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The National Committee on Vital and Health Statistics, 1996-98

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

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CENTERS FOR DISEASE CONTROL
AND PREVENTION

The National Committee on Vital and Health Statistics, 1996-98

National Committee on Vital & Health Statistics

August 24, 1999

The Honorable Donna E. Shalala, Ph.D.
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Shalala:

I am pleased to transmit to you the report of the National Committee on Vital and Health
Statistics (NCVHS) for the period 1996-1998.

This was an extremely dynamic and productive period in the Committee's long history. In
addition to responding to our broad historical responsibilities, the Committee met the challenge
of the Health Insurance Portability and Accountability Act to provide advice on privacy and
confidentiality legislation and on national standards for administrative data.

During this period, the Committee's interactions with the Department benefitted significantly
from its relationship with the HHS Data Council. I am especially enthusiastic about the
collaborative discussions that have been initiated about assuring a health dimension for the
National Information Infrastructure. Our concept paper on this important topic is included in this
report.

It was my privilege to serve as NCVHS Chair during most of the period covered by this report.
My Foreword reflects on some of the accomplishments of the Committee and on challenges that
lie ahead for the Committee, Department and country. I am confident that the Committee will
continue to thrive under the Chairmanship of Dr. John Lumpkin. I remain available to assist you
and the Committee in whatever ways I can to accomplish our shared objectives.

Sincerely,

Don E. Detmer, M.D.

Foreword

I am grateful for the unique opportunity to serve as Chair of the National Committee for 2.5 years of the 3 years covered by this report. Clearly, the most momentous feature of this period has been the redefinition of the National Committee on Vital and Health Statistics (NCVHS) into a national health information policy committee. The Committee has had an illustrious history for the past half century, and today it is moving ahead with a greatly increased mandate.

After describing important recent changes for the Committee, I will summarize my own perspective on the most pressing issues facing us with respect to health policy and more specifically health information policy. The 3-year report that follows summarizes a truly amazing amount of dedicated work by Committee members, staff, professionals outside the Committee and the government, and other citizens who have taken the time to care about these important issues. I am very grateful to each of them for their contributions. We have shared a unique experience and I honor it. The report mentions by name the key individuals involved, so I will not list them here.

Three actions are responsible for a significant redefinition of the National Committee. First and foremost, was the passage of the Health Insurance Portability and Accountability Act (HIPAA) in 1996. This law expanded the mandate of the Committee from being fully a creature of the United States Government and its Department of Health and Human Services, committed solely to advising the Executive Branch on policy and standards for the government to use for its own activities. The HIPAA legislation broadened the mandate of the advisory relationship. Today, the Committee's recommendations will provide guidance for regulations that apply to essentially all health data management within the nation, not simply that within the Federal Government.

The second action also came from HIPAA. The Committee was given a mandate to report to the Congress as well as the Executive Branch. The Committee now has two additional members appointed by the Congress who function in every respect as any other member of the Committee.

The third action was a crucial and very worthwhile departmental reorganization, as a part of which Secretary Shalala created the Data Council within the Department. The Council includes knowledgeable representatives of all agencies within the Department. In addition, the NCVHS Chair participates in the meetings of the Council. As a result, NCVHS now reports directly and regularly to this senior-level council that meets monthly. This allows face-to-face communication and Departmentwide oversight for all health data activities. During the past 3 years, the Data Council has found its own voice and is beginning to offer

clearer direction for the nation's health information policy. The opportunity for these changes to offer substantial benefits to the nation cannot be overestimated.

While the glass of our nation's health system is half full, it is also half empty. The actions listed above give me optimism for the future, but a solid work agenda still awaits the Congress and the Executive Branch. First, our Congress should pass legislation to assure all people in America access to basic, effective health care services. Clearly, our nation has the resources to do this. What it is lacking is the leadership and followership needed to accomplish the goal. A number of other nations around the globe already understand this vision and are taking action to bring it about.

Our nation should decide how much it wishes to spend for health care, and then assure that its expenditures buy as much measured improvement in health status as possible. This is the most prudent policy, since it assures the most productive workforce and the happiest and most secure citizenry. It is the least expensive strategy over the long haul. Appropriate services are likely to encompass not only direct health care interventions, but also a mix of public health and health education initiatives. By measuring the cost and impact of differing approaches, it is possible to drive toward those that create better outcomes in health status for the investments made. Clearly, this will require a solid vision for a national health information infrastructure and the commitment to achieve it. It is impossible to craft sound policy without access to timely, accurate, and specific health data.

The absence of a rational and coherent health strategy leads to many serious problems. A major factor in Americans' anxiety about privacy and confidentiality is their fear that their health information will be used against them in the workplace and to deny them access to health insurance. As long as we lack the assurance of basic health care, we must at least have basic guarantees that people's information won't be used against them and that their information will be handled carefully. This requires the passage, in concert although not necessarily in the same bill, of a) privacy and confidentiality legislation specifying fair information safeguards for all health information, whether it is in an electronic format, and b) antidiscrimination legislation for employment and insurability.

Obviously, it is Congress that must take action; but the onus rests not only with them but with the Executive Branch, the privacy community, and the health sector to make this a priority and bring it to completion. This should happen before Congress adjourns at the end of 1999. It is regrettable that two Congresses have come and gone without action after Congress itself, through HIPAA, mandated steps in this area and there was such wide agreement on such legislation in the 103d Congress. Only the House of Representatives passed a bill through its chamber. Meanwhile, the European Union has regulations coming into play in 1999 that may influence our capacity to do international commerce and research for public benefit. If Congress does not enact health information privacy legislation by August 1999, the HIPAA legislation requires the Secretary to issue regulations for privacy and confidentiality by February 2000, but this mandate only refers to computer-based data. All personal health data deserve to be protected by uniform Federal fair information safeguards without wildly conflicting State protections.

