

Shaping a Health Statistics Vision for the 21st Century

Policy Makers Summary
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Department of Health and Human Services Data Council
Centers for Disease Control and Prevention
National Center for Health Statistics
National Committee on Vital and Health Statistics

Every day, countless decisions are made concerning public and private health. Local, state, and federal budgets are drawn up annually that commit taxpayers' dollars to, or withdraw them from, health programs. Legislatures routinely consider health-related laws with immense human, bureaucratic, and financial consequences. Yet often, decision-makers have access to only part of the information they need to make the best decisions.

Guiding the assessment, development, and evaluation of health policy is a major use of health statistics, the numerical data that characterize the health of a population and the factors influencing it. Health statistics are used, as well, to create fundamental knowledge and to guide population health programs and personal health decisions. But their potential for informing decision-making will be realized only when the health statistics enterprise has adequate coordination and resources and is guided by a broad view of population health.

It is not difficult to imagine ways in which better information could lead to better decisions:

- Coordinated data collection and analysis would result in more reliable statistics and make it possible to draw conclusions from estimates to guide decision-making. For example, national and state surveys currently produce varying estimates of the number of people without health insurance, adding confusion to the efforts of policy-makers to address this issue.
- Information on all the factors that influence population health would make it possible to judge which factors are most significant for particular population health issues and to target appropriate interventions. For example, better information on physician supply could enable policy-makers to understand whether and how an increase in the number of specialists in medium and smaller cities impacts upon the functional status of persons with chronic disabilities.
- Knowing the relative contributions to population health of different investments would make it possible to set evidence-based priorities for future investments. For example, better information could enable policy-makers to determine the relative return on investment from increased funding of skin cancer prevention programs compared to increased funding of skin cancer screening clinics.

- Having access to timely data would allow decisions to be made on the latest evidence. For example, more timely data would enable policymakers to consider the impact of programs before they are reauthorized, or provide early warning signals of new health trends.
- Comparable statistics across geographic levels would provide state and local executives and legislators the tools to target problems of particular significance in their areas, as well as to evaluate success in their program interventions. For example, better information could increase the capacity of the public health and health care systems to identify low rates of immunization in infants and children in specific neighborhoods, enabling more effective, efficient, and timely targeting of immunization programs.

A Vision for Realizing the Potential of Health Statistics

Building a health statistics enterprise that can fully support informed decision-making requires a number of interconnected conceptual, structural, and functional changes in our current system. They are described briefly below and discussed more fully in *Shaping a Health Statistics Vision for the 21st Century*, a new report developed through a two-year, national consultative process. The process involved more than 200 policy makers, public health and health care professionals, health statistics practitioners, researchers, and others in a wide range of locations in the United States. The National Committee on Vital and Health Statistics (NCVHS)*, the National Center for Health Statistics (CDC/NCHS), and the Data Council of the U.S. Department of Health and Human Services (DHHS) coordinated the process and produced the report. NCVHS recommendations for translating the vision into practice are attached to the report.

A view of population health and its determinants

The report begins by defining health statistics and describing the health statistics enterprise. It stresses that to be useful to health and health policy decision-makers, health statistics must represent all the factors influencing population health. That is, in addition to representing all dimensions of health outcomes—including measures of functional status and wellbeing as well as disease in the population—health statistics must

*NCVHS is the statutorily mandated public advisory body on health information policy to the Secretary of the U.S. Department of Health and Human Services. The NCVHS Workgroup on the 21st Century Vision for Health Statistics conducted this project for the Committee.

represent community characteristics, the natural environment, and cultural and political contexts.

This view of population health and its determinants, shown in the model in Figure 1 below, defines the scope of information the health statistics enterprise should obtain and make available. The model can be used to identify gaps in current data and in the enterprise’s capacity to provide the data.

