

**Shaping a Vision for
21st Century Health Statistics**

—Interim Report—

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I dream things that never were and ask, "Why not?" (G.B. Shaw)

INTRODUCTION: THE 21ST CENTURY VISION PROCESS

Building and maintaining a healthy population depends on information, and health statistics are a crucial dimension. Health statistics are health data that can be generalized to a known population of individuals, events, organizations, or institutions. The statistics can be used to design, implement, monitor, and evaluate specific health programs and policies. Properly organized and communicated, health statistics enable us—citizens, policy makers, public health workers, and health care providers—to assess local or national health, mobilize to improve it, and evaluate the success of those efforts.

An effective system of health statistics can take seemingly isolated events and reveal a broader context, identifying patterns and trends that can shape personal, professional, and public decisions. Consider these examples:

- A coalition of community groups and public and private health organizations in King County, Washington, found that the percentages of Vietnamese, Latina, Chinese, Filipina, and Korean women receiving breast and cervical cancer screenings were much lower than the county average. In response, several health plans and hospitals that are otherwise in competition joined to fund a screening and education initiative targeted at these groups. This is typical of the activities of the coalition, called the Community Benefits Program, which analyzes local data to identify worsening trends affecting vulnerable populations and then sets priorities and funds community programs aimed at reversing the trends.¹
- Any pediatrician or emergency physician knows that childhood asthma has increased alarmingly in the last decade. But without health statistics, we would be unaware that African American children are four times as likely as white children to die of this cause—and *ten* times as likely if they are 1 to 4 years old.^{2,3} Information such as this made childhood asthma part of a major child health initiative launched by the President in 1997.
- “Growth charts” based on national survey data are found in every pediatrician’s office. They allow parents and doctors to compare a child to a population reference standard, providing an indicator of whether the child is developing normally or is in need of nutritional or medical attention.

Unrealized Potential

Today's health statistics are the product of an enormous national investment over the past century. Most health statistics systems were designed decades ago to address the pressing health questions of the day using the technology, resources, and structures then available. Their evolution has been shaped by a variety of institutional and public health pressures.⁴

Individually, these health statistics systems—such as data on AIDS and sexually transmitted diseases, registries on cancer and other diseases, birth and death records, household health surveys, and provider records—generally meet the needs they were created for, albeit with room for improvement. But collectively, as a national system of information on the health of the U.S. population, they are deficient. Because they were not planned as a unified system, they are a patchwork of data collection systems, both duplicative and full of gaps. Although rich national health data are collected, they often cannot be broken down to provide information on states or localities. Also, because they are collected using different methods and definitions, it is often not possible to combine health statistics from different states and localities to form a national picture, nor to compare states. Local, state, and national data systems cannot be combined into a coherent whole.

These limitations make it difficult, for example, to answer such basic questions as these:

- Do preventive health measures and medical care have their intended effects for individuals, communities, and the nation?
- How are society's economic and racial inequities affecting the health of communities and individuals?
- How are environmental hazards affecting local and national health?
- Who is benefiting most from medical care, and how? Who has been left out, and why? What do we need to know and do to include the excluded?
- What mix of public health measures (e.g., screening, education, attention to food and water safety) and medical care would maximize improvements in the population's health?

Birth of the Visioning Process

Aware of these limitations and of the tremendous information technology capacities now available—and feeling pressure to address critical information needs—Dr. Edward Sondik, Director of the Centers for Disease Control's National Center for Health Statistics (NCHS), made a challenging request of the National Committee on Vital and Health Statistics (NCVHS) in 1998.

NCVHS is the public advisory committee on national health information policy to the HHS Secretary. Dr. Sondik, who is the Secretary's senior health statistics advisor, asked the National Committee to help articulate a vision whereby health statistics in

the United States could mobilize new capacities and fulfill the potential to promote and protect the country's health in the 21st century.

The Committee rose to the challenge. In early 1999, NCVHS and NCHS joined with the HHS Data Council to launch a national consultation and visioning process that is still underway. The present interim report describes the learning that has emerged in the first year. The report will be used to elicit further input from more stakeholders about their perceptions of future health needs and the best mechanisms for addressing them.

The overarching goal of the visioning process is to provide the information needed to enable the American public to achieve and maintain the best possible health. To this end, the visioning process is addressing a multifaceted set of questions:

- What health information will be needed in the 21st century?
- What conceptual framework meaningfully organizes the information?
- What approaches to collection, storage and communication will most efficiently get high-quality information where it can make a difference?
- What privacy, confidentiality and security protections must be in place to ensure that information can safely be used to promote the public's health?

This process calls for three kinds of vision: a good eye for detail, wide peripheral vision, and distance vision that can see far into the future without depending on outdated lenses. In other words, we need an understanding of what it is important to know, an appreciation of how best to find out, and a vision that can anticipate future needs.