According to the 1995 Harris-Equifax Consumer Privacy Survey, Americans are of three minds with respect to the privacy of personal health information. Harris-Equifax calls them ''the unconcerned,'' ''the pragmatists,'' and ''the fundamentalists.'' Among ''the unconcerned,'' who essentially lack apprehension about the privacy of their own health data, is a subset who have little regard for anyone's health data.

The ''pragmatists'' form the largest group. They wish to have their data protected from abuse but don't wish to impede such valuable uses of data as medical research, public health protection, quality control, accountability for fraud and abuse, and more cost-effective management of care systems. They seek the goal of Justice Brandeis: ''Privacy is the right to be left alone.'' But they do not wish to stop the world from being able to do relevant health-related work.

The third group has been referred to as ''privacy fundamentalists.'' These Americans seek more than the privacy of being left alone in the Brandeis sense. The privacy fundamentalists seek the right to remain unknown. The most extreme of this group would also demand that everyone's data be treated that way as well. So, some prefer total personal control over any and all uses of their data. A few favor legislation that would prevent all uses of computers in health care—having the effect, for example, of even preventing computers from monitoring vital signs inside an intensive care unit. Technophobia is an element here, since we know that paper records have hardly been highly secure over the years.

It is worse than ironic that the second and third groups agree on the importance of privacy, only differing on the degree of protection warranted. Despite whatever terms might be used to describe them, both are appalled by the views of those with no regard for people's privacy. Yet the debate between them has created an impasse that is allowing those with no respect for privacy to carry the day, simply by default.

There has been sufficient debate between all points of view in Congress and no amount of talk will result in a perfect solution. Health care and people are simply too complex for such an aspiration. The Executive Branch has clearly put forward its position. What is lacking is the will and commitment to give this issue the priority it deserves and to move forward with national legislation. In all likelihood, whatever is agreed upon will not be ideal; but it is very hard to believe that it could be nearly as bad as what we are increasingly inheriting in the absence of such law.

The limitations of solid research on the exact nature and extent of abuses are substantial. Far too much of the rhetoric in this debate is based upon anecdotes rather than solid data. The generally excellent record of the Federal Government with the Medicare data files which now cover billions of personal health events and transactions show that the privacy acts passed in the 1970's do work and work quite well. They just don't apply to the entire nation—and that is what needs to change.

In addition, the public health and research communities must do a better job of articulating to the American people the vital role that data and information play in improving health and health care, through such essential activities as medical and health services research, public health surveillance, and discovering health care fraud and abuse. And where they are not giving sufficient attention to confidentiality and security, they need to do better.

Whatever we do, let's not just stand still. Proper placement of the fulcrum beneath the balance board so as to sensibly balance the needs for information with the desires for privacy is what is needed. Health as one value clearly is counterpoised with privacy, another value; in other words, absolute privacy (if such a thing were possible) could only be achieved by sacrificing substantial personal and social health. As a health professional, I naturally lean toward health, and I believe the bulk of the American people share my perspective (69 percent identified health care as a top priority in a Pew Center poll reported on January 18, 1999). To protect the nation's health by allowing legitimate uses of all types of health information in all formats, without sacrificing the basic privacy protections we are all entitled to, we need federal legislation and we need it now. The absence of Federal action will simply allow further inappropriate intrusions into people's lives, the design of more data systems without adequate security considerations, passage of separate well-intentioned but poorly conceived and uncoordinated State laws, and the unrealized promise of computer-based health care records.

It is also ironic that the world's only current superpower is allowing its technologic might to be subverted by a lack of health information policy, particularly with respect to the privacy issue discussed above. Australia, Canada, the Netherlands, and the United Kingdom have each created a terrific blueprint for action for their nation's national health information infrastructure. The United States should be shoulder to shoulder with these and other nations in Asia, Europe, and throughout the world to assure a safer and healthier globe. Like the economy, diseases are also now international in scope. The work to be done in data standards, research, and development could be far more cost-effective if approached collaboratively.

America needs to be a partner in these efforts. It cannot justify a parochial stance when substantial opportunities exist to improve human health, and risks abound that threaten it—for example, through infectious diseases such as HIV/AIDS, Ebola, and strains currently unknown but on the way.

After years of rhetoric quoting such phrases as John Donne's—''No man is an island'' and all humanity is one family—we are finally face to face with the reality that from now forth, ours is a global society. In light of this, this past year the National Committee developed the concept paper on the National Health Information Infrastructure that is included at the end of this report. The Committee is just beginning to reach out to other departments of the government and other parts of the private sector to assure that sufficient scope and commitment is given to this unique opportunity offered at the dawn of the Information Age.

The story of America, of health, of disease, and even of NCVHS is a rolling one. For my tenure as the NCVHS Chair, the time spent has resembled a fast-moving stream more than a mountain that has simply stood there to be scaled. Whatever metaphor one chooses, and however much success comes from our efforts, the past 3 years have witnessed major changes that we hope will create healthier, happier lives. I wish the Committee all the best for the future and will follow its progress with interest and admiration.

