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5 **Recommendations on Maximizing the Value of HealthData.gov**

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8 **National Committee on Vital and Health Statistics**

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HealthData.gov is the US Department of Health and Human Services (HHS) online health information portal that helps to drive economic empowerment, innovation, and transformation in health through the access and use of federal data resources. This national resource powers visibility, competition, community learning, research, and evidence-based decision making by allowing data users to search for and access publicly available data resources in one centralized location. Increased accessibility and efficient use of high-value public data by diverse users is critical to creating the information needed to improve population health and the delivery of value-based health care through activities such as: business innovations; identifying inefficiencies in health services; monitoring fraud and abuse; performing data-driven community health needs assessments, planning, and monitoring; empowering health consumers; and enabling improved decision-making by patients, providers, and policymakers. Data are a critical commodity in today's economy, and problems and solutions are best discovered and evaluated when quality data is publicly available.

The purpose of this report is to transmit the findings of the National Committee on Vital and Health Statistics (NCVHS) regarding the value of HealthData.gov, and provide recommendations for HealthData.gov to enhance the HHS mission by promoting and facilitating the use of publicly available data within HHS operating divisions and among external users. Data from HealthData.gov can be repurposed to improve program operations, generate insights, and develop health innovations. Taking these opportunities to further enhance HealthData.gov as an essential national resource will enable data users to transform public data into health innovations that will benefit all Americans. This requires the continued availability of information on HealthData.gov; stringent privacy,

security, and confidentiality measures so that data may be used with proper stewardship practices; expanding the efficient access and use of publicly available health data; and sustaining the growing community of data entrepreneurs, businesses that innovate using these data, researchers, public health practitioners, medical consumers, communities, health care organizations, and other data consumers interested in using government-produced data for health innovation. The recommendations provided are supported by peer-reviewed research, experiences from open data innovators in the public and private sectors, and input from the NCVHS expert work group on data access and use.¹

Current State of HealthData.gov

HealthData.gov facilitates the discovery, access, and use of health data that is publicly available by providing a searchable online directory of data resources from all HHS operating divisions and several state and municipality open data portals. All HHS operating divisions collect data that are congruent with the HHS mission to “enhance the health and well-being of Americans by providing for effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services.”² Many of these data are released to the public under stringent privacy, security, and confidentiality protections to fulfill multiple objectives including identifying quality gaps and health care inefficiencies, empowering data consumers to address health issues, enabling researchers to make scientific discoveries, providing communities with information about their health problems to inform their planning

¹ See the workgroup charge and activities at: <https://www.ncvhs.hhs.gov/subcommittees-work-groups/working-group-on-hhs-data-access-and-use/charge-of-the-working-group-on-hhs-data-access-and-use/>

² US Department of Health and Human Services. [HHS website] <https://www.hhs.gov/about/strategic-plan/introduction/index.html#mission>. Published March 10, 2014. Accessed February 16, 2017.

56 efforts, and fostering innovation by entrepreneurs such as applications to search for
57 physicians. Prior to HealthData.gov, the process to search for and access HHS data
58 related to a specific topic such as prescription drug abuse or obesity required users to
59 search across multiple HHS websites to determine what data are available, whether they
60 are fit for use, and how to access them. This process incurred considerable costs for users,
61 limiting the pace of data-driven health innovation.

62 HealthData.gov enhances the value of existing HHS data by improving process
63 efficiency for locating data and promoting increased data use among diverse data
64 consumers, who reuse and combine data in new ways to improve health and well-being.³
65 Data users can search for key terms or browse topics to locate relevant datasets, obtain
66 metadata (“data about the data,” such as publisher, years covered, and a description), and
67 click hyperlinks to be directed to an external HHS or state website where users can
68 download the data. HealthData.gov does not replace operating divisions making their
69 data available through their own websites and does not require the collection of new data.
70 Rather, this innovation allows diverse internal and external data users to more efficiently
71 discover, browse, access, and understand publicly available health data. As the only
72 public inventory of all HHS data resources, it reduces data silos and allows HHS staff to
73 make better use of data for internal programmatic, planning, and evaluation purposes. It
74 enables data consumers without detailed content expertise on HHS and health data to
75 identify relevant health data, thereby bringing in new data users including application

³ The HealthData.gov catalogue does not host data. The data are located on external websites including open data portals (e.g. <https://health.data.ny.gov/>) and webpages tailored to specific topics (e.g. <https://dailymed.nlm.nih.gov/dailymed/index.cfm>). The HealthData.gov software continuously reads output files from HHS operating divisions and several state and municipality open data platforms, and updates the HealthData.gov index as data are added or refreshed. The HealthData.gov catalogue provides standardized metadata for each data offering and data users can click hyperlinks to be redirected to external websites where they can access data and additional information about the resource.

