

**National Committee on Vital and Health Statistics**  
**2017 Report to Congress on the Implementation of the**  
**Administrative Simplification Provisions of the**  
**Health Insurance Portability and Accountability Act**

## **I – Introduction**

This report by the National Committee on Vital and Health Statistics (NCVHS)<sup>1</sup> is the 12th such report to Congress on the status of implementation of the Health Insurance Portability and Accountability Act (HIPAA) since its passage in 1996. To mark this important 20-year milestone, NCVHS offers a high-level overview of the major advances, issues, and opportunities related to administrative simplification and the protection of information privacy and security. The report also discusses the wider context in which HIPAA provisions operate, encompassing all the topics on which NCVHS advises HHS including standards; privacy, security, and confidentiality; population and community health data; and data access and use. The purpose of this report is not to offer new recommendations but to review major themes in the Committee's past recommendations and indicate some of the areas in which it expects to offer them in the future.

The landmark HIPAA legislation was a bipartisan effort to meet the healthcare industry's need to simplify information exchange in administrative transactions, among other goals. Since then, information technology and healthcare delivery have changed in ways and to degrees that the Law's authors could not have foreseen. The health system has accommodated the dramatic changes that took place over that period while gradually implementing and adhering to HIPAA and the laws that augmented it. As the law of the land, HIPAA has had a profound impact, and it continues to do so. It has been regularly updated, and its implementation is actively advanced by HHS. NCVHS sources generally agree, with evidence and qualifications explored below, that HIPAA's standards and operating rules have made the health system's administrative and business practices more efficient and cost-effective, while its privacy and security protections have helped to protect the privacy rights of individuals and the security of personal health information. At the same time, more needs to be done because the environment to which HIPAA applies is continually and rapidly changing.

---

<sup>1</sup> Established in 1949, the National Committee on Vital and Health Statistics (NCVHS) serves as the advisory committee to the Secretary of Health and Human Services on health data, statistics, privacy, national health information policy, and the Health Insurance Portability and Accountability Act (HIPAA) (42U.S.C.242k[k]). 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, and data access and use. Its members have distinction in such fields as health statistics, electronic interchange of healthcare information, privacy, confidentiality, and security of electronic information, population-based public health, purchasing or financing healthcare services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. HIPAA requires NCVHS to report regularly to Congress on the status of HIPAA implementation. NCVHS reports and recommendations are posted on its website, <http://ncvhs.hhs.gov/>.

Many factors, including access to data to support evidence-based policymaking, must come together to improve the health of Americans. Among these factors, HIPAA focuses on administrative efficiency and protecting the privacy and security of information. These are closely linked to, and indeed dependent on, continued progress in the accessibility and usefulness of health data and information on the population's health. Accordingly, this report describes the National Committee's work in all these areas and identifies a set of priorities that cut across them.

NCVHS held 12 full Committee meetings and 10 hearings and workshops in 2014 through 2016, the period covered by this report. Based on its findings, during this period it issued 18 letters and 5 reports on various aspects of health information policy. This report draws on those sources. To provide context for the overviews of each of these areas, the next section (**Section II**) outlines four complementary priorities related to data and information that must be pursued simultaneously to achieve maximum benefit for Americans. They concern balancing standardization and innovation, practicing data stewardship, educating and supporting health data users, and leveraging the power of partnerships. **Section III** then describes specific policy goals and themes in the areas of standards, privacy and security, population health, and data access and use. Finally, **Section IV** outlines the steps that NCVHS plans to take in 2017-18 to envision the optimal policy environment for continuing to advance HIPAA; advise on making the impacts of HIPAA more predictable for covered entities; and enhance vital statistics.<sup>2</sup>

Throughout this report, the Committee hopes to convey its judgment that HIPAA's administrative simplification and privacy and security provisions can have the most positive impact when they are based on standards and operating rules that are consistently implemented by all users; when these provisions are an integral part of a predictable and coordinated ecosystem of laws, regulations, and guidance; and when they function within a policy environment that also encourages innovation and assures the availability of information to enable improvements in the health of all Americans.

---

<sup>2</sup> Covered entities under HIPAA include healthcare clearinghouses, health plans, and providers who perform electronic transactions. (HIPAA Title 45, Subtitle A, Subchapter C, Part 164, Subpart A, §164.104)

## II – Cross Cutting Themes

Four themes emerge from the NCVHS work in the aforementioned areas, representing what the Committee sees as essential approaches to continued improvement in the implementation of HIPAA and complementary efforts to advance the public good. The themes concern balancing standardization and innovation, practicing data stewardship, educating and supporting health data users, and leveraging partnerships—all for the purpose of optimizing the investments in data and the efficiency of the health system. The Federal government has a pivotal role to play in helping to ensure that the data it collects is used responsibly and appropriately. Moreover, Federal guidance and expertise will help assure that data collected by others such as States and communities meet the conceptual standards set by HIPAA.

### 1. Balance standardization and innovation to improve efficiency.

In an interdependent and interoperable system, standards enable information to flow and be understood. To be most effective, such standards should be implemented completely and consistently. At the same time, though, the environment in which HIPAA is implemented is changing so rapidly that policy approaches must be dynamic and agile. As healthcare delivery and information technology evolve, the levers of administrative simplification and privacy and security protection must evolve, as well.