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(February 1999)
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State and Community Health Statistics: Kenneth Keppel, Ph.D., NCHS
Health Statistics for Minority and Other Special Populations: P. Ellen Parsons, Ph.D., NCHS
Mental Health Statistics: Ron Manderscheid, Ph.D., SAMHSA
Disability and Long-Term Care Statistics: Carolyn Rimes, HCFA
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About the National Committee on Vital and Health Statistics

The National Committee on Vital and Health Statistics (NCVHS) is the statutory public advisory body on national health information policy. As such, it advises the Department on the information needs underlying national health policy, and stimulates and conducts studies for the Department. It also serves as a national forum on health data and information systems, facilitating dialogue and collaboration between the Federal Government and interested parties in the private sector.[1]

Over the past half-century, the Committee has made groundbreaking recommendations on health surveys; disease classification systems; health data sets; cause-of-injury coding; standards; and privacy, confidentiality, and security. It has contributed to the general evolution of vital and health statistics in the United States by promoting the quality, breadth, and depth of health data and health information systems. Today, it seeks to foster a national health information infrastructure worthy of our nation.

Eighteen individuals serve on the National Committee, of whom 16 are appointed by the Secretary and 2 are appointed by Congress, all for 4-year terms. These individuals are selected for their expertise and distinction as researchers, educators, and practitioners in such fields as population-based public health, epidemiology, health services, privacy/confidentiality, health information systems, and health data standards. The full Committee meets four times a year, and subcommittees and workgroups meet an additional three to five times a year.

A Brief History

NCVHS was founded in 1949[2] in response to a World Health Organization (WHO) campaign to strengthen international vital and health statistics. Initially, its members and consultants were mostly statisticians, representing public and private sectors. They worked primarily with WHO, concentrating on the technical intricacies of building an international health statistics infrastructure, the *International Classification of Diseases* (ICD).

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[1]NCVHS is authorized under 42 U.S.C. 242(k), Section 306 of the Public Health Service Act, as amended. The Committee's most recent charter was signed in April 1998. Under the provisions of the Federal Advisory Committee Act (PL 92–463, 5 U.S.C. Appendix 2), by which it is governed, all NCVHS meetings are announced in advance and open to the public. Transcripts and minutes of the meetings, as well as all Committee reports, are posted on the NCVHS Website (ncvhs.hhs.gov).

[2]For more detail about the period ending in 1994, see the 45-year history published by NCVHS with the Proceedings of its 45th Anniversary Symposium (CDC/NCHS, 1997).

The Committee's work on the U.S. infrastructure in those early years was seminal in the development of the National Health Survey.

Domestic health statistics became the primary focus after 1964, following a 15th anniversary conference that highlighted such still-familiar concerns as the dominance of administrative data; the need for data on communities, socioeconomic status, race, and chronic disease; and the rising cost of health care. International classification issues continued as an interest, especially during the periodic revisions of ICD. In 1974 a new legislative mandate authorized the Committee to actively advise the Secretary of the Department of Health, Education, and Welfare (now Health and Human Services).

Standards development has been a signal activity of the National Committee since 1970, when it began a long effort to develop and promote common data standards, terms, and definitions. The ensuing years have seen many milestones: minimum data sets for hospital, ambulatory, and long-term care; recommendations on core health data elements; and, currently, a key role in administrative simplification activities. The Committee's increasing consultation with private sector organizations and growing partnership with the Department have been hallmarks of these efforts.

The year 1996 was pivotal for the Committee, bringing a strong new mandate, a heavy workload related to administrative simplification and health information privacy, and unprecedented levels of collaboration with the Department and of accountability to Congress. A new charter in January 1996 expanded the scope of the Committee just as nine members were completing their terms and Judith Miller Jones prepared to hand the gavel to Don E. Detmer, M.D., after 5 years as Chair. During this transition, members engaged in a vigorous dialogue with policymakers aimed at preserving the Committee's historic mission and role while reshaping it to emerging needs. The passage of the Health Insurance Portability and Accountability Act (HIPAA) in August heightened the sense of a new era by giving the Committee new responsibilities and directing the Department to consult with NCVHS as it carried out the law's directives. NCVHS geared up to carry out these responsibilities while continuing its work on many other fronts.

In 1997 NCVHS performed many information-gathering and forum functions, some but not all related to the HIPAA responsibilities. The Committee also began exploring a new advisory relationship to the National Center for Health Statistics and launched a visioning process for health statistics. The year marked the retirement after 14 years of service of Executive Secretary Dr. Gail Fisher. Her successor, Marjorie S. Greenberg, is the Committee's seventh Executive Secretary in 49 years. The continuity of service and contributions of these seven individuals is regarded as an important reason for the National Committee's effectiveness.

The completion of the first phase of administrative simplification assignments and progress on two large-scale visioning projects, one on the future of health statistics and the other on strengthening the health dimension of the national information infrastructure was in 1998. The struggle to keep privacy protections apace with administrative simplification grew intense as the Committee began a Congressionally mandated study of the unique health identifier for individuals. Initiatives on population-based health focused on Medicaid managed care, data on the Islands and Territories, monitoring implementation of

the new OMB Standards for the Classification of Federal data on Race and Ethnicity, and data on care provided in nonconventional settings such as long-term care facilities and homes (commonly called "post-acute" care).

Form and Function

The National Committee has worked hard in recent years to ensure that its internal structure reflects and serves the full range of its priorities. The changes in early 1996 stimulated a thoughtful exploration of what structure—conceptual and organizational— would best enable NCVHS to carry out its mission.[3] The challenge posed by HIPAA is not simply the volume of work required in a very short time, but more importantly how to keep longstanding priorities from being eclipsed. Members labored to ensure that standards will enhance information for the public's health and not be an end in themselves.

