



National Committee on Vital and Health Statistics

Comments Submitted by the Committee in Response to the Request for Public Comment on the Draft 2019-2020 Federal Data Strategy Action Plan

July 8, 2019

The National Committee on Vital and Health Statistics (NCVHS) serves as the statutory public advisory body to the Secretary of the Department of Health and Human Services (HHS) in the areas of health data, standards, statistics, national health information policy, and the Health Insurance Portability and Accountability Act (HIPAA) (42 U.S.C.242k[k]). In this capacity, the Committee provides advice and assistance to HHS and serves as a forum for interaction with relevant private sector groups on a range of health data issues.

NCVHS appreciates the mission, principles, practices, and action steps of the Federal Data Strategy (FDS), particularly the aim of assembling Federal data assets to increase access to linkable data. Communities need access to information specific to their geographic area; however, the recent loss of several data tools, such as the Health Indicators Warehouse (HIW), and the Behavioral Risk Factor Surveillance System (BRFSS) county-level estimates, as well as the withdrawal of other previously public data sets into Federal Statistical Research Data Centers (FSRDC), has made it increasingly difficult for states, counties, and communities to get the information they need. The NCVHS *Measuring Health at the Community Level: Data Gaps and Opportunities*¹ report and related 100 Million Healthier Lives' *Well-being in the Nation Measurement Framework*² offer information and measures that should be used routinely by communities to assess health—possible only if the data is available and readily accessible.

The Committee observes that if data (or analytic products) at the community level (i.e., sub-county) were produced out of FSRDCs and made public, it would better support local assessment and evidence-based policymaking. The development of additional action steps to support creation of public outputs from FSRDC data holdings would further this goal.

FDS Action Step 16 partly addresses this need but not adequately. NCVHS recognizes that the first-year action steps are largely focused on federal data structures, processes, governance, and priorities. With that understanding, the underlying purpose of the Committee's comment is to convey that **it is vitally important that the FDS prioritize the development of a process for producing publicly consumable health information from federal health data assets.**

NCVHS' recommendation advances successful implementation of the following FDS Practices: #2 Assess and Balance the Needs of Stakeholders; #3 Champion Data Use; #4 Use Data to Guide Decision-Making; #5 Prepare to Share; and, #26 Share Data Between State, Local, and Tribal Governments and Federal Agencies. The NCVHS

recommendation also addresses two of the FDS Work Groups: Access, Use, and Augmentation; and, Commercialization, Innovation, and Public Use.

NCVHS has a long history of recommending vetted approaches for data users to draw on for ethics and data protection. Three products of the Committee's work directly address FDS Action Steps 3 and 4:

- 1) NCVHS 2013 *Toolkit for Communities Using Health Data*;³
- 2) March 2019 NCVHS *13th Report to Congress on HIPAA*⁴; and,
- 3) June 2019 report, *Health Information Privacy Beyond HIPAA: A Framework for Use and Protection*.⁵

The NCVHS Framework for Health Information Use and Protection directly informs the following FDS Practices: #12 Govern Data to Protect Confidentiality and Privacy; #13 Protect Data Integrity; #14 Convey Data Authenticity; #31 Explicitly Communicate Allowable Use; and #32 Harness Safe Data Linkage.

Additional detail and references in support of these comments are included below.

In its capacity as advisor to HHS, NCVHS welcomes the opportunity to provide additional advice to inform implementation of the FDS as relevant to HHS' mission.

Sincerely,

/s/

William W. Stead, MD, Chair
National Committee on Vital and Health Statistics

Attachment

Additional NCVHS Resources

Well-Being in the Nation:

During 2015-17, NCVHS led a coordinated effort with federal and nonfederal stakeholders to develop the “*Measurement Framework for Community Health and Well Being*,”⁶ which recommended domains for measuring population health that included the social determinants of health. Four principles guided the work:

- 1) development of a parsimonious set of indicators that were useful at the federal, state and local level;
- 2) identification of domains that are priorities for governmental departments and sectors (e.g.: housing, transportation, environment, health);
- 3) promotion of balanced measures to meet the needs of different stakeholders—e.g., leading versus lagging indicators; “tried and true” measures vs more innovative measures that could drive equitable improvement;
- 4) advancement of a simple, intuitively appealing design that would yield meaningful measures that resonate with many potential users.

NCVHS engaged in an important public-private partnership with 100 Million Healthier Lives⁷ (100MLives, convened by the Institute for Healthcare Improvement,⁸ which was already working with numerous federal and nonfederal stakeholders) to facilitate the development of measures to forward implementation of the framework. 100MLives worked with NCVHS to complete a landscape analysis and engage 100+ organizations and communities to identify, select, and test measures through a Delphi/iterative testing process. The National Quality Forum decision criteria were used to identify and select measures that were important, objective and effective, feasible and usable and useful to national and community stakeholders.