The work to envision 21st century health statistics is closely related to another NCVHS project, that of envisioning and developing the National Health Information Infrastructure (NHII).⁵ The NHII is not to be a unitary database. Rather, it is conceived of as a set of policies, practices, technologies, standards, and applications that support communication and the broad array of information needed to improve clinical care, monitor public health, and educate consumers and patients. Community, or population, health information—the essence and focus of health statistics—is one dimension of the NHII, overlapping and sharing data with the personal and provider dimensions.

Process, Participants, and Products

For the health statistics vision, NCVHS, NCHS and the Data Council designed a process with many opportunities for consultation with a broad range of health statistics users, public health professionals, and health care providers from communities around the country and abroad. Special priority has been given to hearing state and local perspectives, by talking with people who use health statistics at state and local levels. The partners also commissioned five scholarly papers to contribute to a common understanding of health statistics and to help identify what

needs improving. (Titles and authors are listed in the Appendix.) Key participants in the process are listed at the end of this report.

The consultative process involved these components in 1999 and early 2000:

- A total of seven workshops and meetings in Harrisburg PA, New Orleans, Albuquerque, and Washington, D.C. (Summaries of these meetings and lists of participants are posted on the NCVHS Website.⁶)
- Presentations and discussions at professional association meetings, including those of the National Association for Public Health Statistics and Information Systems, the Association for Health Services Research, the National Association of Health Data Organizations, and the Council of State and Territorial Epidemiologists
- Meetings with public health and health statistics professionals within the Centers for Disease Control and Prevention (ongoing)
- A two-day workshop on health statistics hosted in November 1999 by the Committee on National Statistics of the National Academy of Sciences, which also invited papers

This consultative process is open and ongoing, and efforts are being made to engage many more stakeholders. To continue the dialogue, NCVHS plans four regional hearings for the last half of 2000 and early 2001. Information on these events and on other ways to contribute are outlined on pages 20-21.

Release of the final Vision document is slated for Summer 2001.

Intended Impacts

Ten principles have emerged from the consultations thus far as key elements of the health statistics vision. These principles, which are discussed below (page 15 ff.), will help focus future discussions as the consensus about the health statistics Vision continues to evolve. They are as follows:

1. The confidentiality of health information on individuals must be protected. This precondition applies to all other principles listed below.
2. An overarching conceptual framework is needed to help organize the different elements of the health statistics system.
3. The health statistics system must be flexible enough to identify and respond to new information needs.
4. Information must be available at a sufficiently detailed level (e.g., geographic area, racial and ethnic subpopulation) to be relevant to real decisions.
5. Data standards are essential and should have maximum usefulness to public health, health care delivery, health statistics, and research.

6. Data should be collected once and then used for multiple purposes, using approaches that promote sharing and efficiency while protecting privacy and confidentiality.
7. Health statistics data must be provided back to communities, community groups, local governments, policy makers, health care providers, and others in ways that maximize data access and ease of use.
8. Approaches should be developed that allow system-wide planning and coordination so that resources can be better managed.
9. Health statistics must be collected, organized, and made available in ways that inform and facilitate decision-making on health.
10. Implementing a broad vision for a 21st century health statistics system will only be possible through collaboration and partnerships including both public and private organizations at the local, state, and national levels.

In addition to articulating the health statistics Vision, the three-year national consultative process is designed to yield a practical description of the components of an integrated information system as well as ideas about how the Vision can guide local, state and federal program planning. The process also seeks to build consensus about health statistics priorities, to clarify roles for the levels of government and for the public and private sectors, and to identify new opportunities for partnership among these components. All of these developments will permit a more rational and cost-effective use of resources. Participants also will lay out criteria and a process for evaluating health statistics systems in the future.

Who Will Benefit?

All Americans stand to benefit from a comprehensive and integrated health statistics system that, while protecting the privacy of individual data, “highlight[s] the distribution of health in relation to the distribution of resources directed to maintaining or improving [it].”⁷ These benefits will be measured not only in improved health at both personal and community levels, but also in more rational and cost-effective decision-making and stronger communities. The potential beneficiaries include families, community leaders, health care professionals and institutions, businesses of all kinds and sizes, educators, local health departments, the media, social service providers, advocacy groups, foundations, and every level and branch of government.

Such enhancements will enable us to make informed decisions about health investments and then evaluate their results. Here are a few examples of potential applications:

- Billions of dollars have been allocated to provide uninsured children with health insurance through the State Children’s Health Insurance Program, or CHIP.⁸ However, currently there is no way to know what difference this is making in their care and health. Better information would permit better outreach, better care, better comparisons of different approaches, and better monitoring of results.

