather and use the information appropriately.

Data quality issues

Data quality combines the attributes of integrity, accuracy, timeliness, and completeness. Questions exist about how to assess and assure the quality of locally-generated data so that communities can depend on their validity. Some experts wonder, in a related issue, whether today's "data liberation" activities might contribute to random data overload rather than fulfilling the intended purpose of providing the kind of local data that can evolve into useful information and knowledge to inform effective decision-making.[23] A targeted investment in technical assistance to help communities analyze and use the data could yield a large return. Concerns also exist about the adequacy of privacy protections for "liberated" local data.

---

[21] Institute of Medicine, Leading Health Indicators for Healthy People 2020, http://iom.edu/Reports/2011/Leading-Health-Indicators-for-Healthy-People-2020.aspx

See also the HHS Office of Disease Prevention and Health Promotion Publication, ODPHP Publication No. B0132, November 2010. www.healthypeople.gov.

[22] "Health Inequalities – A Challenge for Local Authorities." Marmot Review Fair Society, Healthy Lives 2011. http://bit.ly/k6YC8x

[23] "Data liberation" is an informal but apt term for open data and data access. It originated in the computing world and is also used, informally, in the context of public programs such as Open Government and the Community Health Data Initiative. http://www.hhs.gov/open/plan/opengovernmentplan/initiatives/initiative.html

A September, 2011 interview with HHS Chief Technology Officer Todd Park in *Healthcare Technology Management Magazine* said, "His focus is less about optimizing technology and more about increasing the availability of public health information. … Park has overseen numerous initiatives aimed at data liberation and has witnessed firsthand the power of public-private collaborations to make public health information, well, more public. http://www.cmio.net/index.php?option=com_articles&article=29157

Whatever the data source, communities hoping to gather, link, and interpret disparate data need not only analytic capacities to interpret the data correctly but also educational capacities to help the public draw appropriate conclusions from the data. Individuals who are not trained in science, logic, or statistics may mistake correlation for causation or make other errors in interpretation. As community members are exposed to more data about local health, they need to learn how to distinguish between coincidence, association, and causation and to discern which may be involved (or trust others to do so) when they see apparently related events—for example, the introduction of SMART meters and the incidence of brain cancer. This area has ripe potential for education.

Novel ways to combine and use data

The growing interest in using aggregated data from heterogeneous sources for community health work raises a number of challenges that are ripe areas for expert examination. A foundational question is how to aggregate and use data at the community health level in ways that learn from prior data aggregation efforts. These past efforts need to be mined for their lessons on key principles for aggregating data and avoiding known pitfalls. (Appendix 4 contains further observations about aggregation issues.)

Two forums on local data use, hosted in 2010 and 2011 by the Institute of Medicine and HHS as part of the Community Health Data Initiative, have stimulated and highlighted new ways to combine data from disparate sources to produce tools for promoting local health.[24] While these innovations have generated considerable excitement, it will be important to ensure that the information they generate is valid and meaningful, and that they are adequately protecting individual privacy.

There are also challenges related to operationalizing the use of actionable data on social determinants. The aforementioned WHO paper explores the challenges involved in leveraging and combining disparate data sources: "[T]ranslating the social determinants of health through policy and practice is fraught with challenges…. [H]ealth data are typically reported as individual indicators rather than being presented comprehensively by geographic area within the context of non-medical indices that likewise affect health. Without accounting for the relationships between health outcomes and social determinants, there is no way of fully assessing the impact of policies and programs on the health of the people.…"[25] Progress in these areas will help communities leverage local data more rigorously and effectively in pursuit of their objectives.

Stewardship + Privacy Protection + Engagement + Governance = Trust

What worries some people, what they fear, and why

NCVHS has for more than 15 years studied and advised on the policy, legal, and ethical issues associated with data collection, linkage, use, reuse, sharing, release, and dissemination. The relevant domains of data use include research, clinical care, and community and population health.

---

[24] http://www.iom.edu/Activities/PublicHealth/HealthData/2011-JUN-09.aspx. A popular example is Asthmopolis, which combines geo-tracking with asthma inhalers to identify environmental areas that trigger a disproportionate number of asthma attacks (and use of inhalers).

[25] Novilla et al. (see footnote 19)

We use the term *trust* here for the climate that enables the cooperative use of data and information for presumed public benefit by providing the necessary protections and cultivating an engaged and informed citizenry. In the community health context, it is important to understand that different sub-communities and stakeholders have different interests and concerns related to trust and whether it is warranted.