To keep administrative simplification duties in that context, the Committee initially assigned the new responsibilities to a work group within the Subcommittee on Health Data Needs, Standards and Security. Members fully recognized the salience this work would have in the short term; "K2" (for Kassebaum-Kennedy) quickly took hold as an apt nickname for the Work Group in view of the mountain of work before them. A Subcommittee on Privacy and Confidentiality was established to work on those issues within and beyond HIPAA.

Meanwhile, the pressing concerns around population-based health information remained, and members devoted an equal effort to an array of population-related topics. Because of its limited size and financial and staff resources, NCVHS has always struggled to balance breadth and depth in the issues it undertakes. During this period, this tension was particularly strong in relation to population issues, due in part to a desire to stay true to the many constituencies that have traditionally related to the Committee through its subcommittees. Developments in the health and human services environment, notably devolution to the States and the shift to managed care, added to the urgency of these issues. It took the Committee 2 years following its new charter and the passage of HIPAA to institutionalize its historic population-based focus in a way members found fully satisfactory. They adopted a modified structure in June 1998, and affirmed at the November NCVHS meeting that it is working very well.

A Web of Relationships

The Department and Congress stress the Committee's pivotal role in promoting consultation between the Federal Government and organizations and individuals in the private sector. The NCVHS meetings, hearings, and information-gathering activities provide citizens and industry groups a way of speaking to the Federal Government. For its part, the Administration increasingly has been listening.

This facet of the Committee's role has been well exercised in the last 3 years, with some 30 public hearings on a host of topics. Besides inviting a range of voices to its table for

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[3]See the schematic developed by two members as a conceptual framework for the Committee's work, and the organizational chart showing structural changes during this period, both in the Appendixes.

special hearings, the Committee provides opportunities for public comments at every meeting. The NCVHS meetings typically have an audience of 50–80, representing an array of public and private stakeholders in the health arena. The meetings are also broadcast on the Internet, and minutes are sent to 1,100 individuals and organizations. The Committee is charged with directly advising the Department; but much of its value to the Department comes in connecting it to the outside world. It should be noted, as well, that NCVHS fosters collaboration among Federal agencies and departments. It is significant that by the end of 1998, some 14 agencies were providing staff to the NCVHS Subcommittees and Workgroups, in addition to the official HCFA and AHCPR liaisons to the full Committee.

The last 3 years have seen an unprecedented level of collaboration between NCVHS and the Department of Health and Human Services. This has been facilitated by the HHS Data Council and sustained through regular consultation and participation in each other's meetings. For example, the Chair of NCVHS reports monthly to the Data Council and hears all issues it discusses. Fulfilling the mandate of HIPAA has required unusually close working relationships between Committee representatives and HHS implementation teams; but joint projects occur across the full NCVHS agenda. The projects described in the following summary are a kaleidoscope of joint efforts by Committee and Department entities.

Sometimes, of course, the Committee's advisory role calls for a more challenging stance toward Departmental policy. Notable examples are the longstanding campaign for a unified system of procedure coding and the recent effort to encourage a comprehensive approach to data on ''post-acute'' care. Both are described below.

The National Committee entered into a new, closer relationship with Congress in 1996, when, in reauthorizing NCVHS, Congress enlarged it from 16 to 18 members and declared that it would henceforth appoint two representatives. At the same time, HIPAA mandated an annual NCVHS report to Congress on progress in implementing the new law. The Committee has welcomed the heightened Congressional interest in its work and the opportunity to report directly to it.

Finally, the review of relationships would be incomplete without mention of the States. The NCVHS membership historically has included people with State health department expertise, and in setting and carrying out its agenda the Committee is attentive to the data needs of States and local communities. The issue has gained in importance as more and more Federal programs and funding streams have devolved to the States.

Major Activities and Accomplishments

Health Privacy and Confidentiality

NCVHS has long recognized that the information platform for health care and health policy must have as its cornerstone strong measures to protect individual privacy. Promoting the linkage between these two has been a major NCVHS commitment in recent years, but it is not new to the Committee's work. For example, its recommendations about uniform data sets emphasized privacy protection as a critical precondition.

The challenges to privacy, and thus to the Committee's work, became more pronounced with the enactment of HIPAA, as outgoing Chair Judith Miller Jones observed in a prophetic statement in her Foreword to the 1995 Annual Report:

> Congress has inadvertently made the work of the Committee more difficult by including administrative simplification in its recent reforms of the health insurance market without enacting confidentiality safeguards. In so doing, Congress has drawn heightened attention to these issues well before it appears ready to grapple with them. Having looked at these matters for many years now, the Committee would recommend, as always, that confidentiality safeguards already be in place as standardization efforts move forward.

Once charged by HIPAA with moving ahead on administrative simplification, the Committee accorded privacy protection greater salience by giving it full Subcommittee status for the first time. (Previously, there had been a privacy monitor.) That Subcommittee held 6 days of public hearings in 1997 and several roundtable discussions in 1998, serving as a forum for the spectrum of views on privacy and confidentiality issues in research, law enforcement, marketing, health services, and other activities. The Subcommittee worked closely with the Department's Privacy Advocate to develop the NCVHS and HHS recommendations on privacy and to monitor the response to them. As 1998 ended without passage of Federal privacy legislation, they began laying the groundwork for privacy regulations to be promulgated by the Department, as directed by HIPAA. The Committee is urging that sound legislation be passed in 1999, without further delay.