- Currently, there are many concerns but insufficient knowledge about the health impact of toxins in the air, water, and food. With more complete information, we could pinpoint harmful sources, study their impact on health, design preventive measures, and track their effectiveness.
- Comprehensive, integrated local data on prenatal care, infant outcomes, and infant care would allow community health workers to design more effective approaches to prenatal and infant care, and to evaluate the performance of programs and providers.
- Currently there is no way to match the supply of primary care and specialist services to the needs of populations. Having this information would make it possible to target resources to meet the needs of people in different areas and to avoid excesses that generate unnecessary costs for the public.

**WHAT WE'VE LEARNED SO FAR:
TRENDS AND GAPS SHAPING THE VISION**

As noted, this report outlines the themes that have emerged in consultations over the last year about current and emerging health issues, health information needs associated with these trends, and roles and responsibilities for providing information and statistics. The perspectives and experiences of the participants are reflected in the summaries that follow.

The primary questions to bear in mind as we look at these trends, issues, and knowledge gaps are how these forces will shape future information needs, and how a well-defined vision and unified approach might strengthen the country's ability to address the trends.

Socioeconomic, Demographic, and Environmental Factors

Perhaps the strongest theme of the discussions to date has been the need for a broad definition of health, and the need to look further than the presence of disease or the pursuit of medical care in order to understand the health of the population. This means understanding the effects and interactions of the cultural, socio-economic, and environmental domains in which we all live. What trends in these domains are likely to shape future needs and opportunities? What will we want to know about them with respect to health?⁹

Key demographic factors include an aging population¹⁰ and changes in household composition (e.g., there are fewer children, more single parents, and more single-sex households).¹¹ Important socio-economic factors in the U.S. include growing gaps between the resources available to the wealthy and to the non-wealthy, greater differentials in economic and social status, more self-employment and less job security, and an increase in the percentage of the population that is poor, including the working poor.¹²

Other significant trends are the increasing racial and ethnic complexity of American life,¹³ with wide ethnic variations in health status within racial groups (e.g., among Cambodians, Japanese, and Vietnamese) and the growing percentage of multi-racial families; the resurgence of attention to social support as important to health and health statistics; and a rising awareness (and possibly growing presence) of environmental threats to health.

Knowledge Gaps

To address these socioeconomic, demographic, and environmental trends, we need to close the following knowledge gaps, among others, at all geographic levels:

- Ongoing data on economic status, education, language, immigrant status, the availability of social supports, and the relation of each to health status
- Socio-economic and health data on various racial and ethnic groups
- Data on specific environmental factors such as lead and ozone and their impact on health
- Mechanisms for collecting longitudinal data to help us understand emerging trends and threats to the population's health, and mechanisms for sharing and linking information, with adequate privacy protections
- Better ways to characterize the complex interactions among the factors that affect health

The Health of Populations

Vision discussions to date have noted the rise of chronic illness and the growing prevalence of new and newly recognized communicable diseases as important trends in the health of the American population. Serious disparities exist among people in various groups—for example, between certain racial and ethnic groups and between economic levels—in the prevalence and severity of specific diseases and in access to and receipt of appropriate treatment. Additional data are needed at all geographic levels to track new efforts to eliminate the disparities—a major goal of the HHS Healthy People 2010 objectives.¹⁴

Knowledge Gaps

To address health trends affecting populations, the following gaps must be filled, among others:

- Ongoing information—in all categories—about small geographic areas such as small towns and urban neighborhoods
- Information, especially at state and local levels, about specific population groups—e.g., racial and ethnic minority groups (especially Asian and Hispanic)

groups), children, the aged, migrants, the working poor and nonworking poor, and people with disabilities

- Information on individuals related to comorbidity, mental and behavioral health, and health status—including their functional status with respect to physical abilities and cognitive functioning and their access to devices or other means of assisting their functioning

Health Care, the Health Services Delivery “System,” and Health Care Seeking

Discussions to date have stressed that health care services at the start of the 21st century are delivered not within a system but by a disparate and rapidly changing array of institutions and relationships. In terms of information, the most important criticism is that too much of the data now collected is useful only nationally, or only for paying for health services. When the data are used for other purposes, they often produce misleading information.

Business trends in health care are toward capitation,¹⁵ consolidation, and reliance on market mechanisms—with important implications for what information is collected, and how. In clinical care, two major trends are the growing interest in evidence-based medicine and the growing use of expensive, high-tech solutions to medical problems. Other trends are the provision of care outside traditional inpatient settings and pressures away from specialty care and toward primary care.

There is growing attention in the U.S. to outcomes and quality issues—at least partly in response to payer demand, public policy, and media attention. Yet little of the information that is currently collected is useful for these issues. For example, data on hospitalizations is collected completely separately from data collected in other health care settings or by surveys, and these various sources cannot be linked to provide a cogent picture of health needs and how they are being met.