76 developers, businesses, and community planning groups. It enables data customers to
77 discover and understand additional data that may be related to their interest, thereby
78 expanding the appropriate use of data. HealthData.gov also provides a single forum in
79 which to monitor and evaluate the implementation of appropriate data stewardship
80 practices,⁴ which allows consumers to trust that information from them will be used and
81 protected appropriately.

82 Since its development in 2010, the HealthData.gov directory has expanded to
83 cover over 3,000 datasets in diverse areas of clinical outcomes, administration, and
84 monitoring and evaluation.⁵ From 2013 to 2016, web traffic steadily increased from
85 17,561 to 178,334 visitors annually, and the number of times that users accessed the site
86 (sessions) doubled from 508,705 to 1,168,138.⁶ In addition to covering data from all
87 HHS operating divisions, one-third of HealthData.gov resources are federated from state
88 and municipality portals; this increases the value of HealthData.gov by helping data users
89 discover related datasets from geographic areas that could be linked to develop new
90 insights and innovations. The inclusion of non-HHS data in HealthData.gov can also
91 enhance the quality, amount, and timeliness of HHS data as more data users become

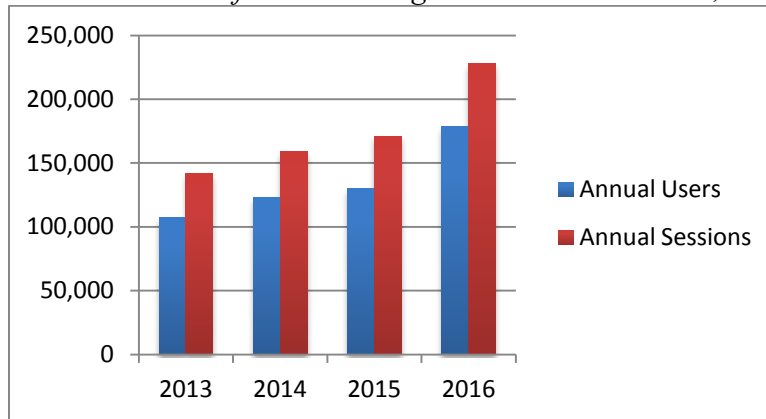
⁴ National Committee on Vital and Health Statistics, Toolkit for communities using health data: how to collect, use, protect, and share data responsibly. <http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf>. Published May 2015. Accessed March 24, 2017.

⁵ Examples include: disease surveillance and mortality data (e.g. Drug Abuse Warning Network (DAWN); Surveillance, Epidemiology, and End Results (SEER) cancer registry; and Nationally Notifiable Diseases Surveillance System); health care access, cost, and quality data (e.g. Medicare Preventable Hospitalizations, HCUPNet query system of publicly available all-payer health care databases; Minimum Data Set Quality Indicator Report; and address tool to locate Health Professional Shortage Areas); and consumer-oriented topics (e.g. Household Products Database on the health safety of consumer brands; Genetics Home Reference on genetic conditions; and DailyMed compilation of pharmaceutical package inserts).

⁶ From NCVHS Data Access and Use Work Group analysis of HealthData.gov Google Analytics data, February 2017.

acquainted with varied data sources and express desires for additional data or alternative data formats.⁷

Annual Number of HealthData.gov Users and Sessions, 2013 to 2016



Source: NCVHS Data Access and Use Work Group Analysis of HealthData.gov Google Analytics data, February 2017

Data indexed in HealthData.gov has already driven economic empowerment, innovation, and transformation in health. Data that are currently catalogued in HealthData.gov and discovered through HealthData.gov or other open data portals have already been used to provide medical consumers with more factual and critical information on local physicians providing the best valued healthcare treatments,⁸ document disparities in the median cost of orthopedic surgeries and appendectomies between hospitals,⁹ illustrate that incorrectly estimating hospitals' costs caused Medicare to overpay hospitals by \$2.6 billion,¹⁰ incorporate food safety inspection data into Yelp's

⁷ Martin EG, Begany GM. Opening government health data to the public: benefits, challenges, and lessons learned from early innovators. J Am Med Inform Assoc 2016; Epub ahead of print.

