
Subject: Recommendations on supporting community data engagement by increasing alignment and coordination, technical assistance, and data stewardship education

Dear Secretary Burwell,

The National Committee on Vital and Health Statistics (NCVHS), your advisory committee on health data and statistics, is pleased to send you its recommendations on ways for the Department to support community health improvement initiatives by strengthening local data engagement.¹ By community data engagement, we mean sustained engagement by community leaders in the effective use of data to accomplish local health improvement goals. Data about the community, which we call “community data,” may be from Federal, State, and/or local sources. Although nurturing community-level data capacities has not been a traditional focus of Federal information policy, local communities have become critical arenas for pursuit of the Triple Aim of health care quality, population health, and reduced costs. NCVHS believes the Federal government could cost-effectively improve population health on a national scale by providing strategic support for community-level data access and use.

The National Committee has inquired into community data practices in recent years and watched these practices evolve in response to the power of technology, the growing role of intermediary organizations, and the Federal data liberation initiative. Two 2011 NCVHS roundtables provided a baseline of community health practices and highlighted the need for a national infrastructure to undergird community work.² In the intervening years, we have held other meetings, consulted with experts, and conducted environmental scans to explore these subjects further. Then at our Fall 2014 Roundtable on Supporting Data Engagement (summarized in the attached report), we brought together representatives of communities, non-governmental data-connector organizations, and Federal data suppliers to identify the barriers to community data use and spark new thinking about solutions. We designed the agenda to optimize creative interaction among these three perspectives. The participants shared compelling examples of community action and improvement and of successful approaches to assisting communities. Descriptions of recent Federal efforts to enhance data-sharing among governmental agencies and directly assist communities led to new ideas for ways in which HHS could facilitate and strengthen community efforts.

¹ 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 issues related to population health, standards, privacy and confidentiality, quality, and data access and use. <http://ncvhs.hhs.gov/>

² National Committee on Vital and Health Statistics, *The Community as a Learning System: Using Local Data to Improve Local Health*, 2011. NCVHS reports on community data are linked on its homepage.

The most striking Roundtable theme concerned the expanding drive for health equity within communities and its implications for data access and use. The emphasis on equity is simultaneously focusing and widening the conversation about the nature of community health and how to improve it, as communities work out how to operationalize the concept of the social determinants of health. There are critical local data gaps, especially with regard to health care access, inequality in health outcomes, costs and affordability, care coordination, and determinants of health specific to each community. Drilling down to population and neighborhood “hot spots” requires data at a much finer level of granularity than are now available; and even if data sources are available, they may be difficult to locate and costs and use restrictions may apply, limiting their utility for community measurement.

Communities are natural settings in which to nurture learning systems for health because local citizens, organizations, and agencies can collaborate for impact on many fronts, including upstream prevention. Actions that lead communities to improve or protect health usually result from their knowing why a problem needs to be solved and how it can be solved to benefit the community at large or subpopulations within it. Thus, articulating that value proposition or value case is critical for community health improvement. Communities are where the clear value case resides for each community stakeholder; and when they determine and own that value case and have information with which to move forward, communities will make positive change. Collaborative approaches are increasingly taking place in community health needs assessment and improvement planning activities across the country. But communities face multiple challenges around data strategies, including locating and acquiring data, conducting sophisticated analytics, and translating the data into actionable information. As a Federal Advisory Committee, we pay particular attention to the role—actual and potential—of the Federal government in fostering communities’ ability to function as learning systems. We believe that now is a critical moment for the Department of Health and Human Service to provide strategic support for community data engagement.

FINDINGS AND RECOMMENDATIONS

The findings and recommendations presented below integrate recent inputs from Roundtable participants with evolving NCVHS thinking on how the Department can support data access and use by communities. They focus on three areas of action: alignment and coordination, technical assistance, and education about the stewardship of health information. The overarching goal of these and forthcoming recommendations is to maximize communities’ ability to enhance local health, health equity, and well-being.

A. Alignment and Coordination

Findings

The Federal data liberation initiative has increased the data available for local use, and some HHS programs are helping to build local capacities in data access and use. Non-governmental organizations play significant roles in this arena, and data and tools with community applications are proliferating. While the expansion of data and tools increases the resources available to communities, it also can create uncertainty about which resources are most relevant and useful and how to integrate information from diverse sources. In order to maximize coordination, cost-effectiveness, and impact, HHS has invested in strategic plans and roadmaps such as the Health IT Strategic Plan and the Interoperability Roadmap. By the same token, the Department's data services, programs, and initiatives relevant to community health could have a greater impact if they were strategically aligned within HHS and guided by an overarching strategy and goals. Further, they should be coordinated with the work of other Federal departments and non-governmental organizations and informed by local expertise.

Recommendations

1. Create a virtual Federal "home" for community-facing data work including the provision of community-level data and the development of tools, technical assistance, and initiatives that support the effective local use of data.
2. Establish an interagency Community Health Data Coordinating Committee, reporting to the HHS Data Council, to actively plan and coordinate the work described above.
3. Develop and publish an HHS Strategic Community Health Data Plan to advance the usability and usefulness of data, tools, and technical assistance deployed by the Federal government as assets communities can use to evaluate and improve community health.
4. Create a mechanism for ongoing input into relevant Federal health data policy from knowledgeable community representatives.
5. Explore opportunities for high-level collaboration and coordination with other Federal departments that operate or fund community-level data and data-relevant programs, including the Veterans Administration and the Departments of Housing, Education, Labor, and Agriculture.
6. Create a mechanism for high-level coordination and collaboration between HHS and non-governmental organizations to support and inform community data engagement.