In terms of health care seeking by consumers, a significant number of Americans are choosing alternative forms of treatment, some of unproven usefulness and possible harm. Consumers also are seeking information on the Web, engaging in self-care, and participating in self-help/mutual aid groups.

Knowledge Gaps

In addition to those noted above, knowledge gaps related to health services delivery lie in the following areas, among others:

- The relationship between the population’s health and relative investments in primary care and ambulatory specialty care
- The effectiveness for the population’s health of specific medical interventions purported to improve health (Examples: What are the implications for survival of radical prostatectomy compared to brachytherapy? How much of the explosion in new and expensive drugs really improves people’s health and well-

being? Is the increasing cost of health insurance compromising health? What types of care produce the best results for the health of the population?)

- Information to determine whether the demonstrated benefits of surgeries, drug treatments, and putative quality of life enhancements extend to all people
- The effectiveness of investments in preventive services versus curative services
- Information about the types of services available to local populations and the balance among them
- The impact of adverse effects of medical care on the health of the population
- Data on alternative therapies (e.g., procedures, providers, consumer care-seeking)

The fragmentation of health care delivery today makes it essential to have integrated, effective information systems in order to understand the health care system and how people fare in it. Without this, we lack a composite picture of the preventive and treatment interventions given to individuals or to communities—making it impossible to evaluate the effectiveness of health services. Tying together information on communities, events, people, providers, and health outcomes from different sources can help create more integrated services and improve efficiency and quality.

Scientific Research

Scientific research provides the evidence base, the stimulus for, and the means of evaluating both public health practice and clinical care. However, some scientific trends raise questions that merit a close look in the context of population health. The development and use of technology is proceeding at great expense to the nation and without a clear picture of its contributions to improving health.

In the 21st century, the impact of current investigations into the human genome will unfold in a host of new approaches to screening and therapy. These developments have major implications for future information needs, not only in clinical areas but also in broader ones related to family, culture, education, ethics, and social policy.

Knowledge Gaps

Keeping up with the public health ramifications of scientific research will require more information in the following areas, among others:

- A population-based assessment of the outcomes of various high-tech interventions, to evaluate the outcomes of large investments in comparison with alternative uses of resources
- Information with which to evaluate whether demonstrated benefits (e.g., of genetic research) extend to all segments of the population

Public Policy and Advocacy

Congress affirmed the importance of standardized information and administrative simplification (and of the NCVHS advisory role) in provisions of the 1996 Health Insurance Portability and Accountability Act (HIPAA).

Elsewhere in the public policy arena, an important trend in the 1990s was the devolution of tax money and program responsibility to states. This devolution compounds the historic decentralization that has interfered with the building of national health statistics and therefore of informed public policy. This is especially the case with regard to consistent privacy protections and comparable information on the health status of all segments of the population. The shift to the states intensifies the need to clarify the respective health statistics roles of local, state, and federal governments so their activities can be complementary.

A striking trend in the late 20th and early 21st centuries is the upsurge of sophisticated advocacy groups intent on influencing policy. The American Association of Retired Persons, the National Alliance for the Mentally Ill, food safety and environmental organizations, and privacy advocates are notable examples. The media play a major role in this arena by directly supplying consumers with information (and sometimes misinformation) about health and health policy and the factors affecting them.

Information Technology

Today's exploding information capacities make it possible to store great amounts of information and retrieve and share it quickly. By permitting rapid communication between data providers and health agencies, technology enables public health workers to promptly address local or national health problems, and to get information out to the public. In clinical care, the computer-based patient record is likely to become a mainstay.

These and other capabilities promise such boons as the extension of medical care to people living in remote places, rapid response to public health emergencies, direct communication to the public about the measures individuals and families can take, and access for health care providers to patients' medical records from any location when it is needed to deal adequately and promptly with their problems.

For some people, these capabilities raise the specter of lost privacy and the abuse of personal information—a concern discussed below. Another issue related to information technology is the gulf between technological haves and have-nots, a byproduct of the country's social, economic and educational disparities. While some people are able to find information and use it to make informed decisions about their health, others lack the equipment and skills to do so. These are issues of access that must be monitored and addressed along with access to care, as information becomes ever more central to health. Certainly, realizing both the NHII and health statistics visions will depend on the continued development and equitable distribution of information technology.

**WHAT WE'VE LEARNED SO FAR:
CROSS-CUTTING ISSUES SHAPING THE VISION**

Privacy and the Common Good

As a new century begins, Americans are coming to terms with the enormous potential for abuse inherent in modern technology. Information sharing is a two-edged sword: used in the right way and for the right reasons, it can save lives; used in the wrong way or for the wrong reasons, it can ruin them.