NCVHS suggests that future HIPAA implementation efforts focus on the handful of transactions that can be universally implemented. Thus the Review Committee (described below) has recommended a focus on achieving consistent implementation of the standards related to the five transactions that are already widely implemented by all participants in those transactions.<sup>3</sup> NCVHS will continue to advise HHS on adapting HIPAA rules and regulations to evolving conditions, in consultation with industry representatives, standards development organizations, and others.

Building on this platform of standardized transactions, NCVHS urges the Federal government to encourage the health system to experiment with new methods for achieving the administrative simplification goals of HIPAA, and also to leverage the innovative approaches of others. Healthcare transactions and privacy and security protections need to keep pace with the rapid changes in information technology, clinical practices, system and payment reform, policy priorities, progress toward open data, increased risks of inappropriate or harmful use, and other areas. The healthcare industry and other partners in health are continuously developing new solutions in response to new challenges and opportunities, and should be encouraged to do so. When appropriate, the learnings from these experiments can then be woven back into existing processes for consideration in subsequent standards development.

The same principle of balancing standardization and innovation applies in the population and community health arena. As discussed below, NCVHS developed a consensus Measurement Framework for community level health and well-being indicators to facilitate local data access

---

<sup>3</sup> The five transactions for which standards are now widely implemented are eligibility, claim, claim status, remittance advice, and coordination of benefits.

and use. The two-fold goal of that effort is a parsimonious measurement tool that enables national-scale coordination and benchmarking and an adaptable menu of metrics to meet diverse local needs. The creation of learning communities in this arena, as in others, will facilitate sharing of the lessons and benefits of innovation.

Finally, it is important to coordinate all of the standards and policies supporting administrative simplification and privacy and security protection so they work together for public good. These components include rule-making, guidance, operating rules, robust testing and pilots, tool kits, technical assistance, methods research, measurement, and enforcement as well as the successful results of voluntary experiments.

## **2. Practice consistent data stewardship to facilitate secure information exchange.**

The discipline of health data stewardship supports efficient information exchange by promoting data quality and creating an atmosphere of accountability and trust. While advances in information technology capabilities make health data more accessible and useful in ways that can significantly benefit Americans, the same capabilities also heighten the risk that inappropriate, unexpected, or unauthorized uses of the information may harm individuals or communities and undermine trust in healthcare and public health providers. Health data stewardship is a responsibility, guided by principles and practices, to ensure the purposeful and appropriate use of data derived from individuals' personal health information. The stewardship principles include accountability, transparency, individual participation and control, purpose specification, data integrity and quality, security safeguards, de-identification of data, and oversight of data uses. These principles are designed both to protect the rights and privacy of the persons whose data are involved and to assure the quality and integrity of the data and their uses. To ensure that data are of optimal quality and appropriately safeguarded, everyone who collects, uses, protects, and/or shares health data must practice data stewardship.

The natural tension between openness/sharing of data and individual privacy protection has had an impact on the progress of administrative simplification. Yet while data stewardship practices may impede information flow in some ways, a failure to practice data stewardship would undermine information exchange and, ultimately, the functioning of the health system. To enable care coordination, analytics, and other critical uses of data, it is essential to find ways to protect data privacy and security while preserving data access for the uses that benefit the American people. The goals of expanded data access must be pursued within a context of strict adherence to data stewardship principles, using the best available technology and practices to protect privacy.

NCVHS has stressed the need to extend the chain of trust and accountability addressed in HIPAA to encompass all uses of individually identifiable health data by all users.<sup>4</sup> In 2015, it

---

<sup>4</sup> NCVHS reports on data stewardship: [Health data stewardship: An NCVHS primer](#) (September 2009); [Enhancing protections for uses of health data: a stewardship framework](#) (April 2008); [Enhanced](#)

released a toolkit to facilitate data stewardship by those using data focused on community health.<sup>5</sup> This toolkit is a model of the kind of practical resource that can be useful for data users, as discussed below.

### **3. Take advantage of technology to educate and support the multiplicity of health data users.**

NCVHS believes that the power of technology can be used more fully and effectively to offer more resources tailored to specific use cases and user needs. Health information and data have many users and uses across the realms of personal health management, healthcare, financing, policy, governance, public and community health, research, and technology, among others. While the interests, needs, and capacities of these data users vary greatly, most need some form of support to help them find and appropriately use needed information. The complexity of available data and the diversity of formats can be challenging for the communities, businesses, and non-profits that rely on health data. The absence of best-practice guidance in the governmental and non-governmental platforms offering access to data and support can undermine the use of those data, because of the burden and cost of figuring out how to use each source. For these reasons, many NCVHS recommendations focus on providing education and optimizing interfaces and services to meet the needs of diverse users.

There are many excellent models of such resources. The Committee commends the HHS Office of the National Coordinator of Health Information Technology (ONC) and the HHS Office for Civil Rights (OCR) for developing and disseminating highly effective educational resources for their constituents through web pages, FAQs, videos, and other forms of targeted user support.<sup>6</sup> In the realm of community health data, intermediary organizations have developed online resources that make such data accessible and usable for community health improvement efforts. The National Committee's own contributions to these resources include the toolkit on data stewardship for community users described above and the Measurement Framework described below. Additional targeted resources continue to be needed, to ensure that data are accessible and usable for public benefit while protecting the rights of individuals.

