

Reconsidering
Shaping a Health Statistics Vision for the 21st Century

Phase I Report to the
National Committee on Vital and Health Statistics

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Background

The publication of the National Committee on Vital and Health Statistics (NCVHS) report on *Shaping a Health Statistics Vision for the 21st Century* (the Vision) in November 2002 marked the first and only comprehensive attempt in the U.S. to define health statistics, present a model of and a vision for the health statistics enterprise, and propose recommendations for achieving that vision.¹

The U.S. health information landscape has changed dramatically since 2002, in four particular ways that affect the health statistics enterprise. First, since 2002, health information technology in the U.S. has grown, as conceptualized by NCVHS in its November 2001 report on *Information for Health: A Strategy for Building the National Health Information Infrastructure*.² The evolution of the National Health Information Network (NHIN), the continued market penetration of electronic health records in ambulatory and acute care settings, the construction of U.S. and international strategies for promoting electronic health records and increasing connectivity for health information, the growing reality of Web-based personal health records, and the creation of the Office of the National Coordinator for Health Information Technology and the Certification Commission for Healthcare Information Technology all have implications for the U.S. health statistics enterprise.

The second change in the U.S. health information landscape since 2002 is the continuing evolution of the public health information technology

¹ Friedman DJ, Hunter EL, Parrish RG (2002 Nov). *Shaping a Health Statistics Vision for the 21st Century*, Washington, DC: U.S. Department of Health and Human Services. Available from: <http://www.ncvhs.hhs.gov/21st%20final%20report.pdf>. Accessed 23 Aug 2009.

² National Committee for Vital and Health Statistics (2001 Nov). *Information for Health: A Strategy for Building the National Health Information Infrastructure*. Washington, D.C.: U.S. Department of Health and Human Services. Available from: <http://aspe.hhs.gov/sp/NHII/Documents/NHIIReport2001/default.htm>. Accessed 23 Aug 2009.

infrastructure, as evidenced by the creation of the National Center for Public Health Informatics (NCPHI) within the Centers for Disease Control and Prevention (CDC);³ the development of CDC's Public Health Informatics Network (PHIN),⁴ Biosense,⁵ and National Electronic Disease Surveillance System (NEDSS);⁶ growing use by state health departments of Web-based tools for obtaining and communicating population health data, such as Web-based data query systems;⁷ and attempts by state health departments to engage with local Regional Health Information Organizations and other health information exchanges.

A third change since 2002 has been the evolution of the Web in ways that may affect the concepts and recommendations laid out in the *Vision*. Web applications in sectors other than health care, such as GapMinder,⁸ Knowledgeplex and DataPlace,⁹ and the State of the USA,¹⁰ set high standards for technological innovation currently unmatched in the health statistics enterprise. Community indicator Web sites set high standards for Web usability and attractiveness.¹¹

The fourth and final major change since 2002 in the U.S. health information landscape has been the resumption of active policy debates around improving the access, quality, and value of healthcare. Health

³ Centers for Disease Control and Prevention [hp]. National Center for Public Health Informatics. Available from: <http://www.cdc.gov/ncphi/>. Accessed 4 Sep 2009.

⁴ Centers for Disease Control and Prevention [hp]. PHIN. Available from: <http://www.cdc.gov/PHIN/>. Accessed 4 Sep 2009.

⁵ Centers for Disease Control and Prevention [hp]. Biosense. Available from: <http://www.cdc.gov/BioSense/>. Accessed 4 Sep 2009.

⁶ Centers for Disease Control and Prevention [hp]. NEDSS. Available from: <http://www.cdc.gov/NEDSS/>. Accessed 4 Sep 2009.

⁷ Friedman DJ, Parrish RG. Characteristics and Desired Functionalities of State Web-based Data Query Systems." *Journal of Public Health Management and Practice*. 2006;12(2):119-129. Full report available from: <http://www.naphsis.org/NAPHSIS/files/ccLibraryFiles/Filename/00000000481/WDS%20final%20report%20final.pdf>.

⁸ GapMinder [hp]. GapMinder home. Available from: <http://www.gapminder.org/>. Accessed 4 Sep 2009.

⁹ Knowledgeplex [hp] Knowledgeplex. Available from: <http://www.knowledgeplex.org/>. Accessed 4 Sep 2009.

¹⁰ State of the USA [hp]. State of the USA. Available from: <http://www.stateoftheusa.org/>. Accessed 4 Sep 2009.

¹¹ Community Health Indicators Consortium [hp]. Indicator efforts. Available from: <http://www.communityindicators.net/indicatorefforts.html>. Accessed 4 Sep 2009.

statistics and the health statistics enterprise are practical endeavors, capable of contributing greatly to policy debates and planning around improving healthcare reform and positively affecting health. Data gathered, analyzed, and communicated by the health statistics enterprise may be used in researching comparative effectiveness, assessing and promoting quality at the provider level, modifying payments to promote efficiency, guiding interventions to deal with disparities, and other means directly supportive of healthcare improvement.

Project Purpose

The challenge now confronting NCVHS is twofold: first, to reconsider the relevance of the *Vision* for population health information in light of recent changes in the health information landscape; and second, to revise the *Vision's* theoretical frameworks and recommendations to ensure their relevance.

The purpose of this project is to support observation of the NCVHS 60th anniversary through first, assessing progress on the recommendations laid out in the *Vision*; and second, reconsidering and revising the *Vision* in light of national and international developments since publication of the *Vision* in 2002 and *Information for Health: A Strategy for Building the National Health Information Infrastructure* in 2001. This report summarizes the findings of Phase One of the project through

1. summarizing progress since 2002 on eight priority recommendations specified by NCVHS in the *Vision*;¹²
2. reconsidering the eight priority recommendations, based on changes since 2002, as identified by interviews with NCHS experts, Web review, and literature review; interviews with twelve key informants from the private and public sectors;¹³ and the consultants' identification of possible options for NCVHS for each recommendation; and
3. suggesting next steps for NCVHS to consider regarding reconsidering the *Vision*, including the possibility of workshops or public hearings.

¹² Through an iterative process conducted in 2009, NCVHS chose eight of the original thirty-six recommendations as priorities for investigation during this project. Appendix—Methods summarizes the process used for selecting the eight priority recommendations.

¹³ Appendix—Methods describes the selection of key informants, the interview topics, and the interview techniques. Appendix—Respondents provides the names and positions of key informants and NCHS experts.

Review of 2002 Recommendations

Priority Recommendations

NCVHS membership in 2009 selected eight of the original thirty-six recommendations in the 2002 report as priorities for consideration. The selected recommendations are:¹⁴

1. Develop systems to actively monitor the population's health and potential influences on the population's health in order to identify emerging problems.

2. Assure that appropriate measures of functional status and well-being are included in ongoing systems that are a part of the health statistics enterprise.

3. Develop person-based, longitudinal data sets and surveys in order to develop portraits of influences on the population's health throughout the life cycle.

4. Develop a toolbox of privacy, confidentiality, and security best practices for use throughout the health statistics enterprise.

5. Support and fund ongoing multi-purpose data collection systems and data integration efforts.

6. Adopt or, if necessary, develop standards for data elements commonly used in all methods of data collection, for electronically transmitting data, for presenting and disseminating data, and for providing electronic access to data.