Experience has shown that trust can be jeopardized by actual, perceived, and feared abuses of information, any one of which can result in the loss of important population health data. In a well-known example, millions of blood-spots taken in Texas for newborn screening were destroyed after a flurry of public concern about the reuse of this material for unknown purposes, thus precluding its use for important genetic research.[26] Some observers attribute the public reaction and data-destroying response to inadequate consent practices and transparency. The fears that persist among some Americans, and particularly members of vulnerable population groups, are understandable in view of perceived betrayals of trust such as those against Henrietta Lacks and her family, as reported in a widely-read recent book.[27] Mistrust can affect people's willingness to share what they regard as sensitive data, thus undermining data quality in areas of important work toward equity in our society. Communities, researchers, providers, and policy makers can learn from past mistakes such as these.

Both fear of violating a privacy law and a proprietary reluctance to reveal trade or organizational secrets can lead to what the Director of NAHDO has called "a lock-box mentality" on the part of data stewards responsible for potentially useful data. This mentality can be a major obstacle to data use for community health.

Local data use (or the prospect of it) can raise issues for neighborhoods and communities as well as for individuals. For example, community leaders might understandably be concerned if local data were used in a campaign against gun use, fearing that this would stigmatize their neighborhood and reduce property values. Similarly, a community or neighborhood might be sensitive about being characterized as obese. Concerns such as these point to the pressing importance of establishing a clear, standardized privacy and security framework for community local data use and involving local citizens in data use decisions. The purpose is twofold: to protect individuals and communities and preserve trust, and to ensure that data continue to be available for appropriate local uses.

Growing linkages and granularity can—and should—heighten privacy concerns

The practical and policy question, then, is under what conditions it is acceptable to use data for public benefit. Although HIPAA authorizes certain disclosures of identified personal health information for specified public health activities,[28] a more common practice is to use aggregate data from which the identifying information about individuals has been stripped—de-identified data—to

---

[26] [Leslie will supply citation and MN example.]

[27] Skloot, R, *The Immortal Life of Henrietta Lacks*, New York City: Random House (2010). The book recounts how cells cultivated from Lacks' cervical cancer became the HeLa cell line of immense scientific value, while Lacks' family drew no benefit from her cells and remained impoverished.

[28] HIPAA 45 CFR 164.512(b)

statistically analyze patterns and trends. As the amount of local information increases, however, even de-identified information is at risk of permitting inferences about individuals. While data linkages and the use of more granular data can enable important population health benefits, they can also increase the risks of re-identification and of compromising individual privacy. Such information also can be abused to treat groups unjustly instead of being used to eliminate disparities.

Ironically, some who use aggregated data for community health work are so persuaded of the benefits of data use that they may have an unjustified degree of confidence in the power of de-identification to protect individual privacy, as discussed below.

Technical solutions alone are inadequate

At the February workshop, some presenters described the solutions they had worked out locally for obtaining consents and protecting privacy—such as Olmsted County's joint HIPAA-FERPA consent form—while others told of their struggles with barriers to data use.[29] At the May workshop, NCVHS members and participants further explored community-level privacy issues, in hopes of identifying guidelines and best practices to enable safe data use for communities. An overarching finding of that workshop was that technological approaches (such as de-identification) are not sufficient to assure the public that health data are being used appropriately and that residents' privacy and confidentiality are being adequately protected.

Dr. Staal Vinterbo of the University of California, San Diego, presented his findings on the limitations of de-identification for providing "believable" privacy protection. He introduced the idea of a finite "privacy budget" in which the more information that is available on a patient, the fewer queries are possible before entering a sensitive area where privacy may be violated. His overall conclusion was that a general and purely technological solution to privacy-preserving sharing of patient data may not be possible. He suggested leveraging the environment to extend the "privacy budget"—for example, by cultivating trust and/or substituting punishment for prevention. Strategies that can be part of such a layered approach are described in Section 2, above.

What is health data stewardship?

NCVHS explored the issues and solutions associated with multiple uses of the same data elements ("secondary use") in a series of reports and recommendations to the Secretary in 2007-2008. The Committee recommended a set of health data stewardship practices and principles: transparency with individuals about the uses of their personal health information; identification of the purposes of data use; participation of individuals; security safeguards and controls; de-identification (when relevant); data quality (including integrity, accuracy, timeliness, and completeness); limits on use, disclosure, and retention; oversight of data uses; accountability; and enforcement and remedies.[30]

---

[29] The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records.