General Recommendations to the Secretary—The Committee issued a major report in June 1997, recommending that the Department and Administration assign a high priority to developing a strong position on health privacy. The report further recommended that the 105th Congress enact a health privacy law before the end of its 1998 session. Secretary Shalala echoed these recommendations in her September 1997 testimony to Congress. The Committee Chair testified before the House Ways and Means Committee on March 24, 1998, and the Committee continues to closely track proposed legislation.

Registries (1998)—The Subcommittee on Privacy and Confidentiality held a roundtable discussion on health and medical registries with participants from interest and advocacy groups, government, the for-profit and nonprofit organizations, the health care industry, the research community, and academia. On the basis of this discussion, the Committee recommended to the Secretary that health data be provided only to registries that conduct research, public health, and related activities. It also recommends that legislation should not undermine the flow of health information into or out of such registries.

Identifiability (1998)—A roundtable of people with backgrounds and viewpoints similar to those listed in the previous section also led to recommendations to the Secretary. They include the caveat that everyone who collects and uses health data should pay attention to and continually evaluate the likelihood that as technology develops, data once believed to be nonidentifiable may at some point lose that status. The recommendations state that institutional review boards, in particular, should be alerted to this issue.

Fraud and Abuse—The Subcommittee on Privacy and Confidentiality sponsored a roundtable discussion with industry investigators in mid-1998, beginning a study of the issue of balancing health data confidentiality and the need to investigate and control health care fraud and abuse. It plans to discuss the same issue with privacy advocates in early 1999.

Review of Health Information Privacy Model Act—In late 1998 the Subcommittee was briefed by the National Association of Insurance Commissioners about the organization's ''Health Information Privacy Model Act.'' Because of concerns about some of the model's provisions, the Subcommittee plans to develop recommendations for consideration by the full Committee in early 1999.

Population-based Health

The activities described below have been spearheaded by the Subcommittee on Populations (previous names: Population-Specific Issues and Populations at Risk). In the 1996 reorganization this Subcommittee was assigned the responsibilities of three NCVHS precursors: the Subcommittees on Mental Health Statistics, Disability and Long-Term Care Statistics, and Minority and Other Special Populations.

Through these groups, the Committee has undertaken many important initiatives in the past 3 years on such wide-ranging topics as race/ethnicity data, Medicaid managed care, ''post-acute'' care, and health statistics for the 21st century. The common denominator has been the search for better data on populations whose defining characteristic—such as age, income, health insurance status, disability, race or ethnicity—heightens their risk of experiencing poor health outcomes (for example, excess mortality), substandard care, inadequate access to services, or other negative responses from the health care system. The Subcommittee identifies priorities, strategies, and opportunities for gathering data and also works to ensure attention to these priorities by the full Committee and other bodies, including the Department.

Medicaid Managed Care—The Subcommittee's major focus in 1998 was studying the data implications of the large-scale shift of Medicaid beneficiaries into managed care. The Subcommittee was motivated by two chief concerns: that the continuity of information on

Medicaid beneficiaries was threatened by the limited data-collection practices of managed care organizations; and that data gaps would make it difficult to monitor the quality of care. In addition to holding five hearings—two of them during site visits to model State programs in Massachusetts and Arizona—the Subcommittee arranged for an investigation of State contracts with managed care organizations, with an eye to the data requirements. The findings of this contract study (that includes a followup with several States) will be part of the Subcommittee's report and recommendations, expected in mid-1999. The report also will analyze the uses of encounter data required by the Balanced Budget Agreement and summarize the site visits.

Race/Ethnicity Data (1996–98)—The review of Directive 15 (Racial and Ethnic Standards) by the Office of Management and Budget has been an ongoing interest of the Subcommittee, working closely with the HHS Office of Minority Health. The Subcommittee submitted comments on the report of the Interagency Committee for the Review of Directive 15 in 1997, endorsing its major recommendations but expressing reservations about some aspects. It offered assistance in developing guidelines for tabulation and other technical matters, and is monitoring the implementation of the revised Directive.

Islands and Territories (1998)—Representatives from the United States—associated insular areas (Puerto Rico, the Virgin Islands, and the United States-associated Pacific Islands) joined the Subcommittee for a 2-day discussion about these areas' health data, and information system needs. Representatives from HHS agencies and regional offices and the Departments of Interior and Energy also participated in the meeting, which featured not only information exchange but problem-solving strategies as well. A report and recommendations are expected in mid-1999.

Healthy People 2010 Data Issues—The ambitious *Healthy People 2010* goal of eliminating disparities among the U.S. population groups in their health status and access to prevention and care was endorsed by NCVHS in late 1998. The Committee's letter to the Department expresses this support and also recommends that a separate chapter on Information Systems and Data Needs be added to *Healthy People 2010*, under the direction of the HHS Data Council. In addition, it recommends the use of geocoding wherever feasible, within the bounds of confidentiality protections. The *Healthy People 2010* objectives necessitate data on a variety of sociodemographic characteristics related to health. The Committee initiated and is continuing to consider appropriate ways to collect these data so that they can be usefully linked with all health care and health data.

Care Across the Spectrum of Settings (1997–98)—A series of activities in this area began when the Subcommittee raised questions about HCFA's plan to mandate the use of the Outcome Assessment Information Set (OASIS) by home health agencies. It recommended that HCFA review all data collection initiatives concerning ''post-acute'' care, with the goal of having consistent data collection methods. The Subcommittees on Populations and on Standards and Security then met with HCFA to consider data requirements for ''post-acute'' care. NCVHS is seeking to work with HCFA and the Department to develop a coherent data policy that focuses on patients' attributes rather than specific features of settings of care. (In this regard, the Subcommittee recognizes the limitation of the terminology ''post-acute'' care. Much of this care is not generated by acute illness, and its characteristics embody continuity of care, often but not always of

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long-term duration, across a wide variety of settings in which health services are provided.) This will be a major focus of the Population Subcommittee in 1999.