### **4. Leverage partnerships to get the most out of data resources.**

As complexity increases and the demands on resources intensify, there is growing interest in strengthening partnerships as a strategy for optimizing data investments. This theme was prominent in the Committee's work in 2014-16. NCVHS has a unique vantage point on the evolution of partnerships through its role as convener and interface between the Federal government and information policy stakeholders. Every arena in which it advises the Federal

---

[protections for uses of health data: a stewardship framework for "secondary uses" of electronically collected and transmitted health data](#) (December 2007)

<sup>5</sup> [Toolkit for communities using health data: How to collect, use, protect, and share data responsibly](#) (May 2015)

<sup>6</sup> ONC resources: <https://www.healthit.gov>.

OCR resources: <https://www.hhs.gov/hipaa/index.html>

government contains multiple communities. And in every one, NCVHS has seen growing recognition of common interests, appreciation for the value of achieving alignment and economies of scale, and determination to avoid duplication of effort. The opportunities for partnership exist on many axes: between governmental and non-governmental organizations (public and private sectors); across geographic levels (nation, state, county, community, neighborhood); and among sectors (health, commerce, labor, education, transportation, agriculture, environment, justice, and so on).

It is not surprising, then, that a vibrant conversation about partnership and collaboration is taking place in all the arenas on which NCVHS advises the Federal government. This includes the standards community, the provider community, and between health plans and providers. In the community health context, local health and well-being cannot be achieved without joint efforts across domains, using information about and from all of them. In these community health efforts, healthcare stakeholders are increasingly active partners with public health and community organizations, now that policy makers are defining healthcare outcomes in terms of the health of entire populations and recognizing that the health of citizens is affected by much more than medical care. To cite a few examples of collaboratives, the Committee's recent work has highlighted the creative joint efforts of the Workgroup for Electronic Data Interchange (WEDI); the Health Datapalooza; and the NGO Coordinating Group formed to work further on the NCVHS Measurement Framework for Community Health and Well-being.

NCVHS anticipates that the role of partners and partnerships will be an increasingly essential part of the American health story in the years to come. In all these endeavors, the guiding questions are the same: What are the goals? Who are the potential partners? What are their respective interests and where do they converge? How can they engage in a joint effort, for the common good? And how can they form effective learning communities to share what each partner is learning?

## III – Progress and Status

### Administrative Simplification

#### Overview

The goal of administrative simplification is to enable electronic information exchange for an efficient and effective healthcare system. Briefly, administrative simplification is carried out in three steps:<sup>7</sup>

- 1) Legislation: HIPAA named the transactions for which standards should be adopted, including requirements to adopt identifiers, code sets, and defined covered entities. The Affordable Care Act (ACA) added the mandate to adopt operating rules for each transaction.
- 2) Rulemaking: HHS was authorized to adopt standards, code sets, identifiers and (later) operating rules, and to define business associate, based on recommendations from NCVHS.
- 3) Implementation by the healthcare industry.

NCVHS has been actively involved in advising and working with HHS on the adoption of standards, identifiers and code sets since the passage of HIPAA in 1996. In 2010, the ACA established a new requirement to name an entity to author operating rules and adopt them for each of the adopted standard transactions (e.g., for claims, eligibility, and electronic funds transfer); NCVHS recommended that HHS designate CAQH as that entity, and CAQH CORE (Committee on Operating Rules for Information Exchange) was designated to serve in that capacity. The ACA required that the Secretary name a Review Committee to review and make recommendations on adopted standards and operating rules; and NCVHS was designated to serve in that capacity. The Review Committee's reports and recommendations, which are based on extensive consultations with industry, inform NCVHS recommendations to HHS and its Reports to Congress on the status of HIPAA implementation.

#### Themes and Findings

##### **1. Significant progress has been made with implementation and expanded utilization of the HIPAA standards, identifiers, code sets, and operating rules.**

HIPAA administrative simplification provisions have created real value across the healthcare ecosystem. By providing a common set of rules for all entities to follow and increasing the volume of electronic data interchange, the adopted standards have met many core business needs of healthcare providers and health plans and decreased the cost and complexity of administrative processes. This progress has enabled the healthcare industry to focus its resources and technology investments more cost-effectively. For example, a 2014 CAQH Index

---

<sup>7</sup> See Appendix 1 for further information.

estimated \$4 billion in savings to date as a result of standards adoption, and projected a total savings of \$8 billion if the standards were routinely utilized.<sup>8</sup> It also found that 91.8 percent of health plans had fully adopted the claim transaction, with a potential provider savings of \$2.23 per claim transaction. The Veterans Administration found that one of greatest benefits from the eligibility transaction was the reduced amount of time needed to verify insurance.