B. Technical Assistance

Findings

Communities need and want more support and technical assistance to improve their ability to find, collect, integrate, protect, and analyze community-level data; but many lack access to appropriate resources for needed capacity-building. The Robert Wood Johnson Foundation's (RWJF) recently released *Data for Health* report³ documents the desire for better community data support and technical assistance. That RWJF initiative held cross-sectoral, day-long meetings in cities across the US. In every locale, local health, business, social services, and community leaders urged action by HHS and others to support their data needs.

Historically, the Department has provided support and technical assistance to communities through activities such as the publication of the landmark NCHS series of *Statistical Notes for Health Planners*⁴; the provision of data through the CDC WONDER system⁵; and DATA2020 to monitor Healthy People program objectives.⁶ The increased focus on smaller geographic areas and population groups now requires renewed commitment and development of new, more directed approaches. The Department can strengthen community-level capacity-building by providing more online and on-site services to help communities access and use relevant data sources to conduct health assessments, develop health improvement plans, and mount local initiatives and projects.

Learning networks and communities of practice can be an effective complement to other forms of assistance. Learning networks such as RWJF's Aligning Forces for Quality and the All-Payer Claims Databases (APCD) Council convene community and state experts working on similar issues across the country for shared learning. These networks are dynamic and are formed in response to a focused common need. Some are grant-based; others are supported by non-profits such as the National Association of Health Data Organizations (NAHDO) or the National Association of Public Health Statistics and Information Systems (NAPHSIS). This peer-based connectivity is a cost-effective and powerful way to transfer best practices and lessons learned. Participants find that the more they contribute and share, the more the collaboration is valued.

Recommendations

7. Develop a curriculum and channels for providing online technical assistance on accessing, using, and augmenting Federal data for local health assessment and improvement planning and for local initiatives and projects.

³ <http://www.rwjf.org/en/library/research/2015/04/data-for-health-initiative.html>

⁴ <http://www.cdc.gov/nchs/products/snhp.htm>

⁵ <http://wonder.cdc.gov/>

⁶ <http://www.healthypeople.gov/2020/How-to-Use-DATA2020>

8. Develop tools to support community data access and use to complement the resources provided by non-governmental intermediary organizations such as Community Commons and County Health Rankings & Roadmaps, working in coordination with such organizations.
9. Where possible, and preferably through a regional system that builds on existing Federal regional offices, expand on-site technical assistance to help local communities access and use available data and tools, focusing on communities with high need and limited resources.
10. Because learning networks have been proven to be a cost-effective mechanism for building community health data capacity in multi-site collaboratives, governmental funding for data initiatives should encourage the use of learning networks to facilitate the exchange of knowledge, best practices, and lessons learned across sites and sectors.

C. Data Stewardship Education⁷

Findings

The availability and use of community-level data depend on an alignment of regulatory, statistical, and governance policies. Such policies work to reduce disclosure risk and build trust between data suppliers and users. When the proper balance between protections and appropriate use is achieved, the community and the general public will benefit. Education of data suppliers and users can help reduce both actual risks and unfounded concerns, thereby removing a significant barrier to data access. Additionally, the American public needs to know how their data are being used and protected, and the societal/public good of such uses. The Department should expand its programs and resources to educate the general public and data suppliers and users about principles of data stewardship.

Recommendations

11. Highlight and document best practices in sharing and releasing state data safely in order to encourage appropriate stewardship practices and stimulate broader data-sharing and release by state governments.

⁷ In a 2009 primer, NCVHS defines health data stewardship as “a responsibility...to ensure the knowledgeable and appropriate use of data derived from individuals’ personal health information.” Further, “[e]veryone who collects, views, stores, exchanges, aggregates, analyzes, and/or uses electronic health data should practice data stewardship.” (NCVHS, *Health Data Stewardship: What, Why, Who, How*. 2009) www.ncvhs.hhs.gov/wp-content/uploads/2014/05/090930lt.pdf

12. Using the NCVHS Community Data Stewardship Toolkit, educate community members and leaders on appropriate data stewardship practices for collecting, storing, preserving, disseminating, and publicizing health data.
13. Collaborate with experts inside and outside government to develop a data-literacy initiative for the public regarding the secondary uses of data and the legal and policy protections of their personal information.

In conclusion, the National Committee on Vital and Health Statistics looks forward to discussing these proposed actions with you and HHS staff members, and to working with the Department to carry out the recommended actions to enhance coordination, technical assistance, and data stewardship for the benefit of our nation's communities. We will continue to explore other ideas generated by the 2014 Roundtable with an eye to developing further recommendations in the coming year or two.

Sincerely,

Walter G. Suarez, MD, MPH
Chair, National Committee on Vital and Health Statistics

Attachment:

NCVHS, *Supporting Community Data Engagement: An NCVHS Roundtable*. March, 2015.