21st Century Health Statistics Visioning and Planning Process (1997–98)—Supporting strategic planning and visioning in the Department is part of the Committee's role. A major effort of this kind was initiated by Dr. Edward Sondik, Director of the National Center for Health Statistics and Senior Advisor to the Secretary for Health Statistics. He sought the Committee's help in developing the 21st century vision for the U.S. health statistics as well as for the Center's work. The Subcommittee (which in 1998 created a Work Group/Project on Health Statistics for the 21st Century) will collaborate with NCHS and the HHS Data Council in developing the 21st century vision for health statistics, and will work with NCHS in specifying the 21st century vision for NCHS and designing the road map for NCHS to follow in implementing that vision. The Work Group is accomplishing this through several collaborative activities with NCHS, described under "Priorities for 1999 and Beyond."

Quality Agenda—Staff of the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry met twice with the Committee in early 1998. Subsequently, the Committee sent letters commenting on the Commission's reports, commending the group for its work and noting complementary NCVHS activities. NCVHS expects to stay in touch with the new organizations created to carry out the recommendations of the President's Commission. In March 1998 the full Committee convened an expert panel on the quality of data needed to assess quality of care. The Workgroup on Quality was created later, as part of the Subcommittee on Populations, to coordinate work on this subject of longstanding interest to the Committee. The Workgroup will focus initially on data on the quality of "post-acute" care and of managed care for Medicaid beneficiaries, as part of larger efforts by the Subcommittee. One of the issues it highlighted at the outset is the shortage of data analysts to mine the data that are available.

Standards

As noted, NCVHS has been an advocate of standardization for nearly 30 years, doing much of the complex detail work to realize this objective in slow, incremental steps. The HIPAA mandate, which came on the heels of the core data elements recommendations, shifted the Committee's focus from governmental programs to all health programs across the nation, and, for the time being, from content to electronic transactions.

The Committee sees the essential goals of administrative simplification as making it easier for providers to serve their patients and enabling the industry to conduct administrative and financial transactions more efficiently and cost-effectively. Pursuing these goals has involved close work with several industry standards development organizations, which took the lead in this area. NCVHS developed its recommendations on proposed Federal rules following consultations with industry. These recommendations were reflected in the HHS Notices of Proposed Rule Making (NPRM).

The Committee also has supported outreach to the public health and health services research communities, to ensure that they understand the implications of HIPAA for them

and are present at the table as decisions are being made. A November 1998 workshop on this subject affirmed the potential benefits of administrative simplification for public health and research purposes and the need for these sectors to be part of the development process. Multiple speeches by Committee members and the Chair have helped fill a communications gap in this area.

Core Data Elements Report and Followup—In 1996 the Committee concluded a major 2-year project, requested by the Department, to evaluate common core health data sets for enrollment and health care encounters. A central purpose was to promote consensus about health data content by identifying areas of agreement on core elements and definitions. This project is described in the 45-year history as "the latest stage of the 25-year effort to generate standardized health care information." It involved an extensive survey of the health field about data-collection practices, together with interaction with HCFA and other bodies also working on core data sets.

The bulk of the project focused on ambulatory and hospital settings, but NCVHS Subcommittees also developed recommendations for long-term care data elements, including mental health. The 50-page final report specifies 42 data elements that it proposes for standardization. Of these, it calls special attention to six for which "no consensus currently exists concerning appropriate or feasible definitions"— namely, personal unique identifier, self-reported health status, functional status, type of encounter, current or most recent occupation and industry, and patient's stated reasons for visit or chief complaint. The Committee urged the Department to give high priority to further development of these elements. Monitoring the implementation of these recommendations, particularly those requiring research and evaluation, remains on the work plan for 1999.

Community Assessment Recommendations—The Standards Subcommittee took on the portfolio of the Subcommittee on State and Community Health Statistics in the 1996 reorganization. As part of the ongoing campaign to strengthen State and local health statistics, the following year the full Committee approved recommendations concerning community health assessment and the respective roles of State health agencies and the Federal Government in facilitating the assessment process. This report was sent not only to the Secretary but also to the Association of State and Territorial Health Officials and the National Association of County and City Health Officials for their consideration.

Administrative Simplification—The Committee is now at the approximate midpoint of a 5-year set of HIPAA-mandated responsibilities to advise the Department on health data standards in the following areas: 10 administrative and financial transactions, including claims attachments; identifiers for payers, providers, employers, and individuals; code sets and classification systems; security safeguards; electronic signatures; privacy; and the electronic medical record.

The Committee's activities and accomplishments in this area are described in detail in the 1997 and 1998 *Annual Report[s] to Congress on the Implementation of the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act*.

To briefly summarize, the Subcommittee on Standards and Security (previously named the Subcommittee on Health Data Needs, Standards and Security) held some 20 hearings,

offered recommendations to the Department on the development of Notices of Proposed Rule Making (NPRM's), and provided comments on the published NPRM. The Standards Subcommittee is working closely with HHS implementation teams on this effort. The nature of the comments on NPRM is seen as confirmation that the Department's process was, in the words of the 1997 report on HIPAA, "extremely open, collaborative and productive."