Having written the Secretary on two occasions to urge no further delays in the implementation of ICD-10, NCVHS welcomed the relatively smooth transition to these new code sets in 2015. This success is a good illustration of the importance of both industry education and collaboration, two of the cross-cutting themes in Section II. In response to widespread concerns about impending ICD-10 implementation, the Centers for Medicare & Medicaid Services (CMS) convened industry partners to explore the challenges and determine how to test between trading partners and prepare industry for this significant change. As a result, the Federal government engaged in extensive testing with its Medicare providers, shared the results, developed guidance on best practices, and conducted aggressive outreach to inform the healthcare industry about available resources. Many other entities collaborated to provide extraordinary education and outreach to small providers and to assist in the transition.

## **2. There continue to be significant challenges in implementing administrative simplification provisions.**

The challenges to HIPAA implementation relate to attaining maximum efficiency and effectiveness, the overall pace to achieve cross-industry consistency, and the consistent measurement of value generation. The existence of differing business models and governance for every component of administrative simplification continues to pose a major challenge. In addition, regulations and practices are misaligned across sectors; and existing regulations must be revised to leverage standards and business practice advances that have emerged through industry collaboration since the passage of HIPAA. NCVHS has heard from industry that maximum value is achieved when all parties to a transaction equally engage in and consistently use the standards. Recognizing these challenges, in February 2016 NCVHS sent a letter to the Secretary with recommendations for HHS, Standard Development Organizations, the Operating Rule Authoring Entity, the healthcare industry, or a combination thereof. The recommendations include exploring the feasibility of expanding the definition of HIPAA covered entities, broadening education, ensuring consistency, enforcing compliance, and ensuring responsiveness to evolving changes in healthcare.

## **3. The healthcare industry needs greater predictability over a long time horizon so it can plan for resource use.**

In its hearings and consultations with the healthcare industry, NCVHS has heard a broad desire for greater predictability and a reduction in reactive, unscheduled costs related to the definition, finalization, adoption, evaluation, advancements, and speed of implementation of administrative simplification provisions. The healthcare industry wants greater predictability in the adoption of

---

<sup>8</sup> <http://www.caqh.org/sites/default/files/explorations/index/report/2016-caqh-index-report.pdf>



standards, code sets, identifiers, and operating rules over a long-term horizon in order to plan resources. It also needs realistic timelines, and attention to overlapping and potentially conflicting changes, to garner efficiencies in adoption effort and time lines. NCVHS plans to address the need for predictability in 2017, as described in Section IV.

#### **4. The levers of administrative simplification must evolve along with the healthcare landscape.**

As the healthcare landscape continues to change rapidly, increasing integration is needed among financial, administrative, and clinical standards. For example, healthcare finance policy now favors integrated care models, and payment models based on value and quality are being developed across the country. This growing need for integration among standards has significant implications for existing and planned administrative simplification provisions. It is important to learn from a changing market and take advantage of opportunities related to technology and new business processes as well as in various types of data standards. One example is the trend in healthcare toward using clinical data to inform system delivery and care reform efforts. There are also opportunities to strengthen the learning health system, supported by a nationwide interoperability roadmap, in order to build more robust public health and bio-surveillance capabilities to support the government's critical role in monitoring disease outbreaks and threats.

#### **5. The impact of traditionally non-HIPAA covered entities continues to expand as a result of the complexity of the healthcare ecosystem, with growing implications and risks.**

The goal of administrative simplification is to maximize system efficiency and cost-effectiveness by getting everyone to follow the same rules and practices. Achievement of this goal is thwarted by the current definition of a HIPAA covered entity. A number of organizational types are currently not included in the definition of a HIPAA covered entity although they engage in exchanging administrative and financial data related to health and/or healthcare. These organizational types include banks and other financial institutions, some employers, worker's compensation plans, and the property and casualty industry. The failure of these and other entities to use electronic transaction standards could result in increased costs because of the need for more translators, customization and maintenance to capture necessary data, and information from those using proprietary methods.

**NCVHS Letter to the National Coordinator of HIT:**

- [ONC's Draft 2017 Interoperability Standards Advisory](#) (October 13, 2016)

**NCVHS Letters to the Secretary on Administrative Simplification, 2014-16:**

- [Recommendations Proposed Phase IV Operating Rules](#) (July 6, 2016)
- [Recommendations for the Electronic Healthcare Attachment Standard](#) (July 5, 2016)
- [ASC X12 XML Schemas](#) (September 23, 2014)
- [Findings from the June 2014 NCVHS Hearing on Virtual Credit Cards and Credit Card Use](#) (September 23, 2014)
- [Findings from the June 2014 NCVHS Hearing on the Incorporation of the Unique Device Identifier \(UDI\) in Administrative Transactions](#) (September 23, 2014)
- [Findings from the June 2014 NCVHS Hearing on Healthcare Claim Attachments](#) (September 23, 2014)
- [Findings from the June 2014 NCVHS Hearing on Coordination of Benefits, Health Plan Identifier \(HPID\), and ICD-10 Delay](#) (September 23, 2014)
- [Electronic Standards for Public Health Info Exchange](#) (June 16, 2014)
- [Findings from the February 2014 NCVHS Hearing on Prior Authorization for the Pharmacy Benefit; Health Plan Identifier \(HPID\); Electronic Fund Transfer \(EFT\)/Electronic Remittance Advice \(ERA\); and, Remaining Operating Rules](#) (May 15, 2014)
- [ICD-10 Delay](#) (May 15, 2014)

