

## SUPPORTING COMMUNITY DATA ENGAGEMENT —AN NCVHS ROUNDTABLE—

### Executive Summary

The participants in the October 2014 Roundtable on Community Data Engagement identified several possible strategies for giving communities access to more relevant local data and enhancing their ability to use them. The National Committee on Vital and Health Statistics (NCVHS)<sup>1</sup> hosted the Roundtable to talk with experts about what promotes community data engagement and how stakeholders in different sectors can work together for greater combined impact. A major impetus was interest in what new opportunities and challenges were being generated by the rapid changes taking place in the community health landscape.

The Roundtable participants work in three sectors: local communities, national “data connector” and support organizations, and federal data suppliers and programs. NCVHS wanted to see what insights would emerge from interaction among these varied perspectives. Stories from four U.S. communities provided the focal point for the discussions, amplified through the experience and insights of the national and governmental organizations represented. Throughout the discussions, NCVHS invited the participants to consider how the Department of Health and Human Services (HHS), which it advises, might contribute to local efforts in a more strategic and concentrated way.

### Stories from the Leading Edge

Omaha/Douglas County, Nebraska; New Orleans, Louisiana; Sonoma County, California; and Seattle/King County, Washington were the communities represented at the Roundtable. Six themes emerged through their stories, representing strong characteristics of today’s community health landscape:

- Community health needs assessment and improvement as a local platform;
- The growing drive for health equity;
- The push for collective impact;

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<sup>1</sup> The National Committee on Vital and Health Statistics (NCVHS) serves as the statutory (42U.S.C.242k[k]) public advisory body to the Secretary of Health and Human Services on health data and statistics. In that capacity, it provides advice and assistance to the Department and serves as a forum for interaction with interested groups on key issues related to population health, standards, privacy and confidentiality, quality, and data access and use. Its 18 members have distinction in such fields as 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. All NCVHS reports and recommendations are online: <http://ncvhs.hhs.gov/>.

- The importance of community engagement;
- The power of data presentation; and
- Philanthropy as an agent of change.

The larger story of the work of national organizations threaded through the community stories, as their representatives shared their knowledge of both community-level data use and the federal data apparatus. The discussions brought to light important recent efforts by the federal government to enhance data-sharing and linkage among agencies and departments; and federal participants also described several promising agency initiatives aimed directly at assisting communities.

### Filling Gaps, Aligning Resources, Propelling Progress

The Roundtable highlighted barriers that stand between America's communities and the growing array of resources, limiting their ability to function as learning systems. Most notably, today's leading-edge communities are working for health equity, and zooming in on hot spots means drilling down to priority population groups and neighborhoods. This requires data at a much finer level of granularity than now exists. Even if more granular secondary data become available to them, as hoped, communities will likely want to strengthen their own abilities to do primary data collection, estimation, privacy protection, and analysis.

Ironically, the very abundance and complexity of available data can be an issue for communities, compounded by a common lack of standardization. Further, the proliferation of governmental and non-governmental platforms offering access to data and support adds to communities' sense that they are "drinking from a fire hose" and don't know which resources are best for them.

The Roundtable participants agreed that data suppliers, connectors, and community leaders share responsibility for addressing these and other challenges, and that the solutions must be based on user-centered principles. One of their ideas for accomplishing this was to institutionalize the presence of a knowledgeable community "voice" whenever the federal government is developing tools, initiatives, or data with potential utility for the community. Another idea was a concerted effort to align platforms.

Finally, a strong and consistent Roundtable theme was that communities need and want technical assistance, tailored to their specific issues and needs and ideally available through a regional network. And there was a strong sense that "the teachable moment" is at hand.

### Priority Areas, Possible Strategies, and Next Steps

The group synthesized their ideas into priorities and possible actions. Their thoughts about possible strategies are organized here in terms of two overarching goals: increasing the data and information that are relevant to community health, and enhancing local data usage.

**Possible strategies for reorienting the country's data enterprises to better serve communities**

*(Goal: increasing the usability and usefulness of data and information for community health)*

1. Increasing mutual awareness and coordination among federal and non-governmental intermediary organizations.
2. Institutionalizing a knowledgeable community voice in relevant federal policy development and data decisions, with a commitment to heed it.
3. Giving greater attention to user-centered design and infographics in the presentation of federal data.
4. Creating mechanisms for more two-way data flow.
5. Filling priority data gaps.
6. Accelerating work on priority technical data issues.
7. Continuing to explore development of core sentinel indicators, allowing room for locally selected measures.
8. Teaching states how to protect data so more can be shared, safely.

**Possible strategies for fostering an evolving process of community data engagement**

*(Goal: enhancing local data usage for health assessment and improvement)*

1. Expanding technical support to communities through accessible "data concierges."
2. Aligning community data and support platforms to allow them to interact, complement each other's strengths, and be easily navigable.
3. Linking data on disparities and diversity to information on what works to improve the health of vulnerable population groups.
4. Developing a reference architecture for state and local web-based query systems.
5. Creating communities of practice across the sectors.

The lessons and insights that emerged from the Roundtable point toward strategies that can increase collective impact for improving health and achieving health equity on a national scale. It is important to stress that these ideas are not recommendations; they are early building blocks for possible recommendations, after much additional examination and development. Over the coming months, NCVHS will explore these ideas further as it learns more about the activities already under way to support communities. Its goal is to identify how the Committee can best contribute, and what priorities to recommend for federal action.