⁸ Lyons L. U.S. News and RowdMap, Inc. team up to help patients make more informed health care decisions. <http://www.usnews.com/info/blogs/press-room/2016/01/19/us-news-and-rowdmap-inc-team-up-to-help-patients-make-more-informed-health-care-decisions>. Published January 19, 2016. Accessed January 12, 2017.

⁹ Crain's New York Business: Health Pulse Extra. January 8, 2014.

¹⁰ Weaver C, Mathews AW, McGinty T. Medicare overpays as hospital prices rise. *Wall Street Journal*. April 15, 2015. <https://www.wsj.com/articles/medicare-overpays-as-hospital-prices-rise-1429151451>. Accessed February 3, 2017.

crowd-sourced restaurant reviews to make timely information readily available to consumers and encourage safer food handling,¹¹ make food restaurant inspections more efficient through data analytics,¹² support community learning initiatives whereby local communities synthesize data across sectors to identify and address locally-defined issues,¹³ improve physician training by benchmarking the case assignments of medical students against the local disease burden,¹⁴ and improve real-time decision making during a natural disaster to save patients' lives.¹⁵ In addition to these products, HealthData.gov has cultivated a health data ecosystem comprised of application developers, community groups, private industry, and other entrepreneurs who were not traditionally engaged with HHS data.¹⁶ After repurposing the data to develop applications and other innovations, ecosystem members share back their data in reusable formats. This cycle improves the

¹¹ Boiles J. San Francisco promotes its restaurant inspection data on Yelp to improve food safety. <https://www.codeforamerica.org/featured-stories/san-francisco-puts-restaurant-safety-data-on-yelp>. Accessed February 11, 2017.

¹² Wold C. In plain sight: is open data improving our health? <http://www.chcf.org/publications/2015/01/in-plain-sight-open-data>. Published January 2015. Accessed February 17, 2017.

¹³ The Office of the National Coordinator for Health Information Technology is currently supporting 10 local communities to synthesize data across sectors (such as clinical health, public health, criminal justice, housing, schools, and the environment) to help them identify and address locally-defined community health challenges. For example, Cleveland, Ohio is combining weather, housing, school, and clinical data to target and reduce childhood asthmatic attacks. Other community goals include better coordination of services for Chicago residents who are unstably housed, developing a more streamlined system of care for children with complex behavioral and other medical conditions in Austin, Texas, and reducing inpatient hospitalizations among pediatric patients in Cincinnati, Ohio. AcademyHealth. CHP program participant communities. <http://www.academyhealth.org/node/4901>. Accessed February 17, 2017.

¹⁴ Martin EG, Helbig N, Shah NR. Liberating data to transform healthcare: New York's open data experience. *JAMA* 2014; 311(24): 2481-2482.

¹⁵ Martin EG, Helbig N, Shah NR. Liberating data to transform healthcare: New York's open data experience. *JAMA* 2014; 311(24): 2481-2482.

¹⁶ One metric of the expanding open health data ecosystem is attendance at the annual Health Datapalooza conference for entrepreneurs, researchers, community groups, the private sector, and other users. This annual conference allows for the exchange of ideas and updates on innovations and technology developments supported by data accessed through HealthData.gov. Its inaugural meeting included 400 participants and featured the work of 21 developers who were provided with web links to a dozen federal datasets and tasked with developing applications to present publicly. It has since grown significantly, with a current attendance of nearly 2,000 individuals from multiple sectors. Presentations communicate the state-of-the-art scientific developments in health data use, government priorities, new health data applications, and examples of business and communities using data to improve health outcomes. (G Downing, personal communication, February 22, 2017.)

value of data as they are repurposed and repackaged in better ways that increase its use by larger audiences while furthering the HHS mission.¹⁷ Beyond the federal open health data ecosystem, HealthData.gov and its growing user community catalyzed an “open data revolution,” inspiring the development of open health data portals at the subnational level and further data-driven health innovation.¹⁸