¹⁴ Source: NCHS, U.S. DHHS Data Council, NCVHS. *Shaping a Health Statistics Vision for the 21st Century*. Washington, D.C.: DHHS; 2002, pages 50-65.

7. Develop and fund a research agenda to explore new data collection strategies that can rapidly and flexibly provide data on emerging influences on the population's health; assess the validity and reliability of items used in key ongoing data collection systems; and estimate any loss in accuracy from early publication of provisional, incomplete data from ongoing data collection systems.

8. Develop methods to validly and reliably estimate important indicators of the health, and of the influences on the health, of state and local populations.

Key Informant Comments Applicable to All Priority Recommendations

Key informants suggested a series of requirements for the eight priority recommendations. These requirements are that each recommendation should be

- explained to end users;
- accompanied by a clear explanation of “why” the recommendation is important and needed;
- strengthened;
- tested, as appropriate, through pilot projects¹⁵; and
- specified through inclusion of outputs or products, and a specific “roadmap” of how to “get there from here.”

Key informants also stressed that achieving the priority recommendations is hampered by the current “shameful lack of adequate funding of health statistics” from federal and state governments.

¹⁵ Testing recommendations through pilot projects would provide an opportunity to develop specific implementation(s) for each recommendation and determine whether the implementation(s) would be feasible. This would provide an opportunity to explore innovative approaches to implementing the recommendations.

Key Informant Comments on Health Information Technology and Health Statistics

Key informants provided the following perspectives on the importance of health information technology (HIT) to health statistics:

- HIT has not significantly impacted health statistics since 2002;
- HIT holds a huge unrealized potential for health statistics in the future;
and
- HIT should be used to improve communication of health statistics to communities.

Key Informant Comments on Priority Recommendations, Options for Modifying Recommendations, and Suggestions for Revising the Recommendations

Recommendation #1: Develop systems to actively monitor the population's health and potential influences on the population's health in order to identify emerging problems.

Developments and changes since 2002:

- In 2006, NCHS issued a report on *Assessing the Potential of National Strategies for Electronic Health Records for Population Health Monitoring and Research*.¹⁶ In 2007, NCHS held a "Workshop on Improving Health-Care Statistics through Electronic Medical Records and Health Information Exchange."
- During 2003 and 2004, New York City, in collaboration with NCHS, conducted the first community health and nutrition examination survey (CHANES), which was modeled after NCHS's National Health and Nutrition Examination Survey (NHANES).¹⁷ The survey provided detailed community level data on health status and objective health measures, such as blood pressure, on a sample of 2000 NYC residents. During 2009, Wisconsin is conducting SHOW, a state-wide health survey also based on NHANES.¹⁸ Forty to 50 other states and communities have expressed an interest in conducting similar surveys, some of which are currently being planned. NCHS has incorporated some novel ideas and approaches from these CHANES into its NHANES.

¹⁶ Friedman DJ (2006 Jan). *Assessing the Potential of National Strategies for Electronic Health Records for Population Health Monitoring and Research*. Vital and Health Statistics, Series 2 (143). Hyattsville (MD): National Center for Health Statistics, Centers for Disease Control and Prevention. Available from: http://www.cdc.gov/nchs/data/series/sr_02/sr02_143.pdf.

¹⁷ New York City Department of Health and Mental Hygiene [Internet]. NYC HANES. Available from: <http://www.nyc.gov/html/doh/html/hanes/hanes.shtml>. Accessed: 2009 Aug 7.

¹⁸ University of Wisconsin [Internet]. Survey of the health of Wisconsin. Available from: <http://www.show.wisc.edu/>. Accessed: 2009 Aug 7.

- Following the events of Sept 11, 2001, CDC increased emphasis on and funding for surveillance of specific hazards. The BioSense system was developed in 2003 to monitor data from various sources (e.g., emergency rooms, pharmacies) to detect and assess the impact of acute health threats.¹⁹ Syndromic surveillance was put into place as a means to quickly identify possible outbreaks of disease before specific diagnoses are made.^{20,21} The Public Health Information Network was implemented to facilitate the rapid exchange of information between public health agencies.²²
- From 2002 to 2004, the CDC enhanced its Nationally Notifiable Disease Surveillance System by developing and supporting the implementation of NEDSS, a standards-based electronic method for states to report diseases to CDC.²³
- In 2009 the Council of State and Territorial Epidemiologists adopted revised definitions for many notifiable diseases to make these diseases more easily identified through the analysis of electronic health records and other electronic data sources.²⁴
- In 2008 CDC released Snap Shots of State Population Data or SNAPS, which provides community profile information nationwide for use in responding to public health emergency events at the state, Tribal, and local levels.²⁵

¹⁹ Centers for Disease Control and Prevention [Internet]. BioSense. Available from: <http://www.cdc.gov/BioSense/>. Accessed: 2009 Aug 7.

²⁰ Centers for Disease Control and Prevention [Internet]. Syndromic Surveillance: an Applied Approach to Outbreak Detection. Available from: <http://www.cdc.gov/ncphi/diss/nndss/syndromic.htm>. Accessed: 2009 Aug 7.

²¹ International Society for Disease Surveillance [Internet]. syndromic.org. Available from: <http://www.syndromic.org/>. Accessed: 2009 Aug 7.

²² Centers for Disease Control and Prevention [Internet]. PHIN. Available from: <http://www.cdc.gov/PHIN/>. Accessed: 2009 Aug 7.

²³ Centers for Disease Control and Prevention [Internet]. National Electronic Disease Surveillance System. Available from: <http://www.cdc.gov/NEDSS/>. Accessed: 2009 Aug 7.

²⁴ Council of State and Territorial Epidemiologists [Internet]. 2009 Position Statements. Available from: <http://www.cste.org/dnn/>. Accessed: 2009 Aug 7.

²⁵ Centers for Disease Control and Prevention [Internet]. SNAPS. Available from: <http://www.bt.cdc.gov/snaps/>. Accessed: 2009 Aug 7.

Reflections by key informants:

- Importance: This recommendation is especially important, compared to the other seven priority recommendations, and constitutes the basis for several other priority recommendations.
- Electronic health records: "Meaningful use" should include the linkage or incorporation of public health systems to actively monitor population health into electronic health records (EHRs) at the point of care. EHRs should also include registry functionalities, which would enable improved population health monitoring. Rather than developing two parallel infrastructures for information technology, public health and health care should develop and share a single infrastructure.
- Recommendation wording and structure: "Systems" is too vague; "strategies" would be more appropriate. The recommendation should also include "and work towards achieving population health equity." The rewritten recommendation would read: "Develop strategies to actively monitor the population's health and potential influences on the population's health in order to identify emerging problems and achieve equity." In addition, the recommendation should subsume Recommendations #3 (functional status and well-being), #4 (toolbox of privacy, confidentiality, and security best practices), and #5 (support and fund ongoing multi-purpose data collection systems and security best practices).