Health statistics data are clearly important to communities, public health professionals, health care providers, researchers, the media, and policy makers. For most purposes, these data can be shared in an aggregated form that protects the privacy of individuals. For some clinical and public health purposes, it may be necessary to share individual record-level data under strict procedures for confidentiality. Although the evidence suggests that health statistics systems have done a good job of protecting confidentiality, there is still fear and even some risk that individuals can be identified and their information misused. The greatest concern is that records collected, created, or compiled for statistical purposes might be used to make substantive determinations about individuals or groups by law enforcement, insurers, employers, or others.

The concerns about privacy violations must be taken seriously. At the same time, other important considerations should be recognized: that the confidentiality of paper records is equally or even more in question than that of electronic records, and that information technology actually can be used to enhance privacy protections. Furthermore, if fears about privacy undermine people's willingness to allow even limited access to or use of personal information for important public health purposes, the result can be incomplete information, leading to wrong policy decisions and wrong public health interventions.

A Vision for 21st century health statistics must address all these factors and strike a balance between individuals' desire for privacy and the imperative to improve everyone's health—a need that cannot be met, as we have seen, without information on such things as communicable disease, health hazards, and treatment outcomes. The issue to be resolved is how we can create adequate protections against inappropriate access and the abuse of personal information while at the same time preserving controlled access for public health agencies, health care providers, researchers, and others who need information in order to care for and improve our health.

Those with a vision for health statistics agree on the need for a two-pronged approach to this critical issue. First, and most important, the country must have strong national and state legislation that implements fair information practices and establishes strong punishments for abuses. Increased sharing of data is inappropriate without increased protections for the privacy of individuals. In order to allow for increased sharing and linkage of data, we need health statistics privacy laws that prevent individual health statistics records from being accessed and used by police, prosecutors, employers,

insurance companies, marketers, and others who might use the data in a way that adversely affects the subjects of the data.

Second, Americans and their policy-makers need to become more aware of the ways in which we all depend on health statistics; and those responsible for health statistics must ensure that health statistics tell Americans what they need and want to know about their health.

Negotiating Boundaries: Proprietary, Governmental, and Other

A central task in realizing the health statistics Vision is to find ways, within the context of privacy protections, to link data that now exist in separate “silos.” Consistent and controlled access to data from various sources are necessary because at present, it is difficult to do any of the following important forms of analysis:

- link or share data from different sites of care (hospitals/nursing homes/ ambulatory care)
- understand the relationships between health status, health determinants, and health services
- link data from surveys and administrative and encounter data
- link complementary data from private and public databases
- combine comparable data from local, state, and federal systems

Because most data systems were created to address specific needs, with no common framework or consensus on an overall “system,” it has been difficult to compare or link data between data systems. There are many reasons for this difficulty: constraints on the use of specific data sets to compensate for inadequate national privacy protections, differing practices and systems within branches and levels of government, the way data elements are defined and coded, and the technical complexity of combining data collected with different methodologies.

It should be understood that the goal is not to replace the data “silos” of today with some sort of consolidated mega-database—the mythical “Central Database in the Sky.” Rather, the goal is to provide controlled mechanisms for accessing and combining data from different sources for defined public health purposes. (This conception is much like that for the National Health Information Infrastructure.) Such linkages could enhance understanding of the causes of ill health and what to do about them. They also could make our statistical system more efficient, less burdensome to data providers, and more responsive to emerging data needs.

With a concerted effort, it should be possible to remove unnecessary barriers to an integrated, efficient system. The barriers can be overcome by greater attention to standardization and comparability, improvements in technology, and creative approaches to making data available for analytic use in ways that do not jeopardize individual privacy.¹⁶

Similar effort will be required to overcome the philosophical and practical differences preventing greater consistency, sharing, and integration across public and private entities. While many of our most historically useful data systems have been conducted by public agencies for public purposes, an increasing array of health information initiatives originate in the private sector, where data are initially justified as being useful for proprietary or institutional purposes. While these data could be of great use if placed in the public domain, it is not always clear that private organizations have the necessary incentives or protections to make data widely available. Similarly, data derived from systems established for non-statistical purposes (e.g., payment systems) can be of broader use, but may not be readily converted to a useful form. A well functioning health statistics system must find ways to encourage such mutually supportive collaborations.

Data Quality Issues

Data quality suffers now because of the lack of standardized terminology, definitions, concepts, transmission formats, analysis, and dissemination. The multiplicity of today's data sources makes it necessary to pay close attention to the quality of each source and its specific limits and capabilities. Ensuring future data quality will involve improving the quality of records through technology and education of data providers. For example, technology can contribute to improved quality by permitting automatic querying while data are being collected, rather than afterwards when incompleteness and inaccuracy are more difficult to correct. In addition, surveys need to be improved by investment in survey research, cognitive research, and evaluation.