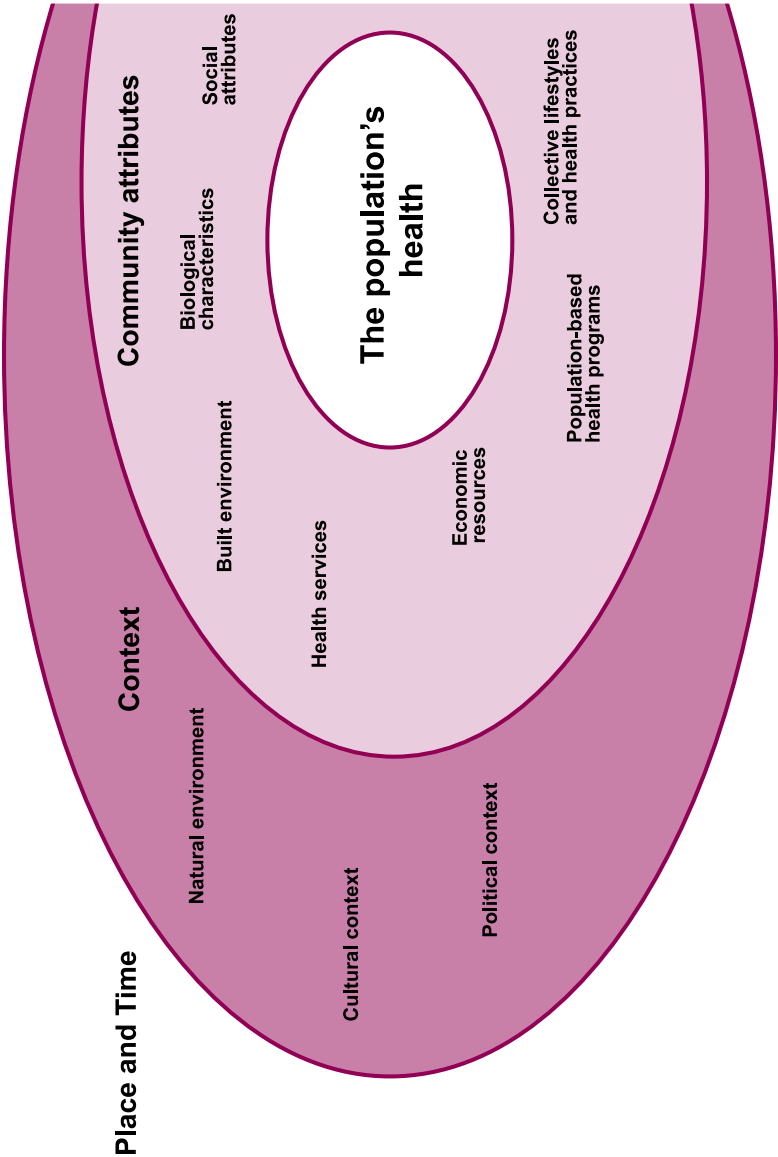


Figure 1. Influences on the Population’s Health

A strengthened hub for the health statistics enterprise

Another model developed for the report (Figure 2) shows the stages and components of an ideal health statistics cycle and specifies the activities of the health statistics enterprise and their interactions.