**Letter and Report from the Review Committee:**

- [Review Committee Findings and Recommendations on Adopted Standards and Operating Rules](#) (October 13, 2016)
- <http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/2016-Ltr-to-Burwell-Findings-of-RC-Adm-Simp-June-2015-Hearing-Word.pdf> (February 29, 2016)

## Privacy, Security and Confidentiality

### Overview

The purpose of privacy, confidentiality, and security protection of personal health information is to preserve a foundation of trust for all uses of health information. In addition to standards for transactions, code sets, and identifiers, HIPAA also called for standards for security to be adopted, as well as for development of privacy regulations if Congress did not enact privacy legislation. The HIPAA Privacy and Security Rules<sup>9</sup> lay out the obligations of “covered entities” and their “business associates,” as defined in the Rules. While the Rules have been regularly updated, the health information ecosystem continues to outpace policy, creating important challenges. The following themes capture these challenges.

### Themes and Findings

#### **1. Consumer engagement and trust can be advanced through greater access to information.**

Research by the HHS Office of the National Coordinator for Health Information Technology (ONC) found that 75 percent of those surveyed expressed concern about the privacy of their information, although this concern did not lead them to withhold information. In 2016, the HHS Office for Civil Rights (OCR) issued new guidance ensuring that neither price nor process would be barriers to patients seeking access to their health information.<sup>10</sup> OCR has stepped up consumer education to help consumers understand the potential risks and benefits of health information exchange as well as their rights with respect to their personal health information.<sup>11</sup>

#### **2. HIPAA standards for privacy and security protection continue to evolve.**

As noted, the Privacy and Security Rules detail responsibilities of covered entities (providers, health plans and clearinghouses) and their business associates (contractors performing specific information duties under explicit agreement with covered entities). Important Rules on privacy and security have been updated over the years and must continue to evolve. For example, Minimum Necessary is a HIPAA standard requiring covered entities and business associates to make reasonable efforts to limit the protected health information that is requested or disclosed to accomplish the intended purpose of the specific use, disclosure, or request.<sup>12</sup> In November 2016, NCVHS sent recommendations to the HHS Secretary reaffirming the importance of the Minimum Necessary standard as an essential provision of the HIPAA Privacy Rule and offering ten practical recommendations for clarifying the regulation and promulgating guidance and education on its implementation.

---

<sup>9</sup> The Privacy Rule is located at 45 CFR [Part 160](#) and Subparts A and E of [Part 164](#). The Security Rule is located at 45 CFR [Part 160](#) and Subparts A and C of [Part 164](#).

<sup>10</sup> <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html>

<sup>11</sup> <https://www.hhs.gov/ocr/>

<sup>12</sup> The HHS Office for Civil Rights has issued guidance on Minimum Necessary in the form of FAQs.

NCVHS also continues to monitor existing standards and the adequacy of existing guidance. In September 2015, the Committee sent recommendations to the Secretary on HIPAA Section 1179, which creates a limited exemption from HIPAA requirements for financial institutions engaged in certain healthcare-related financial transactions.<sup>13</sup> NCVHS also advises and collaborates with HHS on priorities such as the important work of the Office for Civil Rights on HIPAA rights education and the work of ONC on the privacy implications of interoperability and technology advancements such as “computable privacy.” The latter effort is designed to capture, communicate, and process individual choice to enhance interoperability and move toward a learning healthcare system.<sup>14</sup>

### **3. Privacy and security must be strengthened beyond the boundaries of HIPAA.**

Digital health information is more widely available and used by public and private entities today for analytics. The May 2014 report by the President's Council of Advisors on Science and Technology (PCAST) recommended privacy policies for the era of big data.<sup>15</sup> Data for analytics are “de-identified” according to HIPAA standards, but once de-identified, these data are no longer subject to HIPAA. However, there remains a persistent risk of re-identification as data sets are combined and enhanced. NCVHS convened experts in a hearing on de-identification to address the rapidly-expanding use of de-identified data and the growing risk of re-identification associated with increasing opportunities to link datasets. In early 2017, NCVHS will issue recommendations calling for improved guidance on de-identification of protected health information.

Today, health data are frequently collected outside the hospital and doctor's office, often placing the data beyond the boundaries of HIPAA protection. For example, biometric devices collect health information for the personal use of individuals and to share with providers, for example, using cloud-based applications that can raise privacy concerns. Defining the boundary between uses and transmissions of data that are within the scope of HIPAA and those that are not has recently been addressed by guidance from the Office for Civil Rights.<sup>16</sup>

In the areas described above and others, stewardship of privacy and security beyond the boundaries of HIPAA is a critical issue. Public policy must strive to preserve privacy while promoting innovation through use of information. NCVHS developed its aforementioned Toolkit

---

<sup>13</sup> Financial institutions offer far more services in support of the healthcare industry today than when Section 1179 exemption was made part of the HIPAA law. This hearing examined the range of services and the application of the exemption. NCVHS offered recommendations calling for guidance and training to ensure that the exemption was limited to claims payment and funds transfer services as Congress intended.