[30] Report to the Secretary - Enhanced Protections for Uses of Health Data: A Stewardship Framework for "Secondary Uses" of Electronically Collected and Transmitted Health Data, December 2007. http://www.ncvhs.hhs.gov/071221lt.pdf. Also see: NCVHS, "Health Data Stewardship: What, Why, Who, How—An NCVHS Primer," September 2009. http://www.ncvhs.hhs.gov/090930lt.pdf

---

This list of recommended stewardship practices provides a useful perspective on the layers of protection needed for all uses of health data. The explorations undertaken for the present report suggest that some layers may need to be reconceived, added, removed, or replaced when the data use is for promoting community health.

The NCVHS primer on data stewardship describes transparency as "making an individual aware of what information [on them] exists and how it will be used." It recommends that individuals should be notified in advance of data use policies, procedures, and technology, including what information will be shared and under what circumstances (including those where consent is not required). The nature of transparency and disclosure in a community health context warrants further exploration in light of the public health uses authorized under HIPAA and the many uses of health data that lie outside this law. These concepts point to the value of involving citizens in community health efforts so they understand the benefits that accrue to them and their families.

New challenges

The same innovative community spirit and data and technological enablers that inspire hope for widespread community health improvement also present new challenges for data protection. Many communities today are operating at an early, "ad hoc" phase of data use in which data stewardship is not yet part of a formal program. In addition to providing models for building local trust around data use, the workshop participants welcomed guidance about data protection. Historically, data organizations and public health agencies have proven to be good stewards of personal health data, protecting the data under their control. However, the growing power of data available to them through new sources, new linkages, and new forms of storage, analysis, and use raise questions about whether existing practices and models are adequate or what other controls might be needed to protect privacy. Community-level data stewards and users are faced with myriad decisions and options regarding data protection. In addition, they must sometimes contend with barriers erected by the "lockbox mentality" described above, which often result from a lack of clarity in privacy regulations and policy.

Section 2 above discusses the important roles of data stewardship, governance, and community engagement in earning trust. Questions for further consideration include how far data stewards should go in a community setting to ensure that data users comply with expectations (e.g., through notice and consent documents and data use agreement terms and conditions), and how data misuse can be identified, reported, and mitigated. Communities need guidance and models on community engagement, the role of consent, and the level of governance needed to ensure trust. One possibility for them is to adopt a Fair Information Practices framework, as in the recently-published health insurance exchange regulations. The NCVHS Subcommittee on Privacy, Confidentiality and Security plans further work in these areas.

Needed: An Infrastructure to Provide Support, Facilitate Shared Learning, and Create Economies of Scale

In summary, the February and May, 2011 NCVHS workshops identified questions about how to strengthen local capacities; how to improve the data informing local work; how to protect individual privacy; and how to realize the benefits of standardization without undermining local autonomy and creativity. The Committee also learned from its informants about the challenges of sustaining local efforts over time.

A national perspective highlights not only best practices, models, and resources with broad applicability but also the economies of scale that could be realized by supporting many communities at once. The Committee began to envision large, interactive local networks, enabled by accessible and easy-to-use information, for use in enhancing the quality of community life. The presentations and discussions also stimulated thinking about a new kind of infrastructure that could 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.

A publicly (or jointly) supported infrastructure of standardized data, measures and tools would greatly enable and empower communities to use data to improve local health. Providing this kind of support is an appropriate role for the federal government. The following are important components of such an infrastructure:

- A privacy and security framework to guide communities in using local data;

- A standardized set of community health indicators;

- Training and technical assistance to improve data access, management, and analysis methods and competencies;

- Better data visualization tools and skills;

- Support and/or external facilitation to strengthen local financial and human resources, including those for coalition development;

- Support for public health departments to take advantage of Meaningful Use criteria as they evolve;

- Guidance on achieving data-informed improvement through effective leadership for change; and

- Mechanisms to enable communities to share knowledge and information and stay abreast of Federal and state resources and activities

4. Envisioning a Federal Role

The surge of community health initiatives in evidence today presents the nation with a compelling opportunity to strengthen local data and analytic capacities, help communities connect with each other and with adequate resources, and bring more and more communities on line. This report outlines a vision for realizing the public benefits of the informatics revolution by getting usable data into the hands of communities and ensuring that they are equipped with the tools and capacities to use them. The Committee believes that collectively, local initiatives like the ones showcased here could become a powerful engine for population health improvement on a national scale, *if* they had adequate support. This compelling opportunity points to a potential and needed role for the Federal government.