## SUPPORTING COMMUNITY DATA ENGAGEMENT —AN NCVHS ROUNDTABLE—

### I. Introduction: The Project and Its Genesis

Today, Americans on the front lines of the community health movement have unprecedented access to data and the support of a network of intermediary organizations. Their efforts are buttressed by strong recent law and heightened Federal attention. The National Committee on Vital and Health Statistics held a two-day Roundtable in October 2014 to talk with experts about how to reinforce and spread the positive developments so that communities can take fuller advantage of them.

The Roundtable brought together individuals working in this area in a wide range of capacities around the country, to explore from their diverse perspectives what promotes data engagement and how stakeholders in different sectors can work together for greater impact. The participants represented three sectors: local communities, national “data connector” and support organizations, and federal data suppliers and programs. The agenda topics included the status of community health needs assessments and improvement planning, the movement toward collective impact, and the roles of data in community engagement and promotion of a culture of health. On these subjects and others, the stories of four distinctive communities in Nebraska, Louisiana, California, and Washington were amplified by the broad experiences of the national and governmental organizations. (See Appendix 1 for the agenda and list of participants.)

A major impetus for the Roundtable was interest in what new opportunities and challenges were being generated by the rapid changes taking place in the community health landscape. To name a few, the Affordable Care Act (ACA) has heightened collaboration between health care providers and public and non-profit organizations more focused on population health goals, by mandating new approaches to community health needs assessment and improvement. Growing emphasis on health equity and the social determinants of health has expanded attention beyond health data and the Department of Health and Human Services (HHS) to the many federal agencies with relevant data, policies, and programs. Sources and combinations of data are proliferating, for good and ill; and exciting new forms of data presentation are being demonstrated. More and more organizations are producing resources for community use. Meanwhile, thought leaders such as the Robert Wood Johnson Foundation are broadening the frame of reference from community health to community well-being and a culture of health. And all of these processes are generating synergies on a nearly national scale that were manifest in the many connections among Roundtable participants.

NCVHS wanted to see what insights would emerge from structured and extended interaction among the three perspectives—community, data connector, and data supplier. It invited the Roundtable participants to examine how HHS might contribute to local efforts in a more strategic and concentrated way. Many agreed that providing community-level data and other resources is an appropriate federal responsibility, and even priority—one to be carried out in

partnership with non-governmental intermediary organizations, and with close attention to the perspectives of local data users.

The group ended the meeting by distilling their rich discussions into a list of priorities and possible actions for future attention.

## NCVHS on the community as a potential learning system for health

Community health has moved to the center of NCVHS interests in recent years. Besides being the organizing principle for its work on population health, local data use is an integral part of the Committee's work on privacy/confidentiality and standards. Two NCVHS reports, *Information for Health* (2001)<sup>2</sup> and *Shaping a Health Statistics Vision for the 21<sup>st</sup> Century* (2002),<sup>3</sup> provide the conceptual groundwork for this focus. These reports stand today as far-sighted and complementary approaches to information policy that integrate population health and health care perspectives and have much relevance at the local level.

In 2011, NCVHS issued a report, *The Community as a Learning System for Health: Using Local Data to Improve Local Health*, in which it introduced another foundational concept. It proposed that communities have the potential to become learning systems for health through their capacity to deploy all the necessary components including collaboration, clear goals and action plans, relevant measures backed by reliable data, and feedback and evaluation mechanisms to inform future action.<sup>4</sup> Each of the four communities featured in the Roundtable described below is a unique example of a community-based learning system.

In thinking about the community, NCVHS uses a broad and flexible definition: *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.*<sup>5</sup> While communities come in many forms, NCVHS generally focuses on geographic communities, whose members are connected through the place where they live, and around which data gathering (e.g., by county) have been traditionally organized. It is important to note that geographic communities such as cities and counties are composed of many sub-communities with diverse levels of inclusion and opportunity. Poverty, structural racism, illness, and other factors can limit residents' participation and influence. A major Roundtable finding was that the effort to increase equity requires a narrowing of the focus to specific disadvantaged areas and population groups. This prioritized endeavor toward equity and its implications for data, data stewardship, and analysis emerged as a strong theme of the Roundtable and promises to be a major NCVHS focus moving forward.

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<sup>2</sup> NCVHS, *Information for Health: A Strategy for Building the National Health Information Infrastructure*, 2001.

<sup>3</sup> NCVHS, *Shaping a Health Statistics Vision for the 21<sup>st</sup> Century*, 2002.

<sup>4</sup> NCVHS, *The Community as a Learning System: Using Local Data to Improve Local Health*, 2011.

<sup>5</sup> A fuller discussion of the NCVHS definition of community and the notion of the community as a learning system for health can be found on pages 8-10 of the 2011 report.

## II. Stories from the Leading Edge

At the meeting, community leaders described their activities in Seattle/King County, Washington; Omaha/Douglas County, Nebraska; New Orleans and the central Gulf Coast, Louisiana; and Sonoma County, California.