More specifically, the Committee submitted recommendations to the Department on message standards for the administrative and financial transactions specified by HIPAA and on diagnosis and procedure coding used in these transactions. It also recommended a set of principles for technical security because standards in this area are not fully mature, and it submitted recommendations on identifiers for providers and plans. The Committee subsequently offered comments on the proposed rules for standards for electronic transactions and code sets, national provider identifier, and security and electronic signatures, which were published as NPRM in mid-1998. It has deferred substantive recommendations on claims attachments pending testing of the proposed transaction standard. The Committee's related activities and recommendations in the privacy area are outlined above.

Unique Health Identifier for Individuals—The Committee has spoken out for many years on the need for a unique health identifier, while also stressing that security and confidentiality protections are a precondition. The 1996 core data elements recommendations, developed before the passage of HIPAA, state that "agreement on a unique personal identifier has been recognized as a key element to the successful establishment of core data elements and their use." The recommendations advise the Department to "support the formation of a public-private working group to conduct research and provide recommendations in this area."[4] In the course of developing these recommendations, the Committee took testimony on the benefits, costs, and risks of adopting a unique identifier for individuals.

This issue took on greater urgency when HIPAA imposed a timetable on the Department for deciding on a unique identifier, in consultation with the Committee. Since then, it has commanded a great deal of attention and care by the full Committee and two of its Subcommittees (Standards and Privacy), due both to its complexity and to public concerns about real or perceived threats to confidentiality. NCVHS launched its heightened advisory role in this area by commissioning a white-paper analysis of options for the identifier. Then in 1997, with no privacy legislation in sight, it took the unusual step of declining to comply with a HIPAA directive, recommending to the Secretary that it was premature to select a unique health identifier for individuals until security and confidentiality issues are resolved by Congress. The Committee hosted a public hearing on the individual health identifier in mid-1998.

NCVHS is proceeding carefully on the unique health identifier for individuals, guided by its long-held belief that such an identifier, while important, should not be implemented until strict confidentiality and privacy protections are in place. No consensus has yet emerged within the Committee about how to proceed on this matter.

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[4]Quotation is on page 3; also see discussion on page 17.

Computer-based Patient Records—Since the early 1990's, the Committee has asked for regular briefings by such groups as the Computer-based Patient Record Institute and the Medical Records Institute on progress toward the computer-based patient record (CPR). NCVHS created its own CPR Workgroup in 1998 to develop HIPAA-mandated recommendations and legislative proposals on uniform data standards for patient medical record information and its electronic exchange. The group held its first hearing in December 1998, aimed at helping it develop its work plan. Recommendations from NCVHS to the Department and Congress are due by August 2000.

Coding and Classification—NCVHS has been regularly briefed by NCHS and HCFA representatives (including the cochairs of ICD–9–CM Coordination and Maintenance Committee) about the transition from ICD–9 to ICD–10 for mortality coding, and about the development and testing of the clinical modification for diagnostic coding (ICD–10–CM) and a new procedure classification system (ICD–10–PCS) to replace ICD–9–CM, Vol. 3. In addition, the American Medical Association has briefed it on CPT. In 1997 the Committee recommended the continued use of current code sets for diagnosis and procedure coding until replacements are ready (2001 or thereafter). It recommended that the Department advise industry to build and modify their information systems to accommodate a change to ICD–10–CM diagnostic coding in the year 2001. It also recommended a major change by the year 2002 or 2003 to a unified approach to coding procedures, yet to be defined. The Committee has for years been planting seeds for a single procedure classification system; these seeds still are expected eventually to bear fruit.

Concept Paper and Recommendations on the National Health Information Infrastructure

After completing the first round of HIPAA-mandated tasks in late 1997, the Committee turned its attention to its broad mandate to advise on information policy. Many members were eager to define a leadership role for the Department in correcting the imbalance in the national information infrastructure between health and other sectors. With encouragement from the Data Council, the Chair led NCVHS members through an exercise in identifying the essential components of the health information infrastructure—"the technologies, standards and applications that support communication and information" in the health arena—and clarifying the tasks needed to strengthen them.

Perhaps the most challenging aspect of the Committee's effort was applying its customary population-based perspective to an arena that has tended to be more narrowly defined. This means addressing important questions about equity, in terms of both members of the population who are currently outside the "health care system" and those with little or no access to information technology. The final concept paper, which is published at the end of this Report, was well received by the Data Council when it was presented in October 1998.

The paper outlines four key roles for the Committee in promoting this agenda: facilitating dialogue and collaboration; providing expert advice; providing general oversight, especially on the impacts on privacy, accessibility, and disparities; and supporting progress toward national health privacy legislation. The new Workgroup on the National Health

Information Infrastructure (a special project of the Executive Subcommittee) and the Data Council are developing a plan based on the concept paper. A first step is a Departmental inventory of the relevant activities already underway.

Education and Awareness Issues

The Committee has long recognized the importance of educating the public, media, and Congress on health information and statistics. In 1997 it faced up to its own limited resources and expertise and reluctantly decided that it could not mount a national public awareness campaign. However, the need for more education became apparent as time went on. NCVHS has supported the Department's efforts to inform and alert the industry to the implications of HIPAA, including outreach to the public health and health services research communities. But another urgent issue has become clear: that the public, media, and Congress cannot properly evaluate where the public interest lies regarding the uses of health data unless they are far better educated about the purpose and functions of vital and health statistics. Thus, the Committee enters 1999 with new questions about how understanding of these critical issues can be enhanced.