The Federal government can do much to both seed and harness the energy of community health movements. At the most fundamental level, the national health information policy discussion must be expanded to recognize communities as significant actors and data users, elevating systematic

support for local initiatives to the position of a major national policy goal. In addition, the public health information infrastructure must be strengthened so it parallels the clinical information infrastructure and can fully interact with it, with feedback loops between clinical providers and their communities. Achieving this requires a national effort similar to the investment in EHR adoption and health information exchange. Mechanisms are also needed to operationalize local access to and use of relevant data sources on the social determinants of health.

In an era of growing need and shrinking resources, Federal and local activities must be closely aligned so the work at all levels is mutually supportive and cost-effective. Interventions such as those suggested above will not be effective without close familiarity with activities on the ground in local communities. And local communities can and must play central roles in bringing about the improvements. The following list indicates specific ways in which the Federal government can support the development of community-oriented learning systems:

1. Promote the development and use of Federal and state web-based data query systems to provide small area data, easy analytics, and visualization capabilities.
2. Broaden research and development of small area data collection, including state and local surveys.
3. Continue to identify and encourage the adoption of standardized community health indicators, and expand access to the underlying data.
4. Help communities develop frameworks for collecting comparable health status, healthcare, and other health-related data, as well as frameworks for privacy protection.
5. Provide local data on environmental and resource factors (including economic, housing, transportation, and education data) that are routinely generated by state and Federal entities to local communities. Community public health coalitions, government agencies, and health care providers need timely, easy access to this information.
6. Expand national health information policy to build bridges between clinical and public health data systems, and identify ways in which health care professionals and organizations can partner to improve community health.
7. Lengthen funding periods for successful projects, and provide transitional support for institutionalization of promising new policies and programs.
8. Expand technical assistance, mentoring communities in survey design, data collection, data analysis, use of technology, development of computer applications, and mapping/data visualization.
9. Use existing initiatives such as regional extension centers to provide training, technical assistance, mentoring, and technology solutions to local communities, sharing resources to increase efficiency and realize economies of scale.
10. Encourage the National Institutes of Health to continue and expand Clinical Translational Science Awards (CTSA) programs and enable NIH-funded community researchers to collect data that are accessible and useful to the local community.
11. *(New suggestion from Bruce Cohen)* Proactively develop guidelines and resources for non-profit hospitals to facilitate optimal compliance with the ACA community needs assessment requirement.

12. *(New suggestion from Linda Kloss)* Provide some form of reward to communities that use available data to improve health status.

5. Conclusion and Future Directions

This report has described the opportunities at hand to undergird and accelerate the momentum of community health efforts across the country. NCVHS will be seeking ways to contribute in its areas of expertise and mandate, which cut across all four of its subcommittees. We want to emphasize as most urgent the need for a community-oriented infrastructure with the elements outlined above, including privacy and security guidance to help community leaders protect individuals and preserve trust as they work to improve local health.

The environment for local health efforts is moving rapidly, and foundations, state government, and Federal agencies are doing significant work to enhance local efforts. The Community Health Information Project has brought to the Committee's attention areas within the NCVHS health information policy purview where research and/or theoretical work could strengthen the data sources, structures, and uses available to communities. The Committee hopes to work with the Department and others to help address these needs. The areas, several of which are identified in the preceding pages, include a privacy and trust framework for local data use; key principles for data aggregation; guidelines for local knowledge management; and standardization, models, and best practices in many areas. By facilitating the efforts of leading-edge communities and enabling others to follow their lead, those who join NCVHS in recognizing this potential can help open the way for a nationwide, community-based force for better national health.

Appendix 1. Sketches of Featured Communities

— Communities Featured in the February, 2011, NCVHS Workshop —

Boone County, MO: Community Issues Management tool spurs collaboration, research, and action

Stephanie Browning, Administrator, Columbia/Boone County Health Department, Columbia, MO

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.