Options for recommendation #1:

- Subsume Recommendations #3, 4, 5
- Emphasize health equity
- Establish competitive state and local health department cooperative agreement program for CHANES
- Explicitly identify need to monitor access, quality, and value of healthcare
- Increase coordination, collaboration, linkage, data exchange, and joint development between EHR systems and population-based data

- systems (e.g., disease registries; and census, housing, education, and economic data systems)
- Broaden and strengthen federal and state awareness of and support for health statistics
 - Encourage more active use of health statistics in healthcare and public health practice, including comparative effectiveness research
 - Increase availability and improve ease of access to health statistics

Suggested revised recommendation:

Improve strategies, data sources, and systems to actively monitor the population's health and potential influences on the population's health. Objectives of the health statistics enterprise should include identifying emerging problems, measuring access, quality, efficiency, and value of health services, and identifying and targeting health inequities. The health statistics enterprise should meet at least four requirements: (a) where appropriate, provide person-based, longitudinal data; (b) where appropriate, be multi-purpose and support multiple data uses; (c) where appropriate, align with data standards for clinical records; and (d) incorporate privacy, confidentiality, and security best practices.

Recommendation #2: Assure that appropriate measures of functional status and well-being are included in ongoing systems that are a part of the health statistics enterprise.

Developments and changes since 2002:

- The changing demographics of the U.S. population, including the increasing numbers of elders and of the oldest old, together with increasing prevalence of chronic disease, has increased the relevance of obtaining ongoing population measurement of disabilities.²⁶
- In 2006, the Consolidated Health Informatics Initiative endorsed the ICF (International Classification of Functioning, Disability and Health) as a standard vocabulary for the functioning and disability domain in health information technology systems, with its recommendations endorsed by NCVHS.
- In 2007, the Institute of Medicine published its report on *The Future of Disability in America*, in which it recommended that NCHS and other federal agencies should adopt and use the ICF framework for disability monitoring and research. Also in 2007, the Agency for Healthcare Quality and Research published its *National Healthcare Disparities Report*, which included some data on people with disabilities.
- In 2009, the National Library of Medicine included the ICF in its Unified Medical Language System (UMLS).
- Also in 2009, Gallup and Healthways announced a twenty-five year commitment to a new Well-Being Index, with measures of physical

²⁶ The Center for Medicare and Medicaid Services now collects functional status data in its Medicare Advantage Plans, and in the Healthcare Effectiveness Data and Information Set (HEDIS) and Consumer Assessment of Healthcare Providers and Systems (CAHPS), and the Medicare Health Outcome Survey. The Agency for Healthcare Quality and Research now collects SF-12 functional status data in the Medical Expenditure Panel Survey (MEPS). The National Center for Health Statistics collects disability data on its National Health Interview Survey (activity limitation in major activity, activities of daily living, work limitation) and its National Health and Nutrition Examination Survey (activities of daily living).

health, emotional health, healthy behavior, life evaluation, work environment, and access.²⁷

Reflections by key informants:

- Importance: This recommendation is of medium to low priority, compared to the other seven priority recommendations.
- Priorities: Priorities for the development and inclusion of functional status and well-being measures into ongoing health statistics and related systems need to be developed, as well as a well-defined strategy for “how do we get there?”
- Recommendation wording and structure: The recommendation should also refer to improving the consistency and comparability of] tools that evaluate functional status and well being. This recommendation should be combined with Recommendation #7 (develop and fund a research agenda).

Options for recommendation #2:

- Combine with Recommendation #7
- Improve consistency and comparability of tools that measure functional status and well-being
- Clarify the uses of data on functional status and well-being and provide examples of their usefulness
- Continue efforts to improve available tools for collecting data on functional status and well-being, including their validity, reliability, and ease of use.

Suggested revised recommendation:

Assure that appropriate, consistent, and comparable measures of functional status and well-being are provided by the health statistics enterprise. These measures should be valid and reliable, as well as comparable and consistent across the health statistics enterprise.

²⁷ Jennifer Higgs, Gallup-Healthways Well-Being Index measures daily pulse of America,” Axiom News, 3 Apr 2009. Available at: <http://www.axiomnews.ca/NewsArchives/2009/April/April03.html>. Accessed 28 Jul 2009.

Recommendation #3: Develop person-based, longitudinal data sets and surveys in order to develop portraits of influences on the population's health throughout the life cycle.

Developments and changes since 2002:

- With active support and involvement from the National Center for Health Statistics (NCHS), the inter-agency development of the National Children's Study (NCS) has continued. Congress has already appropriated approximately \$180 million to the NCS, and the full study is slated to begin in 2010 and 2011. The NCS will entail longitudinal data collection, following approximately 100,000 children from birth to age 21.²⁸
- The NCHS data linkage program, within the Office of Analysis and Epidemiology, has expanded. NCHS has adopted a strategy of longitudinal linkage of its surveys and mortality data with data sets held by other agencies, as a means of developing longitudinal data with lower costs than conducting longitudinal surveys. For example, the National Health Interview Survey (NHIS), National Health and Nutrition Examination Survey (NHANES), and the Second Longitudinal Study of Aging have each been linked with National Death Index mortality data, Medicare enrollment and claims data, and Social Security Administration Retirement, Survivors, and Disability Insurance (SSA-RSDI) and Supplemental Security Income data (SSA-SSI); and the National Nursing Home Survey has been linked with mortality and SSA-RSDI and SSA-SSI data.²⁹ NCHS record linkage program activities have resulted in publications in such journals as Health Services Research, American Journal of Epidemiology, Journal

²⁸ National Children's Study [hp]. Study questions and answers. Available at: <http://www.nationalchildrensstudy.gov/about/overview/>. Last update 29 May 2009. Accessed 19 Jul 2009; National Children's Study [hp]. The National Children's Study. Available at: <http://www.nationalchildrensstudy.gov/about/overview/Pages/NCS-Presentation-05-29-09-Final.pdf>. Last updated May 2009.

²⁹ National Center for Health Statistics, Centers for Disease Control and Prevention [hp]. NCHS Data Linkage Activities. Available at: http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm. Updated 11 Mar 2009. Accessed 27 Jul 2009.

of the American Medical Association, the *Annals of Internal Medicine*, and *Inquiry*.

- The SNACC³⁰ project has “merged survey data from the Census Bureau and the National Center for Health Statistics with administrative records from Medicaid and from the Centers for Medicare and Medicaid Services. . . to address the longstanding concern about the range of estimates of Medicaid enrollees reported across government surveys and the Medicaid program records.”³¹ SNACC activities have led to a forthcoming article in *Health Services Research*, and numerous reports and presentations.

Reflections by key informants:

- Importance: Key informants provided mixed assessments of the importance of this recommendation, compared to the other priority recommendations. Some rated the importance of this recommendation as high, and others rated it as medium or low.
- Priorities: This recommendation is especially relevant for evaluating health care reform. Health care cost data, as well as health status data, should be incorporated into longitudinal data sets. Adequate sample sizes would be needed for drill-downs to smaller cells that would be useful for policy-making.
- Electronic health records: Electronic health records (EHRs) should be employed as a basis for person-based longitudinal data. EHRs as a source for person-based longitudinal data hold advantages over surveys, especially given attrition and response rate problems with panel surveys.

³⁰ The SNACC project includes the following partners: State Health Access Data Assistance Center, University of Minnesota; NCHS; ASPE (Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services); Centers for Medicare and Medicaid Services; and U.S. Bureau of the Census.