<sup>14</sup> <https://www.healthit.gov/policy-researchers-implementers/computable-privacy>

<sup>15</sup> President's Council of Advisors on Science and Technology, Report to the President: Big Data and Privacy: A Technological Perspective, May 2014.

<sup>16</sup> <https://www.hhs.gov/hipaa/for-professionals/special-topics/cloud-computing/index.html> and <https://hipaaqportal.hhs.gov/community-library/accounts/92/925889/OCR-health-app-developer-scenarios-2-2016.pdf>

to strengthen privacy and security practices in data sharing for community health purposes.<sup>17</sup> NCVHS plans to continue its focus on advancing privacy and security of health information both under and beyond the protections of HIPAA.

#### **4. Compliance with the Privacy and Security Rules must remain a top priority for policy-makers.**

Privacy and security remain, and must remain, a top policy priority in the face of the sharp recent increase in cyber risks and attacks, which include the threat of holding medical information for ransom. In addition, security breaches by HIPAA covered entities continue to be frequent despite carrying stiff fines and consequences. OCR has completed the first phase of its HIPAA compliance audits, and launched Phase 2 in 2016. It also stepped up enforcement activities from 2014-2016, regularly reporting to NCVHS on its enforcement actions. NCVHS supports the steps being taken by HHS to strengthen the understanding of and full compliance with both the Privacy and Security Rules to ensure the privacy of protected health information. As noted above, the Committee commends the achievements of OCR and ONC in industry guidance.<sup>18</sup> New guidance documents are announced on the Newsroom page of the OCR website.<sup>19</sup> Privacy and Security are foundational to trust; and trust is critical if we are to fully use health information to improve the health system and serve the public good.

##### **NCVHS Letters and Reports on Privacy/Confidentiality/Security, 2014-16**

- [Recommendations on the HIPAA Minimum Necessary Standard](#) (November 9, 2016, Letter to the Secretary)
- [Recommendations on the financial services industry and § 1179 of HIPAA](#) (September 16, 2015, Letter to the Secretary)
- [Toolkit for Communities Using Health Data: How to collect, use, protect, and share data responsibly](#) (May 2015)

<sup>17</sup> NCVHS toolkit for community data users (see citation and link on page 13)

<sup>18</sup> For example: <https://www.healthit.gov/sites/default/files/pdf/privacy/privacy-and-security-guide.pdf>.

<sup>19</sup> <https://www.hhs.gov/ocr/newsroom/index.html>

## Population and Community Health

### Overview

The goal of health information and data policy related to population and community health is to increase the availability of useful data from both health and non-health sectors that community leaders can use to assess and improve the health and well-being of local residents.

### Themes and Findings

#### **1. States and communities need better data to inform policy development, resource allocation, and action.**

Community leaders and state and local officials find small area data comparison to be helpful in identifying the priorities for resource use to improve the well-being of residents. They know that social, behavioral, economic, educational, and other factors play key roles in determining individual life course as well as population health status. Reduced medical costs, shortened hospital stays, and quicker recoveries all may be possible outcomes if local data are more available to develop prevention and early intervention strategies. However, decisions and actions on key priorities in all these sectors are hampered by serious gaps and inconsistencies in the availability of local data. While partnerships have formed across sectors to work together to improve local health, they often lack the specific knowledge needed to identify the most vulnerable residents, the greatest threats, and the most cost-effective interventions. During NCVHS workshops and roundtables since 2011, community and public health experts have called on HHS to partner with other Federal agencies and other entities to fill these gaps and address the need for greater access to community-level data.<sup>20</sup>

#### **2. Federal data investments that meet community and local health data needs will also meet the health policy needs of State and Federal government.**

Recent studies of the poor health performance of the United States compared to other industrialized nations have identified profound place-based disparities in life expectancy as a primary driver.<sup>21</sup> A growing body of evidence suggests that existing national, state, and county health data sources are inadequate for identifying and addressing the precise disparities, or “hot-spots,” that disproportionally drive the increases in healthcare costs.<sup>22</sup> The Federal government has helped galvanize attention to health disparities and awareness of the need to address the broad determinants of health to achieve sustained health improvement. To accomplish this, it has encouraged data sharing and strategic data integration. To a great extent, the health of the nation is achieved cumulatively, through targeted local actions across the country. Looking forward, NCVHS sees a vital ongoing role for the Federal government in supporting and informing these local efforts. This is a cost-effective strategy for realizing its

---

<sup>20</sup> See the references on page 16 and the following NCVHS report: [The community as a learning system for health: using local data to improve local health](#) (December 2011)

<sup>21</sup> Endnotes 4, 5, 6 from workshop report?

<sup>22</sup> Endnotes 7 & 8 from workshop report?

national policy goals for the health of the American people. The Federal government, with its expertise in data collection initiatives such as the Census, the National Health Interview Survey, and the cooperative vital statistics system, can help provide technical guidance and support to state and local governments and communities to improve health data available at the community level.