Bronx RHIO: Partnerships to improve care transitions and reduce re-hospitalization

Nance Shatzkin, Shatzkin Systems, Inc., Bronx RHIO, Bronx, NY

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.

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

Debbi Main, Ph.D., Professor and Chair, Department of Health and Behavioral Sciences, University of Colorado Denver, CO

Janet Meredith, B.A., M.B.A., Executive Director, 2040 Partners for Health, Denver, CO

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

In the five Denver neighborhoods that comprise the organization 2040 Partners for Health, local citizens not only help 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 to 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 and do not stigmatize community residents. D-RAD

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 engagement* into *community ownership*.

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

Grand Junction, CO—Collaborative culture lays groundwork for a Beacon Project with population health improvement goals

Patrick Gordon, M.P.A., Director, Colorado Beacon Consortium, Grand Junction, CO

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.

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

Greg Larkin, M.D., State Health Commissioner, Indianapolis, IN (representing Indiana Health Information Exchange)

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 with IHIE toward population health improvement. 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.

King County, WA: Multiple data audiences and partners

Marguerite Ro, Dr.P.H., Chief, Assessment, Policy Development, and Evaluation, King County Public Health Department, Seattle, WA

Washington's large local health department, Public Health Seattle King County, is fortunate to have strong support for epidemiology and evidence-based evaluation from its Board of Health. 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, the education sector, community based health centers, and the health and hospital systems.

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

Matthew Stefanak, M.P.H., Mahoning County Health Commissioner, Youngstown, OH

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 in this three-county region 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. Mahoning Valley has receives valuable technical assistance from the Health Policy Institute of Ohio, which helped mine the survey data to answer questions about uninsured children. Mr. Stefanak notes that academic or think tank expertise is an invaluable partner for local public health programs.

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

Mary Wellik, Public Health Director, Olmsted County Public Health Services, Rochester, MN

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-FERPA[31] consent form to facilitate the process and standardize privacy protection procedures.

---

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

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

Mary Maddux-Gonzalez, M.D., Health Officer and Public Health Division Director, Sonoma County Department of Health Services, Santa Rosa, CA

Sonoma County, California's *Healthy Sonoma* website provides user-friendly access to information on local health, health determinants, and community programs. The website, which links all the county's community health projects together, is recognized as a national model. Sonoma County launched the site and its data visualization tools in 2009 as a platform for 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, M.D., MPH, talked with NCVHS about the benefits of having expert external support of this kind—especially for smaller communities with more limited staffs.

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

David Patterson, Ph.D., Chief, Health and Demographics, SC Budget and Control Board Office of Research and Statistics, Columbia, SC

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. Agency-level data-sharing is mandated by state government. ORS then 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.

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

Gwendolyn Flynn, Community Health and Education Policy Director, Community Health Councils, South Los Angeles, CA

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 also influenced the South Los Angeles General Plan and led to the development of two new full-service supermarkets in the area.

— Communities Featured in the May, 2011, NCVHS Workshop —

Arkansas Obesity Initiative

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

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

Intermountain area research on public attitudes toward data use

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

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

New York City initiative to improve BMI screening for children

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

This consortium of Federally qualified community health centers (FQHC) launched an initiative to spur system changes to improve the BMI screening rate for children (age 2-18), with a goal of reducing the prevalence of childhood obesity. Over three years starting in 2007, CHCANYS led 11 health centers in 20 New York City sites in improving the screening and treatment of childhood obesity. Ms. Alexis said the objectives involved not just more consistent BMI screening but also nutrition referral, clinical follow-up, behavior change, and ultimately helping children reach a healthy weight/BMI. Besides engaging health center leaders and developing partnerships, the project used trained "parent ambassadors" on health center teams as well as young "peer mentors." Despite challenges from staffing shortages and funding cycles, the initiative has had a measurable impact, and CHCANYS hopes to expand it state-wide.

(**Note:** Representatives from Denver's 2040 Partners for Health also participated in the May workshop, as described in the Denver sketch.)

Appendix 2. NAHDO Recommendations

Denise Love, Executive Director, National Association of Health Data Organizations

Excerpt, Testimony to the National Committee on Vital and Health Statistics, at the May 8, 2011 workshop, "The Community as a Learning System for Health: Using Local Data to Improve Community Health, Part II"

NAHDO welcomes a national discussion, led by NCVHS, about the complex issues related to privacy and confidentiality. What is essential is greater cooperation across states and jurisdictions and data sources/agencies. Working together, we can maximize the utility of our large-scale data bases by linking and enhancing across sources, adding more intelligence in the combined data with the potential of reducing burden to the providers and payers collecting the data.