The process and outcome of this effort, “*Well-Being in the Nation (WIN) Measurement Framework: Measures for Improving Health, Well-Being and Equity Across Sectors*,”⁹ was released on June 3, 2019. The WIN Framework represents the first set of national multi-sector measures developed with input from those sectors and from local communities for measuring population health with a social determinant lens. It is already gaining widespread attention from a wide and diverse range of national organizations and communities.

The WIN Framework includes three levels of measures:

- 1) 9 Core Measures that relate to the well-being of people, the well-being of places, and equity;
- 2) Leading Indicators related to 12 domains (community vitality, economy, education, environment & infrastructure, equity, food & agriculture, health, housing, public safety, transportation, well-being and demographics); and
- 3) a Flexible Expanded set, which includes promising measures that don’t yet have full data availability in each domain.

WIN prioritizes sub-county data. An interactive website¹⁰ written at the 9th grade reading level was created to bring many of these multi-sector measures to local

communities to assure equitable access to the data for everyone—from community residents to national policymakers.

Ethics and Data Protection

In our 2013 Toolkit for Communities Using Health Data,¹¹ NCVHS recognized that community groups are using data to tackle important health issues in new ways that were not imagined a few years ago. In the past, access to data was largely limited to government-based public health agencies or health care systems. Now communities can access data from federal and state governments, local health information exchanges, and other organizations, particularly in digital formats, to promote community and individual health. This Toolkit was created to support communities that are using data by promoting sound stewardship practices, while helping them avoid the missteps and potential harm that can result when data users do not follow sound data stewardship practices.

In its March 2019 *13th Report to Congress on HIPAA*, NCVHS noted the growing use of health information in two worlds. One that is regulated by HIPAA; the other is largely unregulated at the federal level (that is, “beyond HIPAA”).¹² Consumer awareness of privacy protection shortcomings is growing rapidly, and consequently there is bi-partisan interest in improving consumers’ information rights and protecting people from the risk of harm from inappropriate use of confidential information.

NCVHS’ 2019 report, *Health Information Privacy Beyond HIPAA: A Framework for Use and Protection*,¹³ addresses these shortcomings and describes improvements for health information protection based on explicit principles that support individuals’ rights to privacy while not stifling innovative legitimate uses for information to improve the health and wellness of individuals and populations. The Framework presents a path for consumer choice, a way for consumers to be reasonably protected from risk of harm and have redress if harm occurs – in other words, it builds the foundations and the guardrails necessary to protect the rights and interests of individuals while supporting the use of information to manage health, generate new knowledge, and support the public good. Done right, ethical use of data builds the trust that is essential for finding, defining, exploring, strengthening, and improving health at the community and individual levels.

Enhanced data ethics and protections are needed to facilitate the agility industry needs to keep pace with the opportunities and challenges of today’s ever-changing health care landscape. While the processes HIPAA set in motion were absolutely essential at the time, they have not kept pace with the rate of change in policy, health care, and technology. In short, the U.S. needs more agile ways to advance privacy, security, and confidentiality of health information, with a way for consumers to have redress for violations of ethics and/or lack of safeguards of their data.

To achieve equity in how health information affects some individuals, policymakers and data holders should incorporate into health information privacy policies protections from discrimination, stigma, and exploitation resulting from use and sharing of health

information, particularly for vulnerable individuals. Because individuals cannot assume that de-identification techniques, even where in use, will permanently protect privacy, individuals should have the right to expect that data holders and downstream recipients of their data will not re-identify it without their permission. Based upon risk analysis, ongoing risk management and rigorous protections should be in place for more granular and sensitive information. Data sharing should only occur under a data use agreement that prohibits re-identification and re-disclosure.

Implications for Federal Data Strategy:

While the NCVHS *Framework* was being developed, four federal data resources used extensively by communities across the country to assess health were shuttered. These included the: 1) Community Health Status Indicators (CHSI) project; 2) Health Indicators Warehouse (HIW); 3) Health Data Interactive (HDI); and, 4) Behavioral Risk Factor Surveillance System (BRFSS) 7-year rolling average data. In September of 2018, NCVHS held hearings¹⁴ with data stakeholders and federal data agencies to hear about community assessment functions and tools that were struggling to find replacement data sources and about early considerations for the FDS that might replace these data resources. These included the Missouri Center for Applied Research and Engagement Systems (CARES), the Community Hospital Corporation, the Public Health Advisory Board, Trilogy Integrated Resources, and a member of the National Academies of Science, Engineering, and Medicine Committee on Accounting for Socio-Economic Status in Medicare payment Programs. At the conclusion of the hearing, the NCVHS Population Health Subcommittee discussed a vision for a set of commonly used data elements from multiple HHS sources, using a common methodology, shared via an API or other standard process without having to go through an FSRDC.