Although HealthData.gov has facilitated the production of health innovations that would not have been possible without its existence, there are a number of resource-prudent opportunities to strengthen HealthData.gov over the short-term to enhance and increase its use by diverse users, assist HHS staff in leveraging data across operating divisions for internal use, and ensuring its long-term success and sustainability as a next generation platform. We outline four actionable steps in the following recommendations. To develop these recommendations, NCVHS solicited input from members of the Work Group on HHS Data Use and Access, whose members are nationally-recognized in diverse fields including bioinformatics, application development, population health, web analytics, and data stewardship; conducted a review of relevant peer-reviewed research, government reports, and other gray literature; solicited input from HHS staff who manage HealthData.gov and two state open health data directors whose data are included in HealthData.gov; and analyzed HealthData.gov’s web analytics data.

¹⁷ National Committee on Vital and Health Statistics, Toolkit for communities using health data: how to collect, use, protect, and share data responsibly. <http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf>. Published May 2015. Accessed March 24, 2017. Martin EG, Begany GM. Opening government health data to the public: benefits, challenges, and lessons learned from early innovators. J Am Med Inform Assoc 2016; Epub ahead of print. Harrison TM, Pardo TA, Cook M. Creating open government ecosystems: a research and development agenda. Future Internet 2012; 4(4): 900-28.

¹⁸ Martin EG, Helbig N, Shah NR. Liberating data to transform healthcare: New York’s open data experience. JAMA 2014; 311(24): 2481-12; Martin EG, Shah NR, Birkhead GS. Unlocking the power of open health data: a checklist to improve value and promote use. J Pub Health Manag Pract [in press].

Recommendations to Maximize the Value of HealthData.gov

HealthData.gov has already transitioned from its initial developmental phase to covering all HHS operating divisions and multiple state and local agencies. Actively outreaching to non-government data consumers through key stakeholder forums, such as the annual Health Datapalooza, has contributed to the development of a health data ecosystem. As HealthData.gov continues to evolve, there are several recommendations for how HealthData.gov can improve the accessibility and usability of high-value health data accessible to a wide range of customers to drive economic empowerment, innovation, and transformation in health.

The following recommendations are designed to address shortcomings identified by NCVHS to make it more efficient for diverse users to discover, browse, and access data from HealthData.gov; encourage visitors to return to the site and bring in additional web traffic from new users; and lay a foundation to ensure its success and sustainability in the long-term. Underlying all recommendations is a continued commitment to good data stewardship, including adhering to best practices for data protection, security, and confidentiality. They are intended as short term and practical actions that HHS can undertake over the next 18 months. Recommendation 1 is designed to move HealthData.gov forward from its initial organic evolution to a targeted approach centered on a strong vision and mission. The NCVHS believes that this can increase the impact of future activities. Recommendation 2 addresses shortcomings in understanding the limited understanding of current HealthData.gov users, and how to release data to have a maximum impact. This is relevant as HealthData.gov draws in new data users who have not traditionally interacted with HHS, including application developers, businesses, and

community planning groups. Recommendation 3 provides strategies to allow HHS to adapt the HealthData.gov site to improve the user experience for diverse audiences. Efficient processes for users to discover, browse, and access data are needed to encourage the innovative use of data. Recommendation 4 addresses improvements in business processes to streamline its operations, facilitate the successful implementation of recommendations 1 through 3, and enable HealthData.gov's long-term sustainability.

1. HHS should develop an integrated and coordinated strategy within its operating divisions to advance the HealthData.gov vision and mission.

Open data platforms are a new technology to facilitate access to and efficient use of public data, and HealthData.gov was a groundbreaking undertaking in 2010. While developing and adapting organically to a rapidly evolving health data environment, it has already succeeded in achieving valuable outcomes related to its mission. The HealthData.gov aspiration to drive economic empowerment, innovation, and transformation in health and health care can be attained at a higher level by focusing future activities around a focused mission. Specific strategies include:

- Promote HealthData.gov as a brand, reinforcing a consistent message about its vision and mission, and add a tag line such as "Public Data Released" to materials to make the website recognizable and memorable.
- Inspire data users to do more with the data by highlighting success stories, encouraging HHS data custodians to post blogs and other reports about their data on HealthData.gov, and organizing regular online user sessions where HHS staff and external users can share ideas.