- Lead the effort to develop messaging to the public and policy makers about the need for identifiable data and how these fields can be captured without compromising the patient's privacy expectations, yet improve the public's health through evidence-based decision-making.

- Encourage uniformity and consistency of patient demographic fields across public health data sets in terms of both the definitions and format. For example, The Health Information Technology Standards Panel (HITSP) is working on a demographic model to define a standard for name (National standards organizations can't accommodate names that have more than three parts, e.g. hyphenated names). Aligning the HITSP effort with public health needs for enhanced data will accrue benefit to many stakeholders including providers being asked to supply various entities with data, and patients seeking healthcare.

- Promote more collaborative discussions across programs and data systems to align data needs and standards. One example is the project underway by the Center for Disease Control and Preventions' National Program of Cancer Registries (NPCR) and NAHDO to identify priorities for harmonizing discharge and cancer registry data bases, this effort needs to occur across more data sets. Harmonization across the two data sets will facilitate linkages between discharge data and cancer registries and also has the potential for reducing the reporting burden of providers.

- Provider and physician identifiers pose other challenges to states; states using the National Provider Identifier (NPI) have discovered that physicians often have multiple numbers, and providers and payers differ in their coding and assignment of the NPI. Public health agencies should work with the Centers for Medicare and Medicaid Services (CMS) to improve the assignment of a unique and stable physician identifier, perhaps developing two separate fields, one for the physician that is unique, and then a separate field for facility/location. This would allow easy aggregation of individual providers' cases, while still retaining capacity to measure physician groups.

- De-identification will continue to play a role in data release/data exchange, but we need more robust public data sets. NCVHS can establish national expert panels to establish an analytic framework to identify and design best practices for enhancing de-identified data sets. For example, for hospital discharge data sets, what indicators/flags can be added by the data agency that will enhance the utility of the de-identified data set? Examples are creating keys that indicate a hospital readmission to the same or different hospital or

adding mother's medical record to the newborn record to facilitate maternal outcomes studies. Another example, is to add parity to birth codes, so that measurement related to birthing can distinguish first births from others, a key indicator related to elective deliveries and cesarean sections. NCVHS can lead the effort to identify new methods to add intelligence in de-identified data sets.

- We need a common definition or definitions of Personal Health Information (PHI). How we define personal health information (PHI) is changing with the advancement of technology and the generation of genetic and bio-signature data, resulting in the handling of more sensitive data.

- NCVHS can help states and public health agencies synchronize privacy messages and create model exchange policies to facilitate data sharing across federal, state, and private sector agencies. More precise data will improve public health practice and health services research, but introduce new challenges that could result in inhibition of data flows. For example, Geo-coding of the data enable us to connect the dots, but this added power poses challenges to patients privacy as well as data exchange.

- We need help with defining a legal standard for inter-state transfer or exchange of our data sources containing PHI. State and federal laws overlap and the current process is complex and onerous. These data gaps inhibit measurement activities, especially in markets where there is a great deal of cross-border migration.

NAHDO's members have been innovators in the aggregation of large-scale health care data bases, the release of public data products, including the release of comparative performance reports on providers, and enhancement of data through data linkage. As our members expand their reporting systems to include all payer claims data bases (APCDs), the issues of identifiers, de-identification methodology, and data exchange will add more complexity. NAHDO welcomes a larger dialogue on these issues, led by NCVHS.

Appendix 3. Toward a Research Agenda on Community Learning Systems for Health

PROVISIONAL – DISCUSSION DRAFT, 11.07.11

Knowledge management guidelines

1. How can knowledge be effectively shared for community health improvement?

2. How can knowledge be readily implemented in health IT to support community health improvement efforts and measure their impact?

Public health informatics: topics in addressing data needs, sources, and gaps

1. Most important and improvable determinants of the public's health

2. Information needed to understand the impact of each determinant on a given population

3. Information needed to inform the improvement of each determinant

4. Information needed to measure improvement (or worsening)

5. Estimated benefits and risks of providing each information element or constellation of elements

6. Security and confidentiality framework for public-health information systems

7. Information currently available from any source

8. Standard definitions and standard concepts in standard ontologies for every needed information element

9. New information elements into the appropriate information systems (e.g., public-health IT, EHRs, networked PHRs, HIEs, payers, PBMs), and workflows.