³¹ Prell M, Bradshser-Fredrick H, Comisarow C, Cornman S, Cox C, Denbaly M, et al. (2009 Apr). Profiles in success of statistical uses of administrative data. Presented at Federal Statistical Policy Seminar, 18 Nov 2008. Federal Committee on Statistical Methodology.

- Research: This recommendation should be defined as a research activity.
- Recommendation wording and structure: This recommendation needs to be “deconstructed,” with clear indications of “how we get there” for individual parts of the recommendations and “how we move” from current data sets to longitudinal data sets.

Options for recommendation #3:

- Increase state health department capacity for developing person-based, longitudinal data sets and surveys through
 - providing ongoing technical assistance from NCHS data linkage program
 - identifying, supporting, and conducting collaborative projects with NCHS data linkage program
- Research electronic health records and personal health records as sources for person-based, longitudinal data sets.
- Strengthen current NCHS data linkage program through:
 - Researching linkages without Social Security Numbers or with partial Social Security Numbers
 - Researching and remediating linkage bias
 - Researching problems with linkages for minority populations
 - Exploring linkages with Internal Revenue Service to capture income and assets
- Clarify the uses of longitudinal data and provide examples of their usefulness

Suggested revised recommendation:

Subsume recommendation #3 under revised recommendation #1.

Recommendation #4: Develop a toolbox of privacy, confidentiality, and security best practices for use throughout the health statistics enterprise.

Developments and changes since 2002:

- In 2005, NCHS developed and made available to other federal and state agencies a software suite “comprising five functions for statistical disclosure limitation in . . . two-dimensional tabular data.”³² Such software will constitute an essential part of a toolbox for privacy, confidentiality, and security best practices for health statistics.
- The Federal Committee on Statistical Methodology published the second version of its Report on Statistical Disclosure Limitation Methodology in 2005.³³ The report includes recommendations essential for privacy and confidentiality best practices for health statistics, including recommendations relating to “seek[ing] advice from respondents and data users,” “standardize[ing] and centraliz[ing] agency review of disclosure-limited data products, “shar[ing] software and methodology across the government,” and developing “formal interagency cooperation. . . for data sharing.”
- NCVHS has played an active role in considering current issues and developing recommendations that will affect privacy, confidentiality, and security in the health statistics enterprise. In June 2006, NCVHS recommended that “individuals should have the right to decide whether they want to have their personally identifiable electronic health records accessible via the NHIN,” while importantly also emphasizing that “this recommendation is not intended to disturb traditional principles of public health reporting.” Also in 2006, NCVHS recommended that “role-based access should be employed as a means

³² Gonzalez JF, Cox LH (2005). Software for tabular data protection. *Statistics in Medicine* 24:659-669.

³³ Federal Committee on Statistical Methodology (2005 Dec). Report on Statistical Disclosure Limitation Methodology. Statistical Policy Working Paper 22 (second version, 2005): 99-103. Washington (DC): Office of Information and Regulatory Affairs, Office of Management and Budget. Available at: <http://www.fcsm.gov/working-papers/spwp22.html>. Updated 2007 Apr 20. Accessed 2009 Aug 4.

to limit the personal health information accessible via the NHIN and its components” and “HHS should investigate the feasibility of applying contextual access criteria to EHRs and the NHIN, enabling personal information disclosed beyond the health care setting on the basis of an authorization to be limited to the information reasonably necessary to achieve the purpose of the disclosure.” Both of the preceding recommendations hold important implications for protecting privacy and confidentiality of EHRs and related NHIN data, while also enabling the generation of health statistics.³⁴

- NCHS has continued to support and expand its Research Data Center.³⁵ The Research Data Center’s remote access system, Analytic Data Retrieval by E-mail (ANDRE), enables approved researchers to communicate with an automated system through e-mail to analyze and retrieve data. In addition, researchers can access NCHS Research Data Center resources through any of the nine Census Bureau Research Data Centers. Further, a Research Data Center for genetics-related research has opened at CDC in Atlanta.

Reflections by key informants:

- Importance: While maintaining confidentiality is of great importance, focusing on privacy, confidentiality, and security “is not the best use of [NCVHS] skills.” Compared to other priority recommendations, this recommendation should be regarded as of lower importance and perhaps tasked to a different group.
- Priorities: Government communication regarding health statistics privacy, confidentiality, and security issues is critical. The public needs to be educated regarding privacy, confidentiality, and security issues, values, and inherent risks that need to be accepted. Human subjects review boards and researchers need to be educated about the inherent

³⁴ National Committee on Vital and Health Statistics (2009 May). Recommendations on Privacy and Confidentiality, 2006-2008. Hyattsville (MD): U.S. Department of Health and Human Services.

³⁵ National Center for Health Statistics [hp]. Research Data Center. Available at: <http://www.cdc.gov/nchs/r&d/rdc.htm>. Updated 2009 Apr 15. Accessed 2009 Aug 4.

differences between clinical and survey research, differences in regulations applicable to each, and the inherent conflicts between increasing data accessibility and confidentiality.

- Research: Research is needed to enhance privacy, confidentiality, and security.
- Recommendation wording and structure: Best practices need to be refined for different types of research. The recommendation needs an education and communications component.

Options for recommendation #4:

- Develop a toolbox of privacy, confidentiality, and security best practices for use throughout the health statistics enterprise.
 - Train state health departments in using NCHS Data Protection Utility software suite
 - Collaborate with state health departments to identify needed software tools to support analyses while enhancing privacy and confidentiality in commonly utilized health statistics data sets
 - Educate state health departments and other users of health statistics data sets in common issues related to privacy and confidentiality
 - Improve communication with the public about the need for health statistics and how the health statistics enterprise protects the public's privacy and confidentiality

Suggested revised recommendation:

Subsume recommendation #4 under revised recommendation #1.

Recommendation #5: Support and fund ongoing multi-purpose data collection systems and data integration efforts.

Developments and changes since 2002:

- Centers for Medicare and Medicaid Services (CMS) data integration efforts include: the Chronic Condition Data Warehouse, which includes linkage at the person level of Medicare Part B claims and claims from institutional providers³⁶; linkage of Medicare claims with the National Cancer Institute’s Surveillance, Epidemiology, and End Results data³⁷; and linkage of data from the renal disease program at the National Institutes of Health (NIH) with CMS data.
- NCHS and NIH continued their long-term collaboration on the development of topic-specific modules for NHIS and NHANES, in particular an NHIS module for complementary and alternative medicine.
- NCHS is considering developing a new health survey that would replace NHIS and NHANES and provide the information currently provided by the separate surveys. NCHS is also exploring the directions that NHIS and NHANES would take if they were to remain separate.
- See also the second and third bullets under Recommendation #3’s Developments and changes since 2002.

Reflections by key informants:

- Importance: This recommendation was not rated highly by key informants.
- Priorities:
- Research:

³⁶ O’Donnell B, Schneider K, Dean D. CMS Chronic Condition Data Warehouse: Technical guidance for researchers calculating population statistics. Des Moines(IA): Buccaneer Computer Systems, 2008. Available from: http://www.ccwdata.org/downloads/CCW_Denominators_TechnicalGuide.pdf. Accessed: 2009 Aug 7.