Several themes resonated through their stories, representing salient characteristics of today's community health landscape. Each has implications for data and information. A simplified version of the story is as follows: The quest for data for local action often begins with a triggering event or set of conditions and/or an initiative for community health needs assessment and community health improvement plans (**CHNAs and CHIPs**). For many communities, this heightens awareness of local health disparities and generates a push for greater **health equity**, both widening and focusing the conversation about the nature of health and how to improve it. Two key facets of collaboration, **community engagement** and **collective impact**, help to create the conditions for the desired changes. Sophisticated **data presentation** can be a critical tool in telling the story, bringing actors to the table and mobilizing them for action. **Philanthropy** can play similar roles in powerful ways.

This section shares highlights from community stories that illustrate these six themes, along with insights from the discussions that explored them. Most of the local stories carry through the highly interconnected themes. The community stories are followed by descriptions of the critical roles of intermediary and data connector organizations and federal agencies and programs.

### The CHNA/CHIP platform

The **Sonoma County, CA** story illustrates several characteristics of the community health landscape and their interactions. The hospitals in this predominantly rural Northern California county have conducted five needs assessments over the years, and several well-established collaborative initiatives are promoting health and well-being in the county. Recently, the health department commissioned a report, *Portrait of Sonoma County*, that highlights significant disparities in health, educational attainment, and economic wellness using census tract data.<sup>6</sup> Based on that analysis, the health department and its community partners have stepped up their efforts in vulnerable areas. Among other things, the report is proving to be a useful tool in broadening the conversation with local hospitals about the nature of health. Similarly, in **Seattle/King County, WA**, local hospitals broadened their view of health beyond clinical indicators and added upstream determinants to their needs assessment instrument.

Our health department is actually talking about education and economic wellness and poverty. We are working with our Office of Education and with our development organizations in the county. The *Portrait* has really pushed that forward. The data is all publicly available, but it is the presentation of it that has gained us a lot of traction.

*Brian Vaughn, Sonoma County*

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<sup>6</sup> The Portrait is produced in collaboration with Measure of America, a project of the Social Science Research Council. <http://www.measureofamerica.org/sonoma/>

Community health needs assessment and improvement planning can provide a platform for an evolving local process. The community representatives described the collaborative assessment and improvement efforts of public health departments and non-profit hospitals in their communities, spurred on by both ACA and public health accreditation requirements and the underlying desire to improve local health.

Most of the connector organizations represented at the Roundtable (see page 10) are engaged in supporting CHNA and CHIP activities, some working closely with supportive CDC programs. On the public health side, the Public Health Accreditation Board requires community health assessment and improvement plans as prerequisites for voluntary public health accreditation, and gives “extra credit” to health departments that collaborate with health care organizations on these activities. The National Quality Forum is piloting a new toolkit it has developed to help communities navigate the CHNA process. And the list goes on.

The people who work on CHNAs say they feel like they are drinking from a fire hose.

*Kaye Bender, National Quality Forum*

My own experience, having worked with communities for many years now, is that the data is there, but most people find it overwhelming. They find it difficult to go from indicators to needs to action.

*Jean Nudelman, Kaiser Permanente*

These resources are essential: The Roundtable participants talked about the challenges communities face in choosing the best measures and data sources for assessment, and then the best interventions for achieving the resulting goals. They also noted the importance of ensuring that CHNAs express a broad understanding of health and generate real benefit for the community.

## The drive for health equity

Health equity is achieved when all people have "the opportunity to 'attain their full health potential' and no one is 'disadvantaged from achieving this potential because of their social position or other socially determined circumstance'"<sup>7</sup> The **King County** story, like that of Sonoma County, illustrates the movement toward explicit work for equity. In Seattle/King County, the health department had used two successive CDC grants to engage partners in working for policy and system changes to encourage better health practices. Then recently, an analysis of vulnerable “hotspots” led to classification of areas of the county into ten gradients of well-being. The maps and storyboards developed from the data told a revealing story that helped engage and mobilize community partners, government agencies, and community members in the latest initiative, called Communities of Opportunity.

**Omaha/Douglas County, NE**, is the site of some of the greatest wealth and some of the most severe disparities in the U.S. The initiatives there to bring sexually transmitted diseases (STDs) under control and improve juvenile justice are being carried out by coalitions brought together by a private family foundation. The story continues below.

<sup>7</sup> Braveman, P.A., Monitoring equity in health and healthcare: a conceptual framework. *Journal of health, population, and nutrition*, 2003. 21(3): p. 181.

The concept of the social determinants of health is now operationalized in at least some communities, a fact that is on full display in our community stories. This narrowed focus on specific areas and populations requires a widening of the lens to all the factors that affect their health and the information needed to address them. This in turn affects the nature of the partnerships, widening them too to include those responsible for education, transportation, housing, and so on. Ultimately, the drive for equity depends on having granular data on specific population groups and neighborhoods, secured by strong privacy protections. We will return to this major Roundtable theme in the final sections of the report.

I see evolving in this movement that when we talk about social determinants of health, it's not just a model and a framework any more; it's actionable. We are in this shift right now: It is not just about using social determinants as demographic data to describe populations; it's about what we do to improve education, to decrease poverty, to improve community safety, to decrease discrimination. That is a very exciting way to look at the transformation of data.