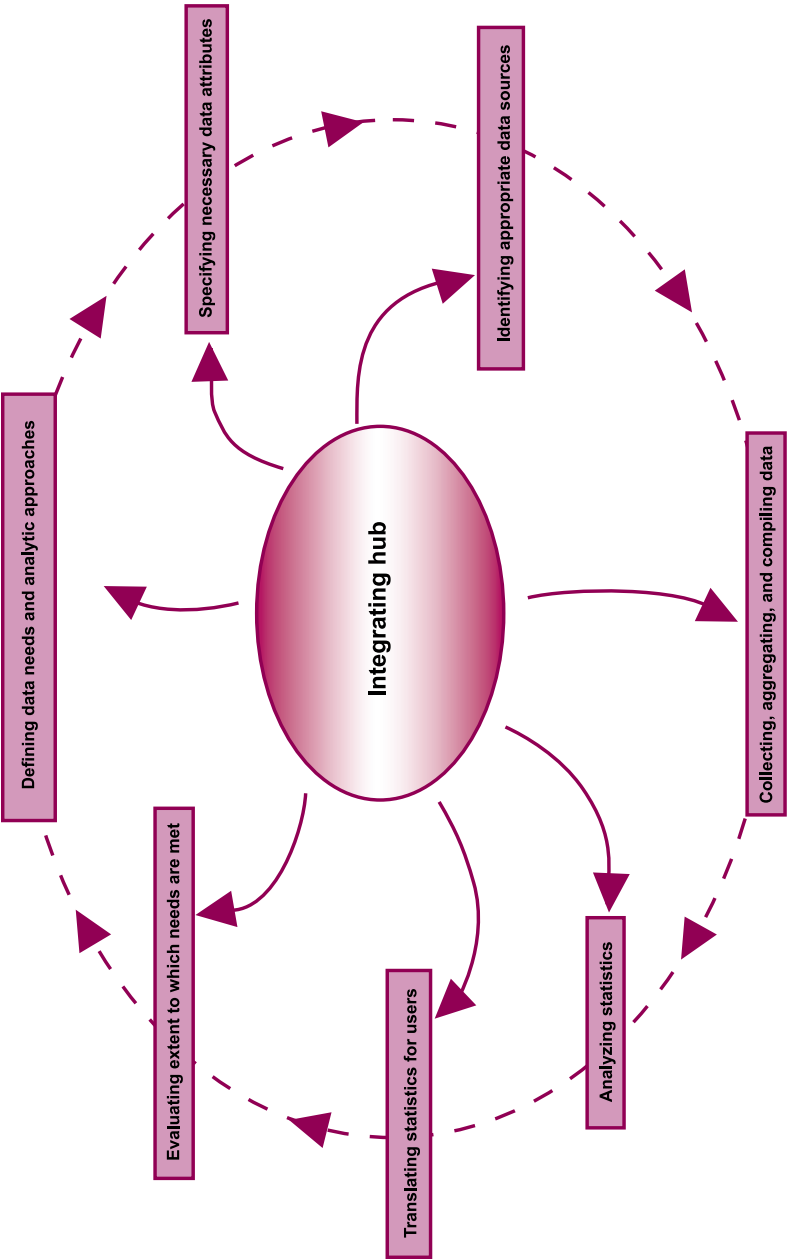


Figure 2. Health statistics cycle

A major difference between this idealized view and current conditions is that the components of this health statistics cycle are tied together by an integrating “hub.” As envisioned, the hub coordinates the activities of the health statistics enterprise, stimulates collaborative efforts, sets standards, reviews and revises the vision, generates new methods and approaches, and protects privacy, confidentiality and security.

The need to strengthen the hub to carry out these functions was a major emphasis of the visioning process. Participants conveyed a strong message that new approaches to enterprise-wide coordination and integration are needed because existing ones are largely ineffective, causing fragmentation and inefficiency.

Conceptual framework, core values, and guiding principles

The report proposes that the mission of the health statistics enterprise is to efficiently provide timely, accurate, and relevant information that can be used to improve the population’s health. It outlines the attributes of the needed conceptual framework, and specifies core values and principles to guide the enterprise in realizing the vision for health statistics.

The overarching *conceptual framework* envisioned for the health statistics enterprise has these characteristics: it focuses on health, the population, and the community; it emphasizes distribution and level of health; it delineates major influences on health; and it guides a research agenda for improving the health of the population. The use of an overarching conceptual framework will remind policy-makers and public health practitioners of the myriad of factors that must be considered and addressed in designing and implementing programs to improve population health, and help to reduce narrow, disease-specific, and categorically-focused programs.