³⁷ National Cancer Institute [Internet]. SEER-Medicare: How the SEER & Medicare Data are Linked. Available from: <http://healthservices.cancer.gov/seermedicare/overview/linked.html>. Accessed: 2009 Aug 7.

- Recommendation wording and structure: This recommendation is related to and should be combined with Recommendations #1, #3, and #5. The recommendation as currently constituted is too general, and needs to become topically specific about where integration would and would not prove productive.

Options for recommendation #5:

- Support and fund ongoing multi-purpose data collection systems and data integration efforts.
 - Explore merger of NHANES, NHIS, and BRFSS
 - Combine Recommendations #1, 3, 5
 - See also Recommendation #3

Suggested revised recommendation:

Subsume recommendation #5 under revised recommendation #1.

Recommendation #6: Adopt or, if necessary, develop standards for data elements commonly used in all methods of data collection, for electronically transmitting data, for presenting and disseminating data, and for providing electronic access to data.

Developments and changes since 2002:

- In 2002, SNOMED CT was created by a merger of SNOMED RT and the United Kingdom's National Health Service Clinical Terms. In 2003, the National Library of Medicine established a federal license for the use of SNOMED CT, and in 2007, property rights for SNOMED CT were transferred to the International Health Terminology Standards Development Organization, which was established in Denmark to maintain and enhance SNOMED CT and other standardized clinical terminologies.³⁸
- In 2005, NCHS in collaboration with the Census Bureau, the NIH, the Bureau of Labor Statistics, and the National Science Foundation released *Q-Bank*, a compilation of evaluated questions from federal surveys with links from each question to its test findings.³⁹
- From 2005 to 2008, the U.S. Health Information Knowledgebase (USHIK) moved from NIH to AHRQ, where it is also supported by CMS and the Veterans Administration. The USHIK updated its metadata on health data standards, as new standards became available from ANSI X12 and the Healthcare Information Technology Standards Panel (HITSP).⁴⁰

³⁸ National Library of Medicine [Internet]. Unified Medical Language System: SNOMED Clinical Terms®. Available from: http://www.nlm.nih.gov/research/umls/Snomed/snomed_main.html. Accessed: 2009 Aug 7; International Health Terminology Standards Development Organisation [Internet]. SNOMED CT. Available from: <http://www.ihtsdo.org/snomed-ct/>. Accessed: 2009 Aug 7.

³⁹ Centers for Disease Control and Prevention [Internet]. Q-Bank. Available from: <http://wwwn.cdc.gov/qbank/home.aspx>. Accessed: 2009 Aug 7.

⁴⁰ Agency for Healthcare Research and Quality [Internet]. USHIK: United States Health Information Knowledgebase. Available from: <http://ushik.ahrq.gov/registry/>. Accessed: 2009 Aug 7.

- In 2009 CMS released the final rule for replacing the 30-year-old ICD-9-CM code set with ICD-10-CM and ICD-10-PCS. All HIPAA covered entities⁴¹ must comply with the new rule by October 2013.⁴²
- Since 2002, HITSP has recognized interoperability specifications on electronic health record laboratory results reports, biosurveillance, and consumer access to clinical information; and released interoperability specifications on immunizations, public health case reporting, and EHR business services.⁴³ The Consolidated Health Informatics Initiative, a collaboration among DHHS, the U.S. Department of Veterans Affairs, the U.S. Department of Defense, and the Social Security Administration, which included public health participation, served as a foundation for the selection of specifications by HITSP.
- Since 2002, the Public Health Data Standards Consortium has been actively working on public health-related standards and the interface between public health data and the EHR; on prototypes for health information exchange between EHRs and public health data systems; and on a privacy toolkit for public health professionals.⁴⁴
- NCHS and the National Association of Public Health Statistics and Information Systems (NAPHSIS) are working with HL7 to align vital records data standards with those of the EHR and to develop messaging standards for the transfer of data between EHRs and vital records.⁴⁵

⁴¹ ICD-10-CM and ICD-10-PCS replace ICD-9-CM, Volumes 1 and 2 and ICD-9-CM, Volume 3, respectively. The former is used by all health care providers, but the latter is only used by inpatient facilities.

⁴² Department of Health and Human Services. HIPAA Administrative Simplification: Modifications to Medical Data Code Set Standards To Adopt ICD-10-CM and ICD-10-PCS. Washington (DC): GPO; Federal Register / Vol. 74, No. 11 / Friday, January 16, 2009 / Rules and Regulations. Available from:

<http://edocket.access.gpo.gov/2009/pdf/E9-743.pdf>. Accessed: 2009 Aug 7.

⁴³ Healthcare Information Technology Standards Panel [Internet]. Welcome. Available from: <http://www.hitsp.org/>. Accessed: 2009 Aug 7.

⁴⁴ Public Health Data Standards Consortium [Internet]. Welcome. Available from: <http://www.phdsc.org/>. Accessed: 2009 Aug 7.

⁴⁵ Centers for Disease Control and Prevention [Internet]. Electronic Health Record System-Vital Records Functional Profile. Available from: <http://www.cdc.gov/nchs/about/major/dvs/ElectronicHlthrec.htm>. Accessed: 2009

Reflections by key informants:

- Importance: Key informants pointed out that other groups are addressing standards issues. Consequently, this recommendation was considered of low importance, relative to other priority recommendations. Standards should be adopted from already working systems, rather than created de novo. The presence of data standards does not create data exchange.
- Priorities: Behavioral health data collected during clinical encounters lack interoperability and standards, such as data on domestic violence screening.
- Research:
- Recommendation wording and structure: This recommendation should be combined with Recommendations #1 (develop systems to actively monitor the population's health) and #5 (support and fund ongoing multi-purpose data collection systems).

Options for recommendation #6:

- Adopt or, if necessary, develop standards for data elements commonly used in all methods of data collection, for electronically transmitting data, for presenting and disseminating data, and for providing electronic access to data.
 - Expand collaboration with HL-7 and state health departments to align health statistics data sets with electronic health record and messaging standards for transfer of data from electronic health records into core health statistics data sets.

Suggested revised recommendation:

Consider deleting this from the high priority recommendations, or combining it with recommendation #1 or #5. See addition to #1.

Aug 7; Centers for Disease Control and Prevention [Internet]. NVSS: Laying the Foundation for Electronic Vital Records Standards. Available from: http://www.cdc.gov/nchs/nvss/about_nvss.htm#foundation. Accessed: 2009 Aug 7

Recommendation #7: Develop and fund a research agenda to explore new data collection strategies that can rapidly and flexibly provide data on emerging influences on the population's health; assess the validity and reliability of items used in key ongoing data collection systems; and estimate any loss in accuracy from early publication of provisional, incomplete data from ongoing data collection systems.