- Continue to support developer challenge competitions; and provide seed funding opportunities to support solutions that make HHS activities more efficient and effective, cultivate the open health data ecosystem, and foster a culture of consumer engagement in driving health innovation.
- Develop data sharing partnerships with as many states as possible to support the diffusion of best practices related to the use of these data to improve state-based programs such as public health and Medicaid.

2. HHS should implement evaluation and performance metrics and solicit data customers' input regularly to increase the use and usefulness of HealthData.gov for diverse consumers, support the work of HHS staff, and facilitate the development of data-driven health innovations.

As health data reach new audiences with diverse ideas and skillsets, a better understanding of who the data customers are and how to release data to maximize their experience and encourage their regular participation is needed. Traditional audiences for public health data include researchers and community health groups. Fostering new health innovation from public data requires the continued engagement of new and diverse data consumers, who have different data requirements, intended uses, technical capabilities, and content expertise. For example, researchers frequently desire historical data over many years to document trends whereas an entrepreneur seeking to connect air quality control, education, transportation networks, and environmental health may only require the most recent data and needs to efficiently understand the structure and format

of the data to determine if these data can be combined meaningfully. Specific strategies to enhance HHS data customer needs include:

- Implement a mechanism to solicit input systematically from diverse internal and external data users.
- Participate in the Digital Analytics Program and use web analytics to improve understanding of HealthData.gov customers and their use patterns, thereby facilitating better tailoring of content to users, evaluation of dissemination strategies, marketing of data to specific groups, increasing the findability of data, and other benefits that result from enhanced data for decision-making and customer engagement.
- Develop a mechanism for engaged data users to share their solutions and coding resources to educate and accelerate others users' abilities to access and use HealthData.gov resources.

3. HHS should enhance the HealthData.gov platform's capabilities to make the data more meaningful to a range of data customers to extend its reach.

The web industry is continuously updating how users interface with information to ensure that consumers find sites engaging, usable, and relevant for their purposes—and likely to return. Similarly, HealthData.gov needs to use state-of-the-art technology in line with web industry standards so that it continues to be acceptable and usable to a range of data customers, to help users more efficiently and effectively discover and understand data, and to ensure data customers view the HealthData.gov brand as a leading source of publicly available health data. One aspect of enhanced capabilities is improved indexing,

which can improve the discoverability of data within HealthData.gov for internal and external users and potentially benefit the HHS data enterprise more broadly by limiting redundancies. Specific strategies include:

- Keep the website in a modern design so that users view it as a current and well-maintained platform.
- Implement additional web features previously recommended by the National Committee on Health and Vital Statistics, including: providing recommendations for other data offerings that may be relevant based on other users' experiences and interests ("other users who used this also look at..."), enhancing the applicability of the content by allowing users to identify their roles (e.g. provider, employer, consumer, etc.), and providing users with drill down menus that display characteristics such as the format and metadata, allowing for customer ratings of datasets.¹⁹
- Improve the automated processes currently in use to extract information from the websites and open data portals that host data to ensure that HealthData.gov entries are timely, complete, and reflect all updates.
- Improve the quality of Healthdata.gov's metadata tagging so that information can be more reliably indexed and discovered; in particular feasibility studies of using existing curated vocabularies such as the National Library of Medicine's Medical Subject Heading (MESH) to tag HHS datasets should be considered.²⁰

¹⁹ Green LA. Steps to improve the usability, use and usefulness of selected online HHS data resources. www.ncvhs.hhs.gov/wp-content/uploads/2014/05/140320lt.pdf. Published March 20, 2014. Accessed January 12, 2017.

²⁰ Marc DT, Beatti J, Herasevich V, et al. Assessing metadata quality of a federally sponsored health data repository. AMIA Annu Symp Proc 2016: 864-873. Marc DT, Khairat SS. Medical subject headings

- Add capabilities to allow users to post APIs and other products that can be searched by other users.