Resource and Burden Issues

Looking back at the characterization of health statistics on the early pages of this report, we see that the lack of comprehensive planning has resulted in gaps, duplication, and high cost. More analysis is needed to tease apart where additional resources are needed and where they simply need to be used more efficiently in the ways outlined below.

Currently, the burden of data collection and reporting undermines both data quality and data providers' willingness to expand collection to include the many other elements on which information is needed. Burden is a concern not only for health care providers and their organizations, but also for local public health officials, especially those with inadequate technology and other resources. A related issue of concern to planners is the shortage of adequately trained personnel to analyze and interpret the data collected.

Underlying all of these concerns is the need for sustained support from knowledgeable policy-makers who understand the importance of health statistics. This, in turn, highlights the need to provide Americans and their leaders with useful information on the public's health status, health determinants, and health care.

INTERNATIONAL DEVELOPMENTS

International trends are favorable for the U.S. health statistics visioning process, with many countries engaged in parallel efforts to enhance their health information capacity. As in the U.S., these efforts are closely and explicitly tied to the goal of improving national health. Many of the same themes being addressed in the U.S., as reflected in this paper, are emerging in other countries' efforts. There is also strong momentum toward collaboration and mutual learning in health information among countries. For example, the U.S. can learn a great deal from other countries about privacy protections. All of the countries described below have national privacy laws and data protection agencies.¹⁷

The United Kingdom, Australia, and Canada all provide valuable models and opportunities for collaboration.

- England's National Health Service (NHS) has been at work on its Health Care Model since the early 1980s, supported by a government that understands investment in information technology as essential overhead for health care. The NHS published its information strategy, *Information for Health*, in 1998.¹⁸
- In Australia,¹⁹ the Commonwealth, six states and two territories have signed a National Health Information Agreement that provides a cooperative framework for the collection, quality, and dissemination of national health information in that country. The agreement has produced a National Health Information Management Group and other bodies, as well as a national health information model, data dictionary, and knowledge base.
- Canadians began a systematic examination of their health information needs in the early 1990s. This led in 1998 to a broad consultative process, coordinated by the Canadian Institute for Health Information and aimed at crafting a "National Health Information Roadmap" to support the country's health objectives.²⁰ These activities have led to substantial new pilot funding from the Canadian government for implementation of the Roadmap. Despite the differences in health care delivery systems, Canada's health statistics have developed much like those in the U.S., and they have similar inadequacies in terms of their completeness, compatibility, and usefulness. The consultations and theoretical work going into Canadian Roadmap development—and the commitment to providing Canadians with accessible, useful information—offer valuable models for our country's visioning process and its products.
- The European Union issued a Privacy Directive in 1998, intensifying the pressure on the U.S. to strengthen its own privacy protections. European nations have had a framework for addressing privacy since 1980, when the Organization for Economic Cooperation and Development (OECD) issued Guidelines on the Protection of Privacy and Transborder Flows of Personal Data. These guidelines cover such topics as limitations on data collection and use, specification of purpose, openness, and accountability.

PRINCIPLES FOR THE 21ST CENTURY VISION

In discussions thus far, the following 10 principles have emerged as qualities that participants see as essential to developing the health statistics Vision. Future discussions will continue to hone the description of central principles.

1. Privacy, Confidentiality, Security, and Fair Information Practices

Protecting the privacy and confidentiality of personal health data is of highest importance. This precondition applies to all other principles discussed below.

The National Committee on Vital and Health Statistics issued recommendations to the Secretary on the privacy of medical records in mid-1997.²¹ The NCVHS recommendations were echoed in those the Secretary made to Congress later that year, and in other Congressional testimony. Then in 1999, the Department fulfilled a HIPAA requirement and issued proposed regulations for protecting the privacy of individually identifiable health information that is electronically transmitted in connection with administrative and financial transactions. NCVHS has offered formal comments on the proposed regulations.²²

The Committee's 1997 privacy recommendations to the Secretary and the Department's proposed 1999 regulations constitute an important step forward in protecting health information privacy. But additional national and state steps are necessary beyond this initial focus on electronically transmitted administrative and financial data, especially directed toward protecting the privacy, confidentiality, and security of all data used for health statistics.

Necessary protections for the privacy and confidentiality of health statistics data would involve a number of essential factors: adherence to strict new national and state legislation; the use of fair information practices that explicate and control data access, sharing and handling; technical security measures within every organization handling data; sanctions and punishment for misuse and abuse; sophisticated approaches to releasing data to avoid inadvertent disclosure of individually identifiable information; and new approaches to using technology to enable data sharing while protecting privacy. Linkages of anonymized or fully de-identified individual record data, or of aggregated data for small areas, must be done in ways that protect privacy and confidentiality. Linkages of individual record data must occur within a newly established legal framework, with appropriate human subject review board approval or permission from data subjects.