*Developments and changes since 2002:*⁴⁶

- NCHS has launched an Extramural Research and Training Program, which includes CDC Grants for Public Health Research Dissertations. Up to \$36,000 for support of individual dissertations is competitively awarded with emphasis on 1) survey methodology and statistics or 2) projects using NCHS data sets alone or in conjunction with other data sets. Dissertation applications must focus on methodological and research topics that address the mission and research interests of CDC. Funded dissertation research includes Migration and Diabetes Risk among the U.S. Foreign-Born, Research and Training on Contextual Effects Impacting Adolescent Health, Cross Survey Comparison of Informal Caregiving to the Disabled Elderly in the U.S., and Emergence of Disparities in U.S. Mortality: A Focus on Prevention and Treatment.
- CDC published its comprehensive research agenda in 2006. Advancing the Nation's Health: A Guide to Public Research Needs, 2006-2015 ("Research Guide") resulted from an extensive consultative process that lasted from 2001 through 2004, and involved both internal CDC staff and external experts. The Research Guide contains almost one hundred pages of examples of priority research, organized into seven categories and linked to CDC's four overarching health protection goals. "Manage and market health information" constitutes one of the seven categories, with sub-sections devoted to public health data and public health informatics. For public health data, examples of priority

⁴⁶ The National Institutes for Health has recently identified five priority areas for research, including "putting science to work for the benefit of health care reform." See <http://videocast.nih.gov/Summary.Asp?File=15247>; accessed 24 Aug 2009.

research are provided for statistical and data science, data collection, data integration, data analysis, and data dissemination. For public health informatics, examples of priority research are provided for analytical methods, information and data visualization, communications and alerting technologies, decision support, electronic health records, and knowledge management.⁴⁷

- In addition to the development of the CDC-wide Research Guide, the National Institute for Occupational Safety and Health also continued and updated its National Occupational Research Agenda.⁴⁸
- Since 2006 NCHS has released a paradata file concerning the NHIS data collection process.⁴⁹ Research has shown paradata to be a useful tool in assessing and monitoring data quality in the National Health Interview Survey.⁵⁰

Reflections by key informants:

- Importance: Key informants regarded this as a high priority.
- Priorities: Any research agenda for health statistics should be practical and tied to existing policy issues; it should include a clear “roadmap” of how to get “there from here.” Health statistics research is currently vastly underfunded; any health statistics research agenda needs to be accompanied by a funded research program.
- Research: Data-driven prioritization of federal-funded research should occur: population health research should be funded based upon

⁴⁷ Centers for Disease Control and Prevention (2006 Dec). *Advancing the Nation's Health: A Guide to Public Health Research Needs, 2006-2015*. Atlanta (GA): Centers for Disease Control and Prevention.

⁴⁸ National Institute for Occupational Safety and Health [hp]. The National Occupational Safety Research Agenda (NORA). Available at: <http://www.cdc.gov/niosh/nora/default.html>. Updated 2009 May 14. Accessed 2009 Jul 13.

⁴⁹ Centers for Disease Control and Prevention [Internet]. National Health Interview Survey: Questionnaires, Datasets, and Related Documentation 1997 to the Present. Available from: http://www.cdc.gov/NCHS/nhis/quest_data_related_1997_forward.htm. Accessed: 2009 Aug 7;

⁵⁰ Dahlhamer JM, Simile CM, Stussman BJ. Using Paradata to Assess and Monitor Data Quality in the National Health Interview Survey (NHIS). Presentation to meeting of NCHS Board of Scientific Counselors, 22 Jan 2009.

evidence-based assessments of what research is most likely to result in the greatest impact on improving health. A research agenda needs to be combined with an agenda for health information technology (HIT), especially as it relates to provision of individual health care. The research agenda should be based upon expanded definitions of health research and evaluation, which are needed in order to improve data collection, use of the Web for research, human/computer interfaces, and data mining techniques. Research is also needed to improve administrative data, which now seems to be broadly defined as data collected for one purpose and then used for another purpose. Finally, research is needed in order to improve surveys, including research on: non-response (such as how extensive is non-response and how to reduce it), especially given the increase in non-response rates; use of "paradata," which are data obtained by interviewers while interviews are in process; multiple and mixed mode data collection, including self-administration; sources of error; and trade-offs between survey costs and reducing errors.

- Recommendation wording and structure: A research component is needed for all eight priority recommendations.

Options for recommendation #7:

- Develop and fund a research agenda to explore new data collection strategies that can rapidly and flexibly provide data on emerging influences on the population's health; assess the validity and reliability of population health items used in key ongoing data collection systems and in electronic health record systems; and estimate any loss in accuracy from early publication of provisional, incomplete data from ongoing data collection systems.
 - Collaborate with NCHS and its Board of Scientific Counselors in developing an NCHS-wide agenda for extra-mural and intra-mural research

- Develop a priority list of research topics for health statistics, suitable for and fundable through CDC Grants for Public Health Research
- Conduct short-term research on specific contributions of health statistics to monitoring and evaluating health care reform
- Increase the use of health statistics in prioritizing federally-funded research by identifying research proposals that would address significant health issues

Suggested revised recommendation:

Develop and fund a research agenda to explore new data collection, linkage, analysis, and communication strategies that can rapidly and flexibly provide data on the population's health. The agenda should include methods to assess the validity and reliability of population health items used in key ongoing data collection systems and in electronic health record systems; address the effects of "non-response" and missing data; estimate any loss in accuracy from early publication of provisional, incomplete data from ongoing data collection systems; and estimate important indicators of health for state and local populations.

Recommendation #8: Develop methods to validly and reliably estimate important indicators of the health, and of the influences on the health, of state and local populations.

Developments and changes since 2002:

- In 2008, all states, the District of Columbia, and three U.S. territories conducted their own Behavioral Risk Factor Surveillance Systems (BRFSS) to provide state-level data on health-related behaviors and self-reported health status.⁵¹ The BRFSS can also provide data for selected metropolitan statistical areas with 500 or more respondents; and several states conduct their own county-level BRFSS to produce estimates for at least some of their counties. In 2009, the BRFSS introduced a “social context” module, which is being used by 12 states, the District of Columbia, and 20 communities and consists of eight questions intended to assess civic engagement and food, housing, and job security.
- In 2008, a coalition of four federal and six private partners released the Community Health Status Indicators (CHSI), which presents estimates of health status and determinants for each U.S. county using data compiled from a variety of federal agencies.⁵² Each county’s demographic profile and health status is compared to a set of peer counties.
- During 2009, the University of Wisconsin’s Population Health Institute is preparing county health rankings for each state in the U.S., based on the Wisconsin model that has been used since 2004 to rank the health of Wisconsin’s counties.⁵³ Mortality data from NCHS, risk factor

⁵¹ Centers for Disease Control and Prevention [Internet]. Behavioral Risk Factor Surveillance System. Available from: <http://www.cdc.gov/brfss/>. Updated 2009 Apr 30. Accessed 2009 Aug 7.

⁵² U.S. DHHS [Internet]. Community Health Status Indicators. Available from: <http://www.communityhealth.hhs.gov/>. Accessed 2009 Aug 7.

⁵³ University of Wisconsin, Population Health Institute [Memo]. Mobilizing Action Toward Community Health (MATCH): The County Health Rankings. Madison: University of Wisconsin; 2009. Available from: <http://www.pophealth.wisc.edu/UWPHI/pha/match/matchRankings.pdf>. Accessed: 2009 Aug 7.