The Foundations for Evidence-Based Policymaking Act of 2018 gave direction to the FDS for creating access to federal data assets to help inform or guide policymaking at all levels of government. On June 5, 2019, the draft Action Plan for the first year of the FDS was released for public comment. Ahead of that release, federal data assets were already being pulled into 29 secure Federal Statistical Research Data Centers (FSRDCs). While this permits access to researchers and sophisticated data users to an even richer array of federal data, it puts most federal data out of reach for most local governments and community stakeholders.

Well-being in the Nation (WIN) offers a vetted framework to the FDS for policy-relevant data products to be produced out of the FSRDCs by federal agencies or contracted partners. Matching the measures to federal data assets, defining an automated routine for analyzing relevant data sets, and offering the analytic outputs publicly and equitably could revolutionize policymaking for local governments across the country, fundamentally achieving the goals of the Evidence-Based Policymaking Act. The *WIN* measures could be used to test the 40 FDS operational elements and 16 action steps to assure that data needed to equitably improve the well-being in the nation is made available to all organizations and communities in a way that fulfills the vision of Public Health 3.0.

In its capacity as advisor to HHS, NCVHS welcomes the opportunity to provide additional advice to inform implementation of the FDS as relevant to HHS' mission. NCVHS has three standing subcommittees, all which touch on the data action steps in the current draft action plan: Subcommittee on Privacy, Confidentiality and Security; Subcommittee on Population Health; and Subcommittee on Standards. NCVHS' experience engaging with community and research stakeholders could also be supportive. Examples of such stakeholder councils could be researcher stakeholders that were involved in the Health Indicators Warehouse initiatives or researchers who have been accessing the Research Data Centers.

Endnotes

¹ NCVHS. Measuring Health at the Community Level: Data Gaps and Opportunities, March 2017: <https://ncvhs.hhs.gov/wp-content/uploads/2018/03/Measuring-Health-at-the-Community-Level-Data-Gaps-and-Opportunities.pdf>

² Well-being in the Nation (WIN) Measurement Framework: Measures for Improving Health, Well-being, and Equity Across Sectors, June 2019: <https://www.winmeasures.org/statistics/winmeasures>

³ NCVHS. *Toolkit for Communities Using Health Data*. 2013: <https://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf>

⁴ NCVHS. *13th Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act (HIPAA)*. 2019: <https://ncvhs.hhs.gov/wp-content/uploads/2019/03/13th-Report-to-Congress.pdf> p.23.

⁵ NCVHS. Health Information Privacy Beyond HIPAA: A Framework for Use and Protection. A Report for Policy Makers. June 2019: <https://ncvhs.hhs.gov/reports/Framework-for-health-information-privacy>

⁶ NCVHS. Measurement Framework for Community Health and Well Being, January 2017: <https://ncvhs.hhs.gov/wp-content/uploads/2018/03/NCVHS-Measurement-Framework-V4-Jan-12-2017-for-posting-FINAL.pdf>

⁷ 100 Million Healthier Lives: <https://www.100mlives.org/>

⁸ Institute for Healthcare Improvement: <http://www.ihl.org/>

⁹ Well-being in the Nation (WIN) Measurement Framework: Measures for Improving Health, Well-being, and Equity Across Sectors, June 2019: <https://www.winmeasures.org/statistics/winmeasures>

¹⁰ WIN website: <https://www.winmeasures.org/statistics/winmeasures>

¹¹ NCVHS, *Toolkit for Communities Using Health Data*. 2013: <https://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf>

¹² NCVHS. *13th Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act (HIPAA)*. April 2019: <https://ncvhs.hhs.gov/wp-content/uploads/2019/03/13th-Report-to-Congress.pdf> p.23.

¹³ NCVHS. Health Information Privacy Beyond HIPAA: A Framework for Use and Protection. A Report for Policy Makers, June 2019: <https://ncvhs.hhs.gov/reports/Framework-for-health-information-privacy>

¹⁴ NCVHS September 2018 meeting of the full Committee: <https://ncvhs.hhs.gov/wp-content/uploads/2018/11/Minutes-FullCommittee-2018Sept13-14.pdf> and <https://ncvhs.hhs.gov/meetings/full-committee-meeting/>