*Julie Willems Van Dijk, County Health Rankings & Roadmaps*

## Striving for collective impact

Omaha/Douglas County and Seattle/King County represent distinct approaches to collective impact.<sup>8</sup> In the STD and juvenile justice initiatives in **Douglas County**, the collective impact approach offers a way to “do it differently” to address what had seemed intractable problems. Broad partnerships now enable strategies that address the range of determinants involved—in the case of truancy, for example, transportation, health, housing, and economic issues. The juvenile justice campaign, which is focusing on alternatives to incarceration, was launched by using data and the business case to engage law enforcement and justice system representatives in setting a common agenda. That agenda is now being taken to the community to enlist their participation. The STD initiative, being carried out in partnership with school districts, is reportedly starting to show an impact. A local private foundation brought partners including the Chamber of Commerce, the local newspaper, and other key stakeholders to the table by making the business case for their support.

I am very optimistic that the conversation [with the community] is different than what has happened in the past. Relationship and trust are gradually being rebuilt, which will be a sustainable factor.

*Kerri Peterson, Douglas County NE*

In **King County**, although the health department has worked with community representatives for a long time, it has found that the ACA “set the stage” for new ways of pulling in different sectors, including city governments, hospitals, and school districts, to effect change. In the

<sup>8</sup> A theory of collective impact by authors John Kania and Mark Kramer in the Winter 2011 *Stanford Social Innovation Review* (p. 35-41) provides an analysis and list of ingredients for successful collaboration that have influenced the community health movement. (The ingredients are a common agenda, shared measurement systems, mutually reinforcing activities, continuous communication, and support from a backbone organization.) In the NCVHS Roundtable and this paper, we use the term in a more general sense, while recognizing that important contribution. The resonance between the theory's conditions for successful collective impact and those that enable communities to become learning systems is worth noting.



Communities of Opportunity Initiative, the community members who are essential to its success urged that *community voice* be added to the list of key components for collective impact (see note 8). Their point was well taken. The representative explained that by “community voice,” they mean authentic engagement of *context* experts—those who live in the community—with *content* experts to co-create solutions.

A Roundtable discussion about the measurement of impact arose in this context. A participant pointed out that by design, the collective impact process can generate changes in interventions, creating a moving target for evaluation. The foundation in Douglas County is now studying ways to measure process, an important dimension of collective impact.

Increasingly, I am thinking that community engagement could be the most important part of this assessment process.

*Julie Trocchio, National Quality Forum*

## Engaging the community

The **King County** story illustrates the place of community engagement at the heart of the work for collective impact. Recognizing that community engagement requires trust and elements of community control and also wanting to encourage innovation, the health department built flexibility into the parameters of its Communities of Opportunity initiative. Foundation partners were holding the department

While we do have a set of outcomes we are interested in moving, we are leaving it open for a community to make some decisions around what they want to see changed. . . . We are not predefining the activities. This is scary, frankly, for government.

*Nadine Chan, King County PH Dept.*

accountable for leaving room for the community to choose its strategies and desired outcomes for impacting health, housing, and economic equity. So rather than predefining the activities, it built a process for community members to co-design them and advise the backbone structure, with staffing assistance from public health and the foundation.

In **New Orleans**, the Louisiana Public Health Institute tethered the community health information resources it was helping to make available to the public to “community buy-in,” structuring community liaisons into the governance of the Healthy NOLA website. At the time of the Roundtable, the online resource had temporarily gone dark pending further community engagement. Meanwhile, a community health project in nearby **Baton Rouge**, spearheaded by the Mayor, is flourishing.

The point about flexibility in goals and strategies in King County led to discussion of the role of evidence in community action and the implications for data and evaluation. The speaker described the need to balance evidence and innovation to permit community engagement and leadership—a point that resonated with other participants. A related theme arose with respect to the merits, drawbacks, and feasibility of developing a set of core indicators for use by all U.S. communities. Several participants pointed out that some causes of local inequities are highly

I want to emphasize [the point] about that balance between innovation and evidence-based. There was a time when we did not know [about major interventions now seen as evidence-based]. We studied them, and we learned.

*Julie Willems Van Dijk, County Health Rankings & Roadmaps*

localized, and community members need the ability to focus on distinctively local factors.

## The power of presentation

Throughout the Roundtable, the *Portrait of Sonoma*, with its clear and persuasive graphics, served as a touchstone for the power of data presentation, demonstrating the possibility of communicating data in a way that conveys meaning and galvanizes action.

This theme carried through the stories of other communities, as well. For example, both **Douglas and King Counties** have successfully used storyboards to highlight issues and “connect the dots,” helping to bring stakeholders to the table and mobilize them. The **Louisiana** representative talked about providing “consumable information” that is tailored to each audience and embedded in a pool of “abundant data,” available as needed to inform decisions about interventions.

[Looking at the storyboards showing the hotspots], they could say, “That is my neighborhood. That is different from neighborhoods elsewhere.” This really motivated and engaged folks.

*Nadine Chan, King County PH Dept.*

It is very important for local community buy-in for the community to have the ability to identify their own [indicators]. If there were to be a core set, there would need to be that wiggle room. Particularly with regard to measuring disparities and health equity and the goals associated with that, this varies so significantly among populations that I do not know how one would go about establishing standard measures.