Four *core values* are envisioned for the health statistics enterprise:

- *Maintaining the confidentiality and security* of individually identifiable health information
- *Maximizing the scientific integrity* of all aspects of health statistics while acknowledging the specific ways in which the political, cultural, and business contexts may affect data collection, analysis, and interpretation
- Optimizing the enterprise’s accountability to its users to *ensure the availability* of the information that is needed for improving the nation’s health

- Ensuring the enterprise's accountability to its data suppliers to *minimize their burden* and to provide them with *timely feedback*

The report concludes by identifying ten *guiding principles* for actualizing the core values:

1. *Enterprise-wide planning and coordination* to ensure relevance to local, state, and national policy and program decision-making and to an overall conceptual framework of the influences on the health of populations
2. *Broad collaboration* among data users, producers, and suppliers at local, state, and national levels to ensure efficiency of the health statistics enterprise and usefulness of the data that it produces
3. Rigorous policies and procedures for *protecting the privacy* of individuals and the confidentiality and security of data
4. *Flexibility* to identify and address emergent health issues and needs
5. *Use of data standards* to facilitate sharing and comparability of data
6. *Sufficient detail* at different levels of aggregation to support local, state, and national policy and programmatic decision-making
7. *Integrated, streamlined data collection* for multiple purposes
8. *Timely production* of valid and reliable health statistics
9. Appropriate *access to and ease of use* of health statistics
10. *Continuous evaluation* of the completeness, accuracy, and timeliness of health statistics and of the ability of the health statistics enterprise to support their production

The NCVHS Recommendations

After working closely with its partners to create a vision for health statistics reflecting the views and concerns of consultation participants, the National Committee on Vital and Health Statistics developed 36 recommendations for realizing the vision. Thirty relate to and flesh out the guiding principles, and six move toward the adoption of an overarching conceptual framework. The recommendations are summarized in the Appendix.

NCVHS believes that the top priority for realizing the vision is to build the integrating and coordinating hub for the health statistics enterprise. This priority is expressed in guiding principle 1, regarding enterprise-wide planning and coordination. Four NCVHS recommendations relate to this priority:

- *Assign responsibility and authority for health statistics leadership within DHHS to a reconstituted National Center for Health Statistics, supported by a strong Board of Scientific Counselors,*
- *Establish a national Health Statistics Planning Board with overall responsibility for planning and agenda setting for health statistics in the United States.*
- *Designate overall responsibility for health statistics planning and coordination activities within each state's government to a single state agency, supported by autonomous state Health Statistics Planning Boards.*
- *Develop appropriate graduate and in-service training and continuous education addressing all elements of the health statistics cycle.*

Carrying out these four recommendations would facilitate the achievement of the Committee's recommendations for the other nine guiding principles. Those recommendations address research agendas, data set development, health statistics reports, dissemination of best practices, training, and other key topics.

Finally, the 21st century health statistics enterprise in the U.S. must be viewed within the context of the National Health Information Infrastructure (NHII), which has the potential to connect all health decision-makers to sound information and to each other. NCVHS recommended a strategy for building the NHII in a November 2001 report.^{*} The vision for health statistics contributes to the development of the Population Health Dimension of the NHII. Participants in the health statistics enterprise must become actively and enthusiastically engaged in this wider effort.

Implications for Policy-Makers

Shaping a Health Statistics Vision for the 21st Century and the NCVHS recommendations are a call to action to colleagues in the fields of health policy, public health, health statistics, and health care to see their activities in the context of this broad vision and to work in their domains to help realize it.

The most important benefits from the proposed changes—which will take many years to accomplish—will accrue to everyone in the American population in the form of improved personal and community health, more

^{*} NCVHS, *Information for Health: A Strategy for Building the National Health Information Infrastructure*, 15 November 2001.

efficient use of public and private dollars, and better support for personal decision-making. In addition, those working on health policy, public health, health statistics, and health care will benefit by being able to do their jobs with greater efficiency and effectiveness.

Appendix: Summary of NCVHS recommendations

Recommendations on data access

- Use the World Wide Web to Improve access to national, state, and local data on the population's health and influences on the population's health. [GP 9.1]
- Disseminate throughout the health statistics enterprise the best methods for maximizing appropriate access to and ease of use of health statistics. [GP 9.3]
- Enhance regularly released health statistics reports to reflect an overarching conceptual framework of influences on the population's health. [CF 4]