- and health status data from BRFSS, and data on health determinants from other sources are being used to prepare the county rankings.
- NCHS is coordinating efforts with BRFSS and the Environmental Protection Agency (EPA) to generate county-level data on air quality.
 - In 2000 the Interagency Working Group on Summary Measures of Health (IAWG) was created to improve the measurement of health and track the burden of disease. It conducted a workshop to develop a research agenda in 2002 and issued a report on the workshop in 2003.⁵⁴
 - See also the second bullet about CHANES and SHOW and the last bullet on CDC SNAPS under Recommendation #1's Developments and changes since 2002.

Reflections by key informants:

- Importance: Key informants rated this recommendation as medium priority, compared to the other priority recommendations.
- Priorities: A community health and wellness index needs to be developed through an iterative approach. In addition to standard measures from traditional health statistics data sets, it should also include measures relating to literacy and education. Such an index should include measures useful at local, state, and national levels.
- Research:
- Recommendation wording and structure: This recommendation should be subsumed under Recommendation #3 (develop person-based, longitudinal data sets) and #7 (develop and fund a research agenda).

Options for recommendation #8:

- Develop methods to validly and reliably estimate important indicators of the health, and of the influences on the health, of state and local populations.

⁵⁴ NCHS [Internet]. Interagency Working Group on Summary Measures of Health. Available from: <http://www.cdc.gov/nchs/otheract/IAWG/IAWG.htm>. Accessed: 2009 Aug 7.

- Develop common standards for indicators and a Web-based indicator library, to be used by state health departments, federal government agencies, and private indicator initiatives
- Develop a broad-based community health and wellness index
- Combine with Recommendations #3 and #7.

Suggested revised recommendation:

Subsume recommendation #8 under recommendation #7.

Next Steps for NCVHS

Suggested Revised 2002 Priority Recommendations

NOTES:

--All recommendations should include action plans.

--All recommendations should include pilot projects.

The mission of the U.S. health statistics enterprise is to provide statistical information that will guide policies and actions to improve the health of the American people.⁵⁵ To realize this mission, the U.S. health statistics enterprise should

1. Improve strategies, data sources, and systems to actively monitor the population's health and potential influences on the population's health. Objectives of the health statistics enterprise should include identifying emerging problems, measuring access, quality, efficiency, and value of health services, and identifying and targeting health inequities. The health statistics enterprise should meet at least four requirements: (a) where appropriate, provide person-based, longitudinal data; (b) where appropriate, be multi-purpose and support multiple data uses; (c) where appropriate, align with data standards for clinical records; and (d) incorporate privacy, confidentiality, and security best practices.

2. Assure that appropriate, consistent, and comparable measures of functional status and well-being are provided by the health statistics

⁵⁵ National Center for Health Statistics [hp]. The NCHS mission. Available from: <http://www.cdc.gov/nchs/about/mission.htm>. Accessed 4 Sep 2009.

enterprise. These measures should be valid and reliable, as well as comparable and consistent across the health statistics enterprise.

(See also Revised recommendation #3.)

3. Develop and fund a research agenda to explore new data collection, linkage, analysis, and communication strategies that can rapidly and flexibly provide data on the population's health. The agenda should include methods to assess the validity and reliability of population health items used in key ongoing data collection systems and in electronic health record systems; address the effects of "non-response" and missing data; estimate any loss in accuracy from early publication of provisional, incomplete data from ongoing data collection systems; and estimate important indicators of health for state and local populations.

Key Informant Suggestions for New Recommendations

Research needs to be conducted on:

- New data collection techniques, and especially flexible, cheaper means to obtain data that augment traditional health statistics surveys, including
 - mixed modes
 - paradata (data obtained while data collection is in operation, such as observations by interviewers)
 - mobile phones
 - cohort of Web respondents
 - new opportunities presented by HIT for developing longitudinal data sets
 - rethink surveys, moving from snapshots to integrated, ongoing data collection
 - develop a mechanism to determine what interventions are being carried out at the community level
- Methodological innovations, including
 - methods to enhance privacy
 - methods to quickly and easily modify data systems to gather or construct new measures of health, for example Years of Potential Life Lost (YPLL), and make these methods generally available
 - expanded drill downs to sub-national areas, below state and local levels
 - use of Bayesian statistics to put more emphasis on current data when pooling data over multiple years
- Survey and data set integration
 - surveys (such as integrating Medical Expenditure Panel Survey and NHIS, and expanding cooperation and coordination between NHIS and BRFSS)
 - data sets (such as insurance claims with other data sets)

- collecting data on genes, gene expressions, and biomarkers together with health statistics and routine health surveillance

Health statistics and Electronic Health Records (EHRs):

- Need to link and integrate health statistics with clinical care through HIT:
 - Bi-directional health information exchange (HIE) with clinical care, including to and from health departments, public and private providers of clinical care
 - Registry functionalities should be developed for electronic health record (EHR) systems
 - Health statistics should provide alerts, clinical guidelines, risk assessments, and statistical context for clinical care
 - Decision support to improve patient screening, based upon health statistics, should be built into EHRs
- Need to devote analysis and research to uses of EHRs for health statistics⁵⁶
- Research on mining techniques to extract health statistics from EHRs
 - Potential for comprehensive measurement of community health through EHRs

Health statistics and Personal Health Records (PHRs):

- Need to devote analysis and research to uses of PHRs for health statistics
- Decision support, based upon health statistics, should be built into PHRs

⁵⁶ It should be noted that since 2002 NCHS has undertaken four research efforts related to EHRs. First, NCHS has included questions relating to EHRs on its INSERT and has published INSERT. Second, NCHS published a report on The Potential of National Strategies for Electronic Health Records for Population Health Monitoring and Research (Friedman 2006). Third, NCHS conducted a workshop on the uses of EHRs for health statistics in May 2007. Fourth, based on its surveys, NCHS has published a series of reports and articles on electronic health record penetration in hospitals and physician offices (see <http://www.cdc.gov/nchs/nhcs/Electronicmedicalrecords.htm>, accessed 24 Aug 2009).

Organization and support for health statistics enterprise

- Health statistics in federal agencies has been hampered by a “shameful” lack of funding
- Role of data collection, dissemination, analysis, and research needs to be elevated at the U.S. Department of Health and Human Services
- Training in health statistics needs to be increased, and academic training in public health and biostatistics needs to be better attuned to health statistics

Consultant Suggestions for Next Steps for NCVHS

NCVHS core concepts from *Shaping a Health Statistics Vision for the 21st Century* (NCVHS 2002), *Information for Health: A Strategy Building the National Health Information Infrastructure* (NCVHS 2001), and *Toward a National Health Information Infrastructure* (NCVHS 2000), and *Assuring a Health Dimension for the National Information Infrastructure* (1997) remain valuable and useful as essential frameworks for improving health statistics. These core concepts include the health statistics enterprise, the conceptualization of the influences on the population's health, and the national health information infrastructure, with its three linked dimensions of healthcare, consumer, and population.

Minimal attention has been given since 2002 to exploring how the population health dimension (or record, as NCVHS first conceptualized it in 1997) should be further developed. Only slightly more than minimal attention has been given to how the population health dimension can and should link with and benefit from the healthcare and consumer dimensions. In contrast, obvious and substantial progress has occurred since 2002 in further developing and implementing both electronic health records in ambulatory and hospital settings in the U.S., in fostering health information exchange for administrative and clinical purposes, and in developing and providing access to personal health records.