In general, research is needed to find technological approaches that enable data sharing while protecting confidentiality. At the same time, Americans and their leaders must tackle the difficult questions about the conditions under which the potential benefits to society justify assuming the small risk associated with using information for purposes such as research and public health monitoring.

2. Conceptual Framework

Other sections of this report discuss the many facets of health and its determinants and the chronic problems of fragmentation and artificial boundaries within health statistics. Future health statistics need an overarching conceptual framework that encompasses all the relevant aspects of the population's health and reflects their interactions. An exemplary model has been developed by Evans and Stoddart and adapted by Charlyn Black and her colleagues.^{23,24}

Combined with an integrated national implementation strategy, such a framework would guide data collection and aid in the rational and efficient deployment of information to address health concerns. The framework would make it possible to expand beyond the medical, infectious disease, and vital statistics models that can restrict the uses of information to understand and address health needs.

3. Flexibility to Identify and Address Emergent Issues and the Health Needs of the Population

21st century health statistics must be able to identify and meet new information needs as they arise. Knowledge gaps are a moving target, not static. Even with good “distance vision” that sees far into the future, unanticipated population health needs are sure to arise, and health statistics systems will need mechanisms for addressing them. The same is true for newly emerging issues and topics with relevance to health and health care. Examples of contemporary issues are the upsurge in the use of alternative medicine and heightened concerns about adverse effects and medical errors.

In addition to being able to identify new information needs and emerging issues, health statistics must be structured so that new information and new categories of information can be easily incorporated.

4. Usefulness at Different Levels of Aggregation

Statistical systems need to provide information in sufficient detail to support decision-making. While many existing statistical systems provide rich resources for analysis and action at the national level and for the population as a whole, increasing levels of detail—both geographic and demographic—are increasingly critical.

The identification of health problems, needs, and interventions is increasingly a local function. Data from the national and state level often provide only a rough outline of real problems faced in individual communities, and cannot provide data to evaluate interventions that may be unique to a given area.

Similarly, health problems, health care access, and health outcomes can be quite different for different racial and ethnic subpopulations. Health officials need data in fine-enough detail to understand health differentials and design effective interventions.

The potential costs of meeting all data needs—for example, for each of multiple racial and ethnic subgroups in each local area—are daunting, and it is unlikely that all needs will be met. An important challenge for the health statistics system will be to develop an overall information framework that takes these and other detailed needs into account, while recognizing the expense and technical difficulty in obtaining such data.

5. Compatible Standards Serving Multiple Purposes

Standards are a necessary precondition for data sharing, linkage, and interoperability. However, only compatible, non-duplicative standards that simultaneously serve clinical, administrative, public health surveillance, and health statistics purposes will permit the kind of information systems and decision-making that are envisioned for the future.

The last decade has seen a proliferation of standards for relatively narrow purposes, and in some cases conflicting standards for a single purpose. This multiplicity is an impediment to developing an integrated and efficient information infrastructure.

Standards are still needed in many areas—for example, administrative data for monitoring care provided by health plans and public health personnel; race/ethnicity classifications; definitions of households; and geocoding. Both modification of existing standards and development of new ones should be governed by the principle of serving multiple purposes.

6. Unitary Data Collection for Multiple Purposes

The principle of collecting data once and then using the data for many purposes is the key to solving many of the current problems with statistics—burden, resource constraints, fragmentation, and so on. The multiple purposes for which unitary data collection could be used include clinical care, health services research, administration, public health programs, public health surveillance, and population health monitoring. Strong legal protections to safeguard confidentiality and privacy, carefully structured data sharing agreements, and appropriate protocols for implementing the legal protections and data sharing agreements will all be necessary if we are to achieve unitary data collection for multiple purposes. Equally essential will be the right conceptual framework and organizational mechanisms.

7. Maximum Access and Ease of Use

In order to improve the public's health and community decision-making about population health programs and priorities, health statistics data must be provided back to communities, community groups, local governments, and health care providers in ways that maximize data access and ease of use. If health statistics are to play their role in improving the population's health, the users of health statistics data

cannot be confined to epidemiologists, statisticians, and other public health professionals.

To maximize access and ease of use, health statistics must be presented understandably, and for a wide range of local audiences. Useful and useable data must be provided to local communities in useful formats. Producers of health statistics must recognize that different presentations and modes of access to health statistics will be needed for different types of users. Current approaches to providing local health statistics data must be expanded upon, such as regularly updated hard copy community health profiles and user-friendly, interactive Web-based health statistics information services.²⁵

Paradoxically, a health statistics system based on the principles described here will be simultaneously more simple and more complex than our current patchwork of data collection systems. On the one hand, the work of data providers (e.g., hospitals, physicians, HMOs, and neighborhood health centers) should be simplified by the adoption of standards and the elimination of duplicative reporting of the same data for billing and administration, multiple “silo” surveillance systems, and clinical purposes. The work of the end users of health statistics data (including community groups, public health professionals, policy makers, community groups, and researchers) also should be simplified, because of the increased understandability introduced by compatible, multi-purpose standards for what are currently called administrative, clinical, and health statistics and surveillance data.