4. HHS should formalize the governance, stewardship, and business operations of HealthData.gov.

Evidence from other US state and local jurisdictions that regularly attract diverse users to their open data sites have established strong governance to make explicit standards for how the data they provide are produced and presented; recommended business rules for data access, use, and publication; and making the release of easily discoverable, accessible, and usable public data a routine public health activity.²¹

Governance sets ground rules helpful to streamlining operations, facilitating the implementation of strategies to better target the site to diverse users' needs, and ensure long-term sustainability. They are also critical to consumer trust in data use. Specific strategies include:

- Establish standards for the datasets that are referenced and other aspects of HealthData.gov and pilot these standards for datasets that are currently indexed.
- Create a feedback loop to inform HHS staff and data stewards about how their data are being used and protected in ways that are responsive to consumers' demands.

(MeSH) for indexing and retrieving open-source healthcare data. *Stud Health Technol Inform* 2014; 202: 157-60.

²¹ Martin EG, Shah NR, Birkhead GS. Unlocking the power of open health data: a checklist to improve value and promote use. *J Pub Health Manag Pract* [in press]; Martin EG, Begany GM. Opening government health data to the public: benefits, challenges, and lessons learned from early innovators. *J Am Med Inform Assoc* 2016; Epub ahead of print.

- Develop a centralized HHS repository of policies and recommended guidelines for preparing data that is more discoverable and usable (such as developing metadata and tags, and providing alternative formats), privacy and security management, and other data policies.

A Strengthened HealthData.gov Benefits the HHS Mission

In less than a decade, HealthData.gov has already made considerable strides towards enabling diverse stakeholders including entrepreneurs, health professionals, researchers, policy makers, community groups, and others to use public data to drive economic empowerment, innovation, and transformation in health and healthcare. By allowing users to more efficiently discover, browse, and access publicly available health data in a centralized location, HHS increases the value of its existing resources by empowering the development of new health and healthcare innovations and catalyzing an open health data ecosystem. HealthData.gov can also be an engine for national and community learning health systems.

Implementing these recommendations would have broad and beneficial effects not only for the Healthdata.gov stakeholders outside of HHS but within HHS itself. For example, future benefits of an enhanced HealthData.gov include:

- Policy makers and other data consumers within HHS will have markedly superior access to timely and interpretable data across the entirety of HHS databases.
- Database developers within HHS can begin to share data models, data dictionaries, and data standards across HHS operating divisions, thus reducing redundancies and costs associated with building and maintaining databases.

291 Sharing database designs will foster interoperability and information exchange
292 across HHS agencies and types of data (such as administrative, survey, or
293 clinical).

294 • Groups with deep expertise in data such as the National Library of Medicine
295 might facilitate the implementation of metadata standards, and best practices for
296 data analysis across HHS databases that can also be referenced in the
297 HealthData.gov index.²²

298 In addition to these actionable short-term recommendations to help
299 HealthData.gov reach its full potential, NCVHS identified a number of longer-term
300 transformative strategies to enhance HealthData.gov and the data sources that its users
301 connect and access. Moving towards the future, additional improvements include:

302 • Including searchable dataset sources from articles published in PubMed Central
303 and leveraging its expertise to enhance best practices for HealthData.gov data
304 curation and ontologies (e.g. types, properties, and interrelationships among data).

305 • Developing a mechanism for user-driven forms of indexing and labeling the
306 resources through social tagging to increase efficiency in finding desired
307 materials, reduce redundancy in searches and increase transparency of data
308 resources.

309 • Develop capacity through toolkits, online applications, and other modalities to
310 enable communities to synthesize and integrate multiple datasets to address local
311 health challenges consistent with the Office of the National Coordinator for
312 Health Information Technology's national interoperability roadmap, thereby

²² The HealthData.gov software refreshes its index by continuously reads output files from HHS operating divisions. Increasing the breadth, quality, and usefulness of metadata in HealthData.gov requires developing metadata standards for all data collected within HHS operating divisions.

313 being a national resource and engine for community and national learning health
314 systems.

315 In summary, NCVHS believes that HealthData.gov is off proven value and has great
316 potential to further benefit the health and well-being of all Americans. NCVHS is ready
317 to provide you with additional insights and results that have emerged through this initial
318 analysis and pursue additional ideas related to a long-term vision for HealthData.gov.

319

320 Sincerely,

321

322 William W. Stead, M.D., Chair
323 National Committee on Vital and Health Statistics

324

325 CC: Acting Executive Director for Innovation
326 Sanjay Koyani
327