Recommendations on data set development

- Develop systems to actively monitor the population's health and potential influences on the population's health in order to identify emerging problems. [GP 4.1]
- Develop mechanisms to rapidly modify the samples, data collection strategies, and data collection instruments of ongoing data collection systems in response to emerging issues. [GP 4.2]
- Geocode all ongoing data sets that feed the health statistics enterprise to the census block group level. [GP 6.2]
- Develop and validate topic-specific question modules for population-based surveys to support state and local agencies' development of small-area health statistics. [GP 6.3]
- Identify duplicative data collection efforts and eliminate redundancy. [GP 7.1]
- Support and fund efforts within individual states to integrate or better coordinate, as appropriate, discrete data systems. [GP 7.2]
- Support and fund ongoing multi-purpose data collection systems and data integration efforts. [GP 7.3]
- Develop and adopt benchmarks for timeliness of release of data and reports derived from those data. [GP 8.1]
- Assure that appropriate measures of functional status and well-being are included in ongoing systems that are a part of the health statistics enterprise. [CF 1]
- Prepare and provide to staff of state and Federal agencies with health statistics responsibilities a manual and a "tool kit" of data sets for use in community-level analyses. [CF 2]
- Develop person-based, longitudinal data sets and surveys in order to develop portraits of influences on the population's health throughout the life cycle. [CF 3]

Recommendations on data standards

- Harmonize the CDC public health conceptual data model with the overarching conceptual framework for the health statistics enterprise in order to facilitate the development of standards. [GP 5.1]
- 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. [GP 5.2]
- Provide guidance for implementing and auditing the use of standards by the health statistics enterprise. [GP 5.3]
- Contribute to the national standards setting process. [GP 5.4]

Recommendations on enterprise structure

- Assign overall responsibility for health statistics leadership within DHHS to a reconstituted National Center for Health Statistics, supported by a strong Board of Scientific Counselors. [GP 1.1]
- Establish a national *Health Statistics Planning Board* with overall responsibility for planning and agenda setting for health statistics in the United States. [GP 1.2]
- Assign overall responsibility for health statistics planning and coordination activities within each state's government to a single state agency. Establish a *Health Statistics Planning Board* in each state with overall responsibility for planning and agenda setting for health statistics within the state. [GP 1.3]

Recommendations on evaluation

- Compile feedback on the practical applications of health statistics to policy, research, and public health practice and disseminate these findings to providers of data, policymakers, and the public. [GP 10.1]
- Conduct periodic evaluations of NCHS' adherence to the National Academy of Sciences' attributes of a Federal statistical agency. [GP 10.2]

Recommendations on policy

- Develop a code of fair information practices for the health statistics enterprise. [GP 3.1]
- Develop guidance on the application of the HIPAA Standards for Privacy of Individually Identifiable Health Information to health statistics. [GP 3.2]

- Develop model state and Federal privacy, confidentiality, and security statutes for government-sponsored health statistics. [GP 3.3]
- Develop a toolbox of privacy, confidentiality, and security best practices for use throughout the health statistics enterprise. [GP 3.4]

Recommendations on a research agenda

- Develop and fund a research agenda for the study of methods and technologies to enhance the privacy, confidentiality, and security of health statistics. [GP 3.6]
- 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. [GP 4.3]
- Develop methods to validly and reliably estimate important indicators of the health, and of the influences on the health, of state and local populations. [GP 6.1]
- Develop and implement methods and technologies that will maximize the timeliness of release from ongoing data collection systems of regularly scheduled reports. [GP 8.2]
- Provide controlled access to potentially identifiable individual-level data on the population's health and influences on the population's health. Such access would be provided, at designated sites, to researchers pursuing approved projects. [GP 9.2]
- Support research into how health statistics can be used more effectively to understand the causal relationships between specific influences on health and functionality and well-being in general and specific high priority diseases. [CF 6]

Recommendations on training

- Expanded graduate, in-service, and continuous training opportunities should be developed and offered in focusing on all elements of the health statistics enterprise. [GP 1.4]
- Develop a model training agenda and training materials for use throughout the health statistics enterprise focusing on fair information practices, privacy, confidentiality, and security. [GP 3.5]

- Provide training about concepts related to the population's health and influences on the population's health at professional meetings attended by staff of state and Federal agencies with health statistics responsibilities. [CF 5]