**3. A collaborative approach to health data collection and dissemination across sectors can maximize improvements for individual and population health.**

In recent years, activities in the areas of public health, mental health, and healthcare have converged in a combined focus on population health. At the local level, this trend is seen in close partnerships among healthcare organizations, local health departments, and other sectors such as education, transportation, and the business community. This work is based on a common recognition that action, partners, and data must be multi-sectoral because health is a product of multiple determinants. Both Federal agencies and non-governmental coalitions have been working on integrated schema for data on health and its determinants, to enable data-driven decision-making.<sup>23</sup> Leaders in these efforts have told NCVHS that a consensus set of indicators or data domains for indicators would add value.<sup>24</sup>

**4. Community health leaders have verified that a consistent, clear framework for organizing multi-sectoral health data would benefit everyone, including local and State health planners as well as Federal health policy makers.**

With broad input from experts, NCVHS has developed a consensus Measurement Framework for community level health and well-being indicators, to address the need for a parsimonious approach to health data in light of a recent proliferation of indicators. The Framework has ten domains (e.g., economy, food and agriculture, health, and housing) and thirty sub-domains (e.g., income/wealth and employment within economy and food availability and nutrition within food and agriculture). The Framework has a dual purpose of enabling both national-scale coordination and local innovation. State and local leaders have affirmed that the Framework provides a straightforward, easily-understood structure for organizing and collecting data that highlight and identify problems and indicate directions for resources and interventions. The feasibility of the Framework was reviewed at a September 2016 workshop and confirmed as directionally correct. The workshop participants determined that it is ready for further development and testing by non-Federal entities, with additional input from community leaders. Experts in the private sector have assumed responsibility for completing development of the Measurement Framework and developing specific measures of value at Federal, State, and local levels.<sup>25</sup> NCVHS will continue to encourage HHS to coordinate and align its community data collection and dissemination efforts internally, across Federal Executive agencies, and with ongoing private sector initiatives to improve greater access to community-focused data.

---

<sup>23</sup> [Environmental scan of existing domains and indicators to inform development of a new measurement framework for assessing the health and vitality of communities](#) (June 2016)

<sup>24</sup> [Advancing community-level core measurement: a progress report and workshop summary](#) (February 2016)

<sup>25</sup> [September 2016 workshop report when approved]

**NCVHS Letters and Reports on Population and Community Health 2014-16**

[Environmental Scan of Existing Domains and Indicators to Inform Development of a New Measurement Framework for Assessing the Health and Vitality of Communities](#) (June 2016 report)

[Advancing Community-Level Core Measurement: A Progress Report and Workshop Summary](#) (February 2016 report)

[NCVHS Seminar at the 2015 National Conference on Health Statistics – Community Health Data, Data Stewardship and Data Access and Use: Tools and Resources](#) (August 25, 2015)

[Recommendations on supporting community data engagement by increasing alignment and coordination, technical assistance, and data stewardship education](#) (May 28, 2015, Letter to the Secretary)

[Supporting Community Data Engagement – An NCVHS Roundtable](#) (October 2014 report)



## D. Data Access and Use

### *Overview*

The goal of health information and data policy related to data access and use is to expand appropriate access to and use of HHS data assets.

### *Themes and Findings*

#### **1. HHS can learn from the best practices of industry leaders about how to improve the accessibility and usability of HHS data.**

The Work Group on Data Access and Use was created within NCVHS at the request of the Chief Technology Officer of HHS to explore innovative uses and applications of HHS data to improve health and healthcare and provide recommendations for promoting and expanding access to HHS online data. The Work Group is composed of NCVHS members and consultant members who are nationally recognized for their expertise in the development of innovative data applications as well as being active users of government data. The Work Group reviewed available online HHS data, focusing primarily on HealthData.gov, the Health Indicators Warehouse, and the Health System Measurement Project, and evaluated the usability, use, and usefulness of the online data. (HealthData.gov is the HHS website designed to make high-value health data more accessible to entrepreneurs, researchers, and policy makers to support better health outcomes for all Americans.) In March 2014, NCVHS sent recommendations to the Secretary on three topics: the user-friendliness of HealthData.gov, data documentation and metadata,<sup>26</sup> and improving the timeliness of HHS data. NCVHS recommended that HealthData.gov borrow applicable best practices from industry leaders, and it provided examples of such practices. The Committee also recommended that where practical, HHS data publishers apply elements of the common core metadata schema.<sup>27</sup> Finally, it noted that the currency and timeliness of HHS data sets vary from the current year to several years old, and it offered examples of HHS efforts to accelerate release and suggested approaches to expediting data release.

#### **2. Further recommendations on HealthData.gov are forthcoming.**

In late 2016, the Work Group on Data Access and Use conducted an intensive review of HealthData.gov. Since launching in 2011, HealthData.gov has played an increasingly prominent role in facilitating access to data and information used to improve value-based care, the quality of health services, and research about health issues important to a range of communities. It also has contributed to more broadly fostering healthcare innovation. The Work Group has identified opportunities for further enhancing HealthData.gov, building on the portal's successful

---

<sup>26</sup> Metadata is structured information that describes, explains, locates, or otherwise makes it easier to retrieve, use, or manage an information resource (NISO 2004, ISBN: 1-880124-62-9).

<sup>27</sup> The common core metadata schema provides a standardized format and common vocabulary to facilitate communication about data. <https://project-open-data.cio.gov/v1.1/schema/>

implementation and use and early enhancements. NCVHS expects to issue recommendations on this topic in early 2017.