10. Effect of determinant improvement on population health (in order to revise as needed)

Enabling a learning health system for community health: creating a roadmap with the key principles of aggregation

The task: to articulate the key lessons learned from prior efforts at data aggregation and the related key issues, in order to make aggregation easier to do and avoid the known pitfalls. This would not be a detailed technical blueprint, but rather a roadmap of sorts that highlights the key principles.

Questions include:

1. What are the methods we may use to learn from the entire community data aggregation or mash up process, both up and down the stack (from data source to aggregate or composite data report) and also learn from experiences across community health data sites, combining multiple disparate data sources?

2. How do we use this learning to revise the technical stack, as well as the breath of data used in community health measures?

3. How do we aggregate (or "mashup") and use data at the community health level in a way that learns from all prior efforts of data aggregation at each and every level at which it has occurred? For example:

   o Ancillary department > HIS
   o Clinic(s) > hospitals
   o Hospitals and clinics > international data numbers (IDNs)
   o IDNs > Nationwide Health Information Network (NHIN)

A sample set of issues:

- Standards for terminology (e.g., data representation, binding to available standards for nomenclature, standards for information model(s), standards for metadata)

- Standards for the messaging framework (e.g., to facilitate distributed query, data send/retrieval for aggregation, message standards, meta-data standards relevant to messaging)

- Standards for data acquisition and characterization (by data source [patient, provider, device] and metadata standards for data provenance)

- Suggestions for aggregate data representation standards at the population or aggregate data level (e.g., population information model[s])

- Suggestions for analytics on this population data resource (e.g., definition of the prototypical standard population/community health queries that are sought at the outset to ensure we have the right data sources, the right data roll-ups, and the right reports specified to answer actionable community health questions)

- Suggestions around the methods to ensure appropriate security of health information, and the maintenance of privacy of PHI, especially as it transits from source to aggregate community health data sets, and further to any derivative uses

- Suggestions around the appropriate methods to assess the quality of the data that are aggregated data integrity and data validity

- Suggestions regarding the types of quality reports that will be sought:

   o Appropriate data sources available
   o Appropriate reports designed to inform community health decision makers (patient, providers, public health)
   o What are the measures of community health that are validated and useful and actionable for community health activists, policy makers, patients, and providers
   o Standards for report design

Appendix 4. Bibliography

NCVHS REPORTS AND RECOMMENDATIONS OF SPECIAL RELEVANCE

(All reports and recommendations are posted, in reverse chronological order, on the NCVHS website at http://www.ncvhs.hhs.gov/reptrecs.htm)

Letter to the Secretary with Recommendations on Community Health Assessment, July 2, 1997.

Information for Health: A Strategy for Building the National Health Information Infrastructure, November 2001.

Shaping a Health Statistics Vision for the 21st Century, November 2002.

Report to the Secretary - Eliminating Health Disparities: Strengthening Data on Race, Ethnicity, and Primary Language in the U.S. November 7, 2005.

Report to the Secretary, Enhanced Protections for Uses of Health Data: A Stewardship Framework for "Secondary Uses" of Electronically Collected and Transmitted Health Data, December 2007.

Health Data Stewardship: What, Why, Who, How—An NCVHS Primer, September 2009.

Concept Paper, Toward Enhanced Information Capacities for Health, May 26, 2010. (Published as part of the NCVHS 60th Anniversary Compendium)

60th Anniversary Symposium and History, 1949-2009 - NCVHS 60th Anniversary Compendium. April 19, 2011.

OTHER REFERENCES AND USEFUL RESOURCES

Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee TaskForce on the Principles of Community Engagement, Principles of Community Engagement, Second Edition. NIH Publication No. 11-7782, June 2011.

Gibbs, Deborah and Brown, Brett, "Community-Level Indicators for Understanding Health and Human Services Issues: A Compendium of Selected Indicator Systems and Resource Organizations," prepared for the DHHS Office of the Assistant Secretary for Planning and Evaluation, September 2000.