*Kaye Bender, National Quality Forum*

Indeed, the critical role of presentation was a major theme of the Roundtable. The participants agreed that having graphics that communities can understand, perhaps drawn from a toolkit of standardized graphics, could make information far more usable. They also agreed that effective data presentation is a responsibility shared by communities, data connectors, and data suppliers. Communities and data connectors are already giving attention to presentation; so now the issue is to move this attention upstream to the sources of the data. As will be seen below, this theme carried into the group’s discussion of future priorities and generated the suggestion that data suppliers make a greater effort to present their data effectively, using the many tools and techniques now available.

## Philanthropy as an agent of change

The **Douglas County** representative now works for a private foundation in Omaha, after having directed a community health organization there. She described using the power of philanthropy to leverage change, and showed how that foundation helped bring stakeholders to the table where they could agree on a common agenda. The experience in Douglas County also shows how foundation leadership can engage local government and hold it accountable.

The **King County** story shows the strategic use of funding from both public and private sources to effect change. As described above, the health department used federal grants to build targeted initiatives, passing on mini-grants to community partners. In the latest project, The Seattle Foundation shares leadership, provides funding, and holds the county government accountable for using collective impact principles and acting on community priorities for the Communities of Opportunity initiative.

Hurricane Katrina made **New Orleans** a special case in many ways. One is that it generated donations from across the country to support the relief effort. Some of these funds are administered by the Louisiana Public Health Institute, which has used them to organize for well-informed community action and to provide online information resources on community health. The process takes time, and Roundtable participants heard about the slow movement toward community buy-in and efforts to seed these approaches in several Gulf communities. The New Orleans experience may serve as a reminder that funding, even when combined with extreme need, will not by itself assure engagement.

The participants noted that besides being more nimble than government, philanthropy can provide a neutral and sometimes more trusted partner for community members. These attributes, combined with their financial resources and acumen, enable foundations to be significant agents of change.

It is about relevance. It is about getting people to the threshold of commitment across sectors, to get to critical mass to make meaningful change. [That includes using data] for predictive modeling in the ROI equation to show sectors why it is relevant to them.

*Eric Baumgartner, LA Public Health Institute*

On the national scene, the Robert Wood Johnson Foundation (RWJF, a funder of several of the organizations and initiatives represented at the Roundtable) is a leading example of the influence of philanthropy. The foundation contributed to the meeting through a presentation on its new Culture of Health initiative, which is articulating concepts, measures, and programs to cultivate a national movement for equity and healthy choices. Conversation about well-being had already threaded through the Roundtable discussions, with calls for a broad framing of local

Thinking about well-being, we are a country that does not measure that well. And communities want to know about well-being.

*Vickie Mays, NCVHS/UCLA*

endeavors that takes local assets, not just problems, into account and aims for wellness and well-being. The presentation on RWJF's Culture of Health initiative helped to crystallize that theme. After selecting measures from among 30 to 40 candidates, the foundation will test an instrument in sentinel communities later in 2015.

## Support from data connectors and other intermediaries

Threaded through the community stories is the larger story of the work of a host of national organizations. To varying degrees, these organizations are data aggregators, tool developers, coaches, networkers, researchers, and standards-setters. All are advisors, facilitators, and advocates. Representatives of these organizations contributed to the Roundtable discussions out of their broad experience helping hundreds of American communities. Their deep knowledge of both community-level data use and the federal data apparatus not only enriched the discussions but amplified the accounts of community representatives.

To somewhat oversimplify, the ten intermediary organizations represented at the Roundtable can be grouped into the categories listed below, allowing for many overlaps. The work of these non-governmental organizations is often closely related to work going on in many federal offices to support and inform community-level work, as discussed in the next section.

- **Data connectors:** County Health Rankings and Roadmaps, Community Commons, Healthy Communities Institute
- **Facilitators and standard-setters:** Public Health Accreditation Board, National Quality Forum
- **Data organizations:** National Association of Health Data Organizations, Association of State and Territorial Health Organizations
- **Health care organizations and associations:** Kaiser Permanente, Catholic Health Association
- **Philanthropy:** Robert Wood Johnson Foundation

While many of these non-governmental organizations are older, as a sector that intermediates between federal data suppliers and community data users they reached critical mass and the collective status of an informal infrastructure only in the last several years.<sup>9</sup> Many reflect the strong role of major foundations, providing philanthropy and the federal government with economies of scale for reaching communities. The broad conceptualization of health adopted by many of these organizations has helped communities implement approaches to the social determinants of health that integrate the work of health care organizations, public health departments, community action agencies, and community-based organizations.

Some representatives of this sector agreed with other participants about the desirability of making the multiple data and support platforms more navigable for communities and more cost-effective by aligning their structures and contents. This idea is explored in sections III and IV below.

## A multifaceted and evolving Federal role

The full extent of the federal role with respect to community health is far too complex to be meaningfully summarized here. The federal roles that were prominent in Roundtable discussions were as data-supplier, generator and funder of community health initiatives and research, source of significant laws and regulations, and current and potential source of technical assistance.