As its sixtieth anniversary approaches, NCVHS confronts an unparalleled opportunity to assume a national and perhaps even international leadership role in conceptualizing the population health dimension and the population health record. NCVHS can specify means through which electronic health records and personal health records specifically and health information technology more generally can contribute to improved health statistics. In addition, NCVHS can delineate means through which health statistics can improve clinical care.

As next steps in its process to Reconsider *Developing a Health Statistics Vision for the 21st Century*, we suggest that NCVHS sponsor a series of highly focused workshops, with each workshop exploring a specified topic: maximizing the contribution of the health statistics enterprise to any restructuring of healthcare, including its formulation, planning, and implementation; developing the population health dimension; using electronic health records to improve health statistics; using personal health records to improve health statistics; and using health information technology to increase the contribution of health statistics to clinical care. Each workshop would be developed around the single specified theme. Workshop participants would be provided with a clear specific statement of purpose for the particular workshop, specific questions to address for the particular workshop, and a brief background paper. Brief proposals for workshop presentations would be both solicited and invited. Both solicited and invited proposals would be reviewed by NCVHS and its staff, with final selection through a peer review-like process. NCVHS and its staff would select some number of workshop presentations for further development and presenters would then be invited to participate in a published compilation of NCVHS working papers.

Appendix

Interviewed Key Informants

David Blumenthal, M.D., M.P.P.
National Coordinator for Health Information Technology
Office of the National Coordinator

Carolyn M. Clancy, M.D.
Director, Agency for Healthcare Quality and Research

Theresa Cullen, M.D., M.S.
Director, Office of Information Technology
Indian Health Service

Elliott S. Fisher, M.D., M.P.H.
Director, Center for Health Policy Research
Dartmouth University

William D. Hacker, M.D., FAAP, CPE
Commissioner for Public Health
Kentucky Department for Public Health

Muin J. Khoury, M.D., Ph.D.
Director, National Office of Public Health Genomics
Centers for Disease Control and Prevention

Raynard S. Kington, M.D., Ph.D., M.B.A.
Acting Director,
National Institutes of Health

Jim Lepkowski, Ph.D.
Institute for Social Research
University of Michigan

Farzad Mostashari, M.D., M.Sc.
Assistant Commissioner and Chair of Primary Care
New York City Department of Health and Mental Hygiene

Thomas Reilly
Deputy Director
Office of Research, Development and Information
Center for Medicare and Medicaid Services

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics

Roni Zeiger, M.D.
Product Manager
Google Health

Interviewed NCHS Experts

Lewis Berman, M.S.
Special Assistant for Research, Informatics, and Community Health and
Nutrition Examination Surveys
Office of the Director
Division of Health and Nutrition Examination Surveys

Amy B. Bernstein, Sc.D.
Chief, Analytic Studies Branch
Office of Analysis and Epidemiology

Virginia S. Cain, Ph.D.
Director of Extramural Research
Office of the Director

Christine S. Cox
Branch Chief, Special Projects Branch
Office of Analysis and Epidemiology

Lawrence H. Cox, Ph.D.
Associate Director
Office of Research and Methodology

Marjorie S. Greenberg, M.A.
Chief
Classifications and Public Health Data Standards
Office of the Director

Debbie Jackson
Senior Program Analyst
Classifications and Public Health Data Standards
Office of the Director

Richard Klein
Acting Chief
Health Promotion Statistics Branch

Rob Weinzimer
Special Assistant for Outreach
Office of the Director

Methods

Selection of priority recommendations

NCVHS members and staff selected priority recommendations from the thirty-six recommendations included in *Shaping a Health Statistics Vision for the 21st Century*. During the February 26th, 2009, NCVHS meeting, members and staff were provided with a sheet including the thirty-six recommendations, and were asked to (a) rate the priority for each recommendation as high, medium, or low, and (b) select the highest priority recommendations. NCVHS members and staff who did not complete the exercise on February 26th were also sent an e-mail invitation to complete the exercise, together with an explanation and instructions. Twelve NCHS members, four staff, and one anonymous respondent completed the exercise. Ratings for each recommendation were calculated, based upon scores of three for "high priority," two for "medium," one for "low," and zero for not ascertained. Following review by NCVHS membership and staff, based upon the combined scores for NCVHS members and staff, the eight highest rated recommendations were selected for further consideration during this project.

Key informant interviews

Selection of key informants:

NCVHS Population Subcommittee ("Subcommittee") members, NCVHS staff, and Drs. Friedman and Parrish ("consultants") selected potential key informants through an iterative process. The consultative process included development of a list of potential key informants by the consultants, review and discussion of the list with the Subcommittee and staff in e-mail exchanges and conference calls, solicitation of additional potential key informants from Subcommittee and staff, designation by Subcommittee and staff of high priority key informants, development of a final list by the consultants, and final review of the final list by Subcommittee and staff. Sixteen key informants were selected.

Interview topics:

The consultants drafted possible topics for discussion during conference calls with key informants. The Subcommittee and staff then reviewed the topics, and the consultants incorporated helpful suggestions. Four questions were selected:

1. Which of the eight priority recommendations do you consider to be most important for improving U.S. health statistics specifically and U.S. population health more generally and why?

2. How have developments in health information technology (HIT) since 2002 impacted on these priority recommendations? What impact might future HIT developments contribute to their implementation?
3. How would you suggest modifying these recommendations, including changing individual recommendations? For example, how would you further specify these recommendations, or add necessary action steps?
4. What new recommendations would you add in order to address additional health statistics or health information issues not addressed by these recommendations?

Solicitation of key informants:

Staff sent potential key informants a detailed invitation via e-mail to participate in conference calls with the consultants. The consultants then sent a follow-up e-mail to key informants who responded positively, requesting dates and times for a conference call not to exceed sixty minutes. Once a conference call was scheduled, the consultants then sent an additional follow-up e-mail with an explanatory attachment that (1) summarized the project, (2) listed the questions for discussion (see above) and the eight priority recommendations, and (3) provided the four core values and the eight guiding principles from *Shaping a Health Statistics Vision for the 21st Century*.

Interviews were conducted with twelve key informants who responded positively to the invitation. Five potential key informants responded negatively or failed to respond.⁵⁷ The consultants sent a reminder e-mail note on June 1st to all potential key informants who had not scheduled a conference call by May 29th.

Interviews:

The consultants conducted interviews via telephone conference calls during May and June, 2009. One consultant took lead responsibility for guiding the discussion and asking questions, and the other consultant took lead responsibility for recording the conversation. Conference calls have lasted from thirty to sixty minutes. Conference calls were followed by thank you notes and requests for additional information and citations as needed.

Literature review

⁵⁷ One additional key informant was added as a result of information obtained during the key informant interviews.

Consultants reviewed peer-reviewed literature, grey literature, Web sites, and various periodicals to identify major changes related to the eight priority recommendations since 2002. Reviewed periodicals include *e-Health Europe*, *Health Affairs*, *iHealthBeat*, *Journal of the American Medical Informatics Association*, and *New England Journal of Medicine*. Consultants also reviewed reports from NCVHS, the Markle Foundation, the Robert Wood Johnson Foundation, U.S. DHHS, and other sources. Only directly relevant publications are cited in footnotes in the text.