Institute of Medicine, Leading Health Indicators for Healthy People 2020, 2011. http://iom.edu/Reports/2011/Leading-Health-Indicators-for-Healthy-People-2020.aspx

Institute of Medicine Roundtable on Value & Science-Driven Health Care, The Learning Health System Series: Continuous improvement and innovation in health and health care (11 vols.), 2011. http://www.iom.edu/Reports/2011/~/media/Files/Activity%20Files/Quality/VSRT/Core%20Documents/LearningHealthSystem.pdf

National Commission on Community Health Services , Health Is a Community Affair, 1966 (called the Folsom Report after its Chair). See also Dean W. Roberts, MD, "Health is a Community Affair: Preview of the Final Report of the National Commission on Community Health Services," Journal of the American Medical Association, April 25, 1996, Vol 196, No. 4.

Novilla L, Barnes M, et al., "How can we get the social determinants of health message on the public policy and public health agenda? For WHO World Conference on Social Determinants of Health, Rio de Janeiro, Brazil, 19-21 October 2011.

PolicyLink & California Endowment, Why Place Matters: Building a Movement for Healthy Communities, 2007.

Public Health Reports Supplement 3, "Data Systems and Social Determinants of Health," Volume 126, Issue 9 (2011). http://www.publichealthreports.org/issuecontents.cfm?Volume=126&Issue=9

Appendix 5. National Committee on Vital and Health Statistics Membership

CHAIR

Justine M. Carr, M.D.
Chief Medical Officer
Steward Health Care
Boston, MA

HHS EXECUTIVE STAFF DIRECTOR

James Scanlon
Deputy Assistant Secretary
Office of Science and Data Policy
Office of the Assistant Secretary for Planning and Evaluation, DHHS

EXECUTIVE SECRETARY

Marjorie S. Greenberg, M.A.
Chief
Classifications and Public Health Data Standards Staff
Office of the Director
National Center for Health Statistics, CDC

MEMBERSHIP

John J. Burke, M.B.A, MSPharm.
Vice President, Corporate Compliance Programs
Harvard Pilgrim Health Care, Inc.
Wellesley, MA

Raj Chanderraj, M.D., F.A.C.C.
Nevada Heart & Vascular Center
Las Vegas, NV

Bruce B. Cohen, Ph.D.
Director, Division of Research and Epidemiology
Bureau of Health Information, Statistics, Research and Evaluation
Massachusetts Department of Public Health
Boston, MA

Leslie Pickering Francis, J.D., Ph.D.
Distinguished Professor of Law and Philosophy
Alfred C. Emery Professor of Law
University of Utah
Salt Lake City, UT

Larry A. Green, M.D.
Professor and Epperson Zorn Chair for Innovation in Family Medicine and Primary Care
Department of Family Medicine
University of Colorado Denver
Aurora, CO

Mark C. Hornbrook, Ph.D.
Chief Scientist
The Center for Health Research, Northwest/Hawaii/Southeast
Kaiser Permanente Northwest
Portland, OR

Linda L. Kloss, M.A., RHIA, CAE, FAHIMA
President
Strategic Advisors Ltd
Chicago, IL

Vickie M. Mays, Ph.D., M.S.P.H.
UCLA Department of Psychology & Health Services
Los Angeles, CA

Blackford Middleton, M.D., M.P.H., MSc
Corporate Director, Clinical Informatics, Research and Development
Chairman, Center for Information Technology
Partners Healthcare
Wellesley, MA

Sallie Milam, J.D., CIPP/G
Chief Privacy Officer
West Virginia Executive Branch and West Virginia Health Care Authority
Charleston, WV

Len Nichols, Ph.D.
Director, Center for Health Policy Research and Ethics; Professor of Health Policy
College of Health and Human Services
George Mason University
Fairfax, VA

William J. Scanlon, Ph.D.
National Health Policy Forum
Washington, DC

W. Ob Soonthornsima
Senior Vice President, Chief Information Officer and Security Officer
Blue Cross and Blue Shield of Louisiana
Baton Rouge, LA

Walter G. Suarez, M.D., M.P.H.
Director, Health IT Strategy & Policy
Kaiser Permanente
Silver Spring, MD

Paul C. Tang, M.D.
Vice President and Chief Medical Information Officer
Palo Alto Medical Foundation
Mountain View, CA

James M. Walker, M.D., FACP*
Geisinger Health System
Danville, PA

Judith Warren, Ph.D., RN
Christine A. Hartley Centennial Professor; Director of Nursing Informatics
KUMC Center for Healthcare Informatics
University of Kansas School of Nursing
Kansas City, KS