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<sup>9</sup> The need for a formal infrastructure to support community data use has been a theme of NCVHS discussions for many years. Thus in its 2011 report on communities as learning systems (page 30), the Committee called for “a new kind of infrastructure [to] support, connect, and inform vanguard community health initiatives and enable others to follow their lead.” In the recent Roundtable, it was apparent that many elements of that envisioned infrastructure (enumerated in the 2011 report) are now in place or under development. They include privacy and security guidelines for community data use (in a new NCVHS data stewardship toolkit for communities), access to technical assistance and coaching, sophisticated data visualization tools and skills, tools to support coalition development, and national networks that enable communities to access and share knowledge and information. But these components are only a beginning. Moving forward, the vision and goal of an actual infrastructure could help guide further efforts to consolidate support for communities.

The discussions brought to light important recent efforts to enhance data-sharing among federal agencies and departments, recently intensified by an OMB directive. Participants welcomed the data liberation initiative and the efforts by the IDEA Lab, Healthy People 2020, and others to orient to users' needs and improve communication about data. They expressed interest in accelerating current federal research on provisional data release, small area estimation, and the mosaic effect. In addition, an ONC initiative to unite personal health data and public health data is likely to generate valuable new information for community use.

Several federal participants drew attention to initiatives with particular local relevance. For example, SAMHSA is seeking new ways to serve communities, and plans to station a "data concierge" (a term coined, with pleasure, by Roundtable participants) in each of its regional offices. ODPHP has promulgated a social determinants of health dimension in Healthy People 2020 and provides a number of tools for users. And CDC has several programs that support local community health needs assessment and improvement activities.

In the Roundtable discussions, federal staff who work on policy and planning tempered the discussions by pointing out the constraints within which the federal government operates, including limited funding, competing mandates, legislative restrictions, and respect for state prerogatives. Still, the evidence of all that is happening now stimulated a good deal of creative thinking about what else might be possible to facilitate and strengthen local efforts.

We [at SAMHSA] are working toward building capacity to provide technical assistance, provide advice on the kinds of metrics that people might be interested in capturing, and around doing surveillance as well as surveys to capture community-level data by communities. We recognize we can't fund every community in the nation to collect their own data, but we can provide really good, solid technical assistance.

*Sharon Larson, SAMHSA*

### III. Filling Gaps, Aligning Resources, Propelling Progress

In addition to showcasing leading-edge community stories, the Roundtable highlighted barriers that stand between America's communities and the growing array of resources, limiting their ability to function as learning systems for health. This section describes key data-related challenges facing communities and the participants' thoughts about addressing them.

As seen in the previous section, the Roundtable stories made it abundantly clear that leading-edge communities today are working for health equity. This fact points to a major data issue whose solution must become an increasing national priority: Zooming in on hot spots means drilling down to priority population groups and neighborhoods, and this requires data at a much finer level of granularity than now exists. Even if more granular secondary data become available to them, as hoped, communities will likely also want to strengthen their own abilities in the areas of primary data collection, estimation, privacy protection, and analysis.

Ironically, the very abundance and complexity of available data, together with a common lack of standardization, are also an issue for communities. Available data may not align with local

priorities; and communities don't always know how to choose and use what's best for them. Opportunities may be missed because community members lack the skills to use and analyze the data; or such skills and expertise may be limited to a few professionals. Local decision-makers may need help to link data on problems to information on what to do about them. In addition, some community members may not understand how data about them are being used, or should be used, raising concerns about community data literacy. The latter is a particular concern with respect to "big data," a topic beyond the scope of this report but with great relevance to it.

Another set of challenges stems from the proliferation of governmental and non-governmental platforms that provide access to data and support, sometimes with little or no coordination or communication. As a result, the "left and right hands" of this nationwide enterprise may be unaware of each other's activities. Tools, too, are proliferating. All these redundancies cut into the cost-effectiveness of public and private dollars. In short, there are many unrealized opportunities for alignment, dialogue, and coordination across this space.

The Roundtable participants agreed that addressing concerns such as those outlined above is a responsibility shared by data suppliers, connectors, and community leaders—one that must be approached according to user-centered principles. As we will see below, a major thrust of the discussions was that federal agencies should keep community activities and priorities in mind as they develop data-related policy. To accomplish this, participants proposed institutionalizing a community presence or "voice" whenever tools, initiatives, or data with potential utility for the community are being developed. The voice could be provided by people with both community-level knowledge and data sophistication, perhaps recommended by trusted intermediaries.

Finally, a strong and consistent Roundtable theme was that communities need and want technical assistance, tailored to their specific issues and needs. There was a strong sense that "the teachable moment" is at hand. This theme led participants to envision a regional system that would provide community leaders access to in-person technical assistance. Several models were cited, including SAMHSA's plans to position data concierges in 10 regional centers to assist communities.

This brings us to the participants' priorities for future action and ideas for possible strategies.

I wonder if we need to be more activist. Just throwing out data or money is probably not going to be enough to achieve local impact; even a toolkit is not going to be enough. We have to go listen to the problems that people have and then help them make use of the available data. In the Meaningful Use program, the Regional Extension Centers were critical to reaching providers in smaller communities. I think that is what we are dealing with here. We have to figure out how to replicate both the listening and the implementation assistance at the teachable moment.

*Paul Tang, NCVHS/Palo Alto Medical Foundation*

## IV. Priority Areas and Possible Strategies

The group spent the final several hours of the Roundtable culling and synthesizing their ideas and discussing priorities and possible actions. The results are summarized below in relation to two overarching goals: increasing the data and information that are relevant to community health, and enhancing local data usage.