**NCVHS Letter on HHS Data Access and Use, 2014-16**

[Steps to Improve the Usability, Use and Usefulness of Selected Online HHS Data Resources](#) (March 20, 2014, Letter to the Secretary)

## **IV – Next steps: priorities for 2017-18**

NCVHS has identified significant areas of priority for the next two years, along with its continued work in the areas described above. Three of those priorities, which address the pressing need for coordinated yet flexible policy levers, are outlined in this section. The Committee looks forward to additional input from HHS on areas where advice and consultation will be needed in the coming years.

### **1. Predictability and Burden on the Healthcare Industry**

As noted above, the healthcare industry has for many years expressed concern to NCVHS about the lack of predictability in regard to the updating and adoption of standards. The lengthy and complicated processes now associated with these standards make it virtually impossible for affected businesses and organizations to align their planning, budgeting, and work with end-users with the standards process. In 2017-18, NCVHS will develop recommendations for the more efficient development and testing, adoption, and implementation of HIPAA transactions and operating rules. Based on a review of opportunities for efficiency in the overall process and by the organizations responsible for given steps, NCVHS will develop recommendations to HHS aimed at achieving greater predictability in updating HIPAA transaction implementation specifications and operating rules.

NCVHS plans to identify a baseline of existing processes in applicable organizations, including Standards Development Organizations (SDOs), Operating Rule Authoring Entity (ORAE), Designated Standards Maintenance Organization (DSMO), and HHS/CMS. It then plans to hold a workshop to identify enhancements from key industry stakeholders and Federal partners. After the options identified at the workshop are made available, NCVHS will hold a hearing to receive testimony on these options. On that basis, it will develop recommendations to be conveyed in a letter from NCVHS to the HHS Secretary.

### **2. Beyond HIPAA**

As noted above, HIPAA was designed 20 years ago when healthcare was largely paper-based and providers and health plans were the acknowledged stewards of health information. Many of the issues commented upon by testifiers, and thus facing NCVHS for consideration, extend beyond HIPAA. Moreover, HIPAA has changed the culture of healthcare in ways that now make it possible for private sector stakeholders to take initiative and act in partnership with government to create a more nimble and effective system of care. In its proposed *Beyond HIPAA* project, NCVHS will explore these issues and opportunities, including the governance mechanisms that can pick up where HIPAA leaves off. A framework that sits alongside HIPAA is needed to enable health data users to deal with new challenges. With HIPAA and the laws that have modified and enhanced it as the foundation, this project will explore key drivers of health information policy that are beyond the scope of HIPAA or are bumping up against its boundaries. To name a few, these new drivers include big data and analytics, cybersecurity

challenges, population and community health initiatives, and personalized medicine and genomics.

In this project, NCVHS plans to develop policy guidance in the following areas: Guiding principles to advance the governance of health information and inform navigation of the changing landscape beyond HIPAA; consistent privacy policy across federal agencies, states, and the private sector; the shift to predictability and flexibility to enable responsiveness to changing business models; levers, such as Quality Payment Programs, that HHS can apply; best practices, education, and guidance; and legislative mechanisms such as fines for unauthorized or misuse of health information.

### **3. Next-Generation Vital Statistics**

NCVHS is charged with helping HHS to strengthen its data enterprise and assure its safety, for maximum efficiency in assessing and promoting the population's health. The Vital Statistics system is a national asset and a key component of identity protection and our national security. However, as currently constituted, this federated, state-based data system is cumbersome and at risk. It has considerable unrealized potential for enabling public health surveillance, increasing the effectiveness of the healthcare and health financing system, and being useful to business and commerce. To address these concerns, NCVHS plans to convene a 1-2 day hearing in 2017 to obtain input from HHS and other federal sources as well as state jurisdictions, researchers, healthcare providers, and other experts. The hearing will focus on the role of the vital statistics system, assess its current status and risks to its viability, look at questions such as linkage of vital records data with other data systems (e.g., health records), and consider what actions are needed to protect and improve the vital statistics system.

## APPENDICES

*(to come)*

**Appendix 1:** Updated appendix on administrative simplification “journey” (adapted from RTC-10, pp 12-19)

**Appendix 2:** The Privacy Rule’s Four Tiers of Protection *(from Appendix A, Minimum Necessary letter)*

The Privacy Rule tailors the four distinct tiers of privacy protections to specific circumstances:

- Tier 1 reflects HIPAA’s base-line protection: disclosing a person’s PHI requires individual authorization, and the individual’s expressed will, rather than the minimum necessary standard, governs the scope of disclosure.
- In Tier 2, the Privacy Rule recognizes that certain discrete uses of data (listed in Appendix A, Table I) offer societal benefits so compelling as to justify the use or disclosure even without the individual’s authorization. Here, the individual receives the protection of the minimum necessary standard, which allows disclosure *only* to the extent necessary to serve the beneficial use, and no more.
- Tier 3 addresses certain disclosures required by law. Here, applying the minimum necessary standard could obstruct justice, so the Privacy Rule sets out alternative due-process standards to protect the individual.
- Tier 4 outlines a very narrow set of circumstances (treatment and regulatory compliance) where covered entities may disclose data with neither authorization nor minimum necessary limitations.