On the other hand, the work of the data collectors (including state and federal agencies) may become more complex, due to several factors: the need to carefully structure data distribution and sharing partnerships that conform to new legal requirements, the need to manage agreements on compatible data standards, and the need to scrupulously adhere to new security and confidentiality protocols.

8. Adequate, Well-Managed Resources

As has been noted, some of what is perceived as inadequate funding is in fact a function of a lack of an overarching framework or mechanism for system-wide planning and coordination, and a resulting suboptimal use of existing resources. Nevertheless, it is also the case that a strong health statistics infrastructure will depend on adequate, stable, and predictable funding.

9. Policy Relevance

As noted elsewhere, health statistics exist so that decision-makers of all kinds can promote and monitor the health of individuals and communities and anticipate or respond to problems. Information that is useful to policy makers will help clarify what the right questions are with respect to health and provide “actionable” answers in a timely, accessible, and usable manner. Tying information to national, state and local objectives, such as in the Healthy People 2000 and 2010 process, can be an excellent way to shine light on information gaps and to make data useful to policymakers. Finally, health statistics must be evaluated continually for their utility in informing policy.

10. Broad Collaboration

Implementing the health statistics Vision will require the full participation not only of the government agencies responsible for public health but also of related government agencies, many facets of the private sector, the media, local community leaders, and individual citizens. Because implementing the Vision will depend on multi-party partnerships, mechanisms that elicit the views of stakeholders and provide ways for them to collaborate and contribute will be as important as the other mechanisms discussed above.

The potential collaborators include the following:

- Local, state, and federal government (with clear delineation of roles and responsibilities)
- Private sector organizations (e.g., health industry, media, advocacy groups, local and national health coalitions, information technology/informatics industries]
- Related sectors (education, housing, justice, transportation, environmental protection, health, alternative health, nutrition)
- A public constituency: citizens and leaders who recognize the essential role of health statistics and help shape decisions about their collection and use

NEXT STEPS

As we have stressed, this is an evolving Vision that is still coming into focus. To fulfill the goal of allowing all Americans and all American communities to achieve and maintain the best possible health, the Vision must reflect true national priorities and perspectives. It also must include specific suggestions for local, state, and national action by both private and public entities.

The more the Vision represents the views of community leaders, public health workers, health professionals, data users, and policy-makers in communities across the nation, the more valid and useful it will be. Therefore, we need and welcome *your* input on any and all aspects. You may convey your input in any of the following ways:

- On the Web (WWW.NCVHS.HHS.GOV/HSVSION)
- Through e-mail (HSVSION@CDC.GOV) and other written comments (to this address: Health Statistics Vision, National Center for Health Statistics, 6525 Belcrest Road, Room 1120, Hyattsville, MD 20782)
- At one of the four NCVHS hearings (see below)
- At conferences and meetings where the Vision is being discussed
- Through your organization or association

The following events and milestones lie ahead:

- Hearings (Summer/Fall 2000. The first will be in Chicago on July 10. Subsequent hearings will be announced on the Website.)
- Another draft of the health statistics Vision (Winter 2000)
- Final Vision report (Spring/Summer 2001)
- Use of the health statistics Vision to guide program plans at local, state, and federal levels
- Ongoing consultations with key stakeholders

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NOTES

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⁵ See the NCVHS June, 2000 paper on the NHII vision, Better Information for Better Health: Toward a National Health Information Infrastructure.

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⁷ Black C, Roos N, and Roos L, "From Health Statistics to Health Information Systems: A New Path for the 21st Century," p. 11 (commissioned paper).

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APPENDIX :

PAPERS COMMISSIONED FOR THE VISIONING PROCESS

Charlyn Black, Noralou Roos, and Leslie Roos
(University of Manitoba)
"From Health Statistics to Health Information Systems:
A New Path for the 21st Century"

Lorraine V. Klerman
(School of Public Health, University of Alabama at Birmingham)
"The State Children's Health Insurance Program: A Case Study
with additional material on Data Needs in the Area of Child Health"

Richard Kronick
(Department of Family and Preventive Medicine, University of California, San Diego)
"Numbers We Need: Health Statistics and Policy"

Daniel Melnick
"Building Robust Statistical Systems for Health"

Jennifer Zelmer, Shazeen Virani, and Richard Alvarez
(Canadian Institute for Health Information)
"Recent Developments in Health Information: An International Perspective "