Some of the Roundtable ideas apply to many sectors and actors. Those with implications for governmental action are framed in terms of HHS because NCVHS advises the Secretary; however, some also may apply to other departments. It must be stressed, though, that far from being recommendations, these ideas represent early building blocks for possible recommendations, after much further examination and development.

### A. Reorienting the country's data enterprises to better serve communities

***(Goal: increasing the usability and usefulness of data and information for community health)***

#### **Possible strategies:**

1. **Increasing mutual awareness and coordination among federal and non-governmental intermediary organizations.** The purpose of this effort would be to inform federal departments and agencies about the variety of community groups, the range and nature of local activities, and the nature of major gaps and needs, to provide a foundation for knowing their data users. A related purpose would be to inform government about the roles of intermediary/connector organizations and to encourage more interaction, sharing of content, and collaboration between them. One suggestion, for example, was to post community stories on healthdata.gov.
2. **Institutionalizing a community voice in relevant federal policy development and data decisions, with a commitment to heed it.** The idea here is to create mechanisms for ongoing community input and governmental learning about what communities know, want to know, and need, and to make this attention to local perspectives a consistent priority.
3. **Giving greater attention to user-centered design and infographics in the presentation of federal data.** It was suggested that data suppliers work with each other and with communities to develop a set of purpose-specific data visualization motifs that work in various settings.
4. **Creating mechanisms for more two-way data flow.** Ideas for bidirectional data flow included getting data on community health determinants to health care providers at the point of care; developing ways to get academic research data into the implementation and dissemination phase in the community; and feeding CHNA findings and priorities into federal data policy development.

5. **Filling priority data gaps.** Roundtable participants flagged the following data gaps as top local priorities: mental health, substance abuse, small populations, and costs.
6. **Accelerating work on priority technical data issues.** The priority issues include using provisional release, where appropriate, to improve timeliness, and developing methodologies for local data collection and/or small area estimation. Both priorities stem from the pressing need for data below the county level and on specific population groups, to further community engagement and the work for equity.
7. **Continuing to explore development of core sentinel indicators.** Participants envisioned a public-private partnership with strong community input that would build on the work already under way in this area. They also cautioned that any common measure set must also allow room for locally selected measures.
8. **Teaching states how to protect data so more can be shared, safely.** Participants pointed out that states might share their data assets more freely if they were confident that they could protect confidentiality while sharing the data appropriately.

## B. Fostering an evolving process of community data engagement

*(Goal: enhancing local data usage for health assessment and improvement)*

### Possible strategies:

1. **Expanding technical support to communities through accessible “data concierges.”** Roundtable participants strongly endorsed the idea of using an expanded network of federal regional centers to provide regional “data concierges” offering communities robust, face-to-face technical assistance on data analysis and use.
2. **Aligning community data and support platforms to allow them to interact, complement each other’s strengths, and be easily navigable.** Participants suggested convening data connectors, funders, and data suppliers to explore ways to align their efforts and work together. This alignment could include integrated mechanisms to help communities find the resources that are most relevant and useful for them.
3. **Linking data on disparities and diversity to information on what works to improve the health of vulnerable population groups.** Communities want ready access to information on what to do about the problems they prioritize. The alignment and cross-referencing described above (#2) could contribute to the solution by creating a unified directory of the many “what works” resources that are already available.
4. **Developing a reference architecture for state and local web-based query systems.** Development of such a reference architecture would facilitate comparisons across communities and the tracking of progress toward explicit goals, and would provide a platform for inputting community-specific data. It should include specifications for easy-to-



use tools for data analysis, mapping, dashboard development, visual presentation, and report writing.

5. **Creating communities of practice across the sectors**, to facilitate ongoing communication, coordination, and shared learning.

## V. Commentary and Next Steps for NCVHS

The Roundtable provided a national perspective on the endeavors occupying communities across the country. Strikingly, many of the predominant local themes—needs assessment and improvement, equity, collective impact, community engagement, presentation—have just as much significance on a national level.

From its vantage point as a federal advisory committee, NCVHS sees its role as helping to identify the priorities, models, and potential economies of scale that warrant federal attention to heighten the impact of these endeavors. There are many ways in which the goal of national-scale population health is best achieved through knowledgeable and targeted community-level action. The lessons and insights that emerged from the October 2014 Roundtable point the way to specific actions that can increase collective impact on a national scale. Below, we note the areas in which NCVHS will consider focusing its attention over the coming year.

1. Continue to learn about the relevant activities of the federal government and other entities, to help reinforce and build on positive developments.
2. Develop recommendations to the Secretary in appropriate areas.
3. Continue to develop the Data and Methods Framework and explore its utility as a tool for aligning data and support platforms.
4. Facilitate platform alignment, with connectors serving as prime movers.
5. Recommend and assist in the establishment of communities of practice for Roundtable participants and others, and engage its members in vetting NCVHS products, including recommendations to the Secretary.
6. Continue work on community data stewardship and related work to assure the privacy and confidentiality underpinnings of data sharing, use, and reuse.
7. Support acceleration of the work on public health data standardization, with priority given to data relevant to a core set of sentinel indicators of community health.

**APPENDIX 1. ROUNDTABLE AGENDA**

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**  
**Subcommittee on Population Health**  
**Roundtable on Supporting Community Data Engagement**  
**October 27 – 28, 2014**

Hubert H. Humphrey Building, Department of Health & Human Services, Washington, DC

**Day One – October 27, 2014**

8:30 a.m.	Welcome and Introductions	Drs. Bruce Cohen and William Stead, Population Health Co-Chairs
9:00 a.m.	<p><b>Current Reality Regarding Community Health Needs Assessments (CHNAs) and Community Health Improvement Plans (CHIPs)</b></p> <ul style="list-style-type: none"> <li>• <b>Opening comments: The new world of CHNA/CHIPs</b></li> <li>• <b>Panel Exchange:</b>                      Brian Vaughn, Sonoma County, CA                      Kay Bender, National Quality Forum                      Jean Nudelman, Kaiser Permanente (via phone)</li> </ul> <p><i>Discussion in pairs and large group</i></p>	Monte Roulier, Facilitator
10:15 a.m.	<p><b>Community Engagement &amp; The Role of Data</b></p> <ul style="list-style-type: none"> <li>• <b>Community Case Stories:</b>                      Eric Baumgartner, Louisiana Public Health Institute                      Megan Miller, Assoc. of State &amp; Territorial Health Officials                      Julie Trocchio, National Quality Forum</li> </ul> <p><i>Discussion in pairs and large group</i></p>	

11:00 a.m.	<p><b>Moving Toward Greater Collective Impact</b></p> <ul style="list-style-type: none"> <li>• <b>Community Case Stories:</b>            Kerri Peterson, Douglas County, NE            Nadine Chan, Seattle/King County, WA</li> </ul> <p><i>Full group dialogue</i>  <i>Reflections on the morning</i></p>	
1:00 p.m.	<p><b>The View from Data Connectors</b></p> <p>Leslie Safier, Healthy Communities Insti.            Chris Fulcher, Community Commons            Julie Willems Van Dijk, County Health Rankings and Roadmaps            Denise Love, Natl Assn of Health Data Organizations</p> <p><i>Full group dialogue</i></p>	
2:30 p.m.	<p><b>The View from Data Suppliers</b></p> <p>Carter Blakey, ODPHP            Chris Cox, CMS            Sharon Larson, SAMHSA            Jim Craver, NCHS            Ms. Chandler, VA/VHA            Jon White, AHRQ &amp; ONC</p>	
3:30 p.m.	<p><b>Using Data to Promote a Culture of Health</b> — Kathy Hempstead, RWJF</p>	
4:15 p.m.	<p><b>Final Group Dialogue</b></p>	
5:00 p.m.	<p><b>Wrap Up &amp; Next Steps</b></p>	
5:15 p.m.	<p><b>Adjourn Day 1</b></p>	

**Day 2 – October 28, 2014**

8:30 a.m.	<b>Start Up</b> <ul style="list-style-type: none"> <li>• Review of Day One themes and findings</li> <li>• Small group dialogue, identifying 4-6 broad buckets in which to focus gap analysis and recommendations</li> </ul>	
9:00 a.m.	<b>Bridging the Gaps</b> Small group discussion, using the From/To Gap Analysis Framework	
11:15 a.m.	<b>Next Steps for Shaping and Vetting Recommendations</b>	Drs. Bruce Cohen and William Stead, Population Health Co-Chairs
12:00 p.m.	<b>Wrap Up</b>	
12:30 p.m.	<b>Adjourn Roundtable</b>	

## **APPENDIX 2. NCVHS ROSTER (as of October 2014)**

**Chair:** Larry A. Green, MD, Department of Family Medicine, University of Colorado Denver

**HHS Executive Staff Director:** James Scanlon, Deputy Assistant Secretary, ASPE, HHS

**Acting Executive Secretary:** Debbie Jackson, MA, National Center for Health Statistics

### **MEMBERSHIP:**

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Raj Chanderraj, MD, FACC, Nevada Heart & Vascular Center

\*Bruce B. Cohen, PhD, Massachusetts Department of Public Health (Subcommittee Co-Chair)

\*Llewellyn J. Cornelius, PhD, University of Maryland School of Social Work

Leslie Pickering Francis, JD, PhD, University of Utah

Alexandra Goss, Pennsylvania eHealth Partnership Authority

Linda L. Kloss, MA, Strategic Advisors Ltd.

\*Vickie M. Mays, PhD, MSPH, UCLA Department of Psychology & Health Services

\*Sallie Milam, JD, CIPP, CIPP/G, W. Virginia's Chief Privacy Officer, WV Health Care Authority

\*Len Nichols, PhD, Center for Health Policy Research & Ethics, George Mason University

W. Ob Soonthornsima, Blue Cross and Blue Shield of Louisiana

\*William W. Stead, MD, Vanderbilt University Medical Center (Subcommittee Co-Chair)

\*Walter G. Suarez, MD, MPH, Kaiser Permanente

James M. Walker, MD, FACP, Siemens Medical Solutions, Inc.

*\*Population Health Subcommittee members*

### **Population Health Subcommittee Staff:**

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Tammara Jean Paul, Ph.D., NCHS

Susan Queen, Ph.D., ASPE

### **Participating Members of the Working Group on HHS Data Access and Use (not otherwise mentioned):**

Leah Vaughan, MD, MPH,

Paul Tang, MD, MS

**Susan Baird Kanaan, Consultant Writer**