The Committee and Department have worked diligently on the excellent NCVHS Web site (ncvhs.hhs.gov). It is actively contacted, with more than 76,000 hits in the last 5 months of 1998.

Priorities for 1999 and Beyond

The National Committee reaches a significant milestone in 1999 with the observance of its 50th birthday. This is a time for looking backward and forward. Most of the Committee's 1998 activities remain on its agenda in some form in 1999—some moving from the periphery to the center of attention, and others receding to a monitoring status. The 1999 work plans of the full Committee and all subcommittees and work groups are posted on the NCVHS Web site. A few of the main interests are listed below.

The Subcommittee on Populations will develop and release its reports on Medicaid managed care and health data in the islands and territories. It will conduct a major study of the continuum of care, and it will continue to monitor race/ethnicity classification and reporting issues, the status of core data elements recommendations, and development of *Healthy People 2010.*

> **The Workgroup on Quality** will develop recommendations in four areas: quality of care in the Medicaid Managed Care report; quality of care issues concerning the continuum of care; data issues for quality of care related to the recommendations of the President's Commission on Quality; and data needs for quality improvement.

> **The Workgroup and Project on Health Statistics for the 21st Century** will advance the project described above through the following activities:
> (a) convening expert groups to identify key 21st century issues in health,

health care, and technology and their implications for health statistics, and also to define health statistics and its purposes, roles, and boundaries; and (b) commissioning papers identifying strengths of existing health statistics systems, alternative systems, and unmet health statistics needs. The products of these activities will be provided to the Committee on National Statistics of the National Academy of Sciences for its consideration in organizing a workshop on this subject. The Workgroup also will work with NCHS and the HHS Data Council on soliciting broad public and professional input on key health statistics needs.

The Subcommittee on Privacy and Confidentiality will continue its study of fraud and abuse control and begin review of the use of health data by employers and for pharmaceutical marketing. It will continue to monitor proposed privacy legislation and to advise the Department on the development of privacy regulations.

The Subcommittee on Standards and Security will monitor comments on the HIPAA-mandated NPRM already released and work with HHS implementation teams on new NPRM's.

> **The Workgroup on Computer-based Patient Records** will lay the groundwork for future recommendations on the CPR.

Under the auspices of the Executive Subcommittee, **the Workgroup on the National Health Information Infrastructure** will collaborate with the HHS Data Council in several projects stemming from the NCVHS concept paper ("Assuring a Health Dimension for the National Information Infrastructure").

This report was prepared by Susan Baird Kanaan, M.S.W.

Assuring a Health Dimension for the National Information Infrastructure

With the Health Insurance Portability and Accountability Act (HIPAA) of 1996, Congress essentially transformed the nearly fifty-year-old National Committee on Vital and Health Statistics (NCVHS) into the nation's primary external advisory group for health information policy. While in the past, NCVHS was responsible for making recommendations only to the government, the HIPAA legislation mandated a number of national health data standards to encompass both the government and the private sector. The Committee has worked for two years on specific HIPAA policy mandates. It is now evident that the Department of Health and Human Services (HHS) needs to craft a comprehensive approach to health information policy to guide development of the nation's information capacities for optimal use in improving the health status of all Americans. NCVHS is committed to helping the Department address this important policy matter. This paper is intended for HHS, through the HHS Data Council, as a preliminary description of opportunities and challenges in this area.

The national information infrastructure (NII) can be an essential tool and resource in promoting the nation's health. However, it is a largely untapped resource. The health sector has not applied information and communication technologies as effectively as have other sectors, and health is under represented in the NII relative to the scale of the national health enterprise and its importance to the American public. Making the health component congruent with the NII and an integral part of its development requires two concurrent processes: building the health information infrastructure (HII), and integrating it into the broader national information infrastructure.

It is important to emphasize that neither ''NII'' nor ''HII'' refers to a database but to a set of technologies, standards and applications that support communication and information. It encompasses all aspects relating to health, computers, and telecommunications. (''Telehealth'' is now the accepted umbrella term for the full spectrum of applications using computers and telecommunications for health. The Secretary of DHHS officially endorsed it over 18 months ago, and the FCC has also adopted it.) Many, possibly most, of these technologies are common across sectors or share common elements. As the linkages between the NII and the HII are strengthened, solutions developed in other sectors, such as security measures, will emerge that can be adapted to solving problems in the health arena. The information content of an eventual HII will be diverse, reflecting an array of purposes such as improving clinical care, monitoring public health, and educating consumers and patients. While clinical encounter data will be a core component of the HII, data from population surveys and other information about the determinants of health will also be important. Multiple stakeholders will have a role to play in its development and maintenance, including public agencies, health care and research

institutions, professional and standards organizations, consumer organizations, and the telecommunications and computer industries.

A great deal of work is already underway on the health dimension of the NII. However, these activities are fragmented and in some cases serve limited interests. Because of its diverse responsibilities as policy maker, payor, regulator, and generator of information to all audiences, HHS is the most appropriate body in the federal government to mobilize efforts to consolidate and augment these advances and move the health information infrastructure to the next stage. The National Committee on Vital and Health Statistics therefore proposes that the Department, working through the Data Council, assume a leadership role in developing 1) a detailed vision for the health dimension of the NII, and 2) a strategy for realizing that vision in partnership with other stakeholders in government and the private sector. We offer our support and assistance in this effort. We note, moreover, that comprehensive approaches to national health information infrastructures have been developed in other countries, including Canada, the European Union, and the United Kingdom. They reflect similar visions of an information strategy to enable professionals and the public to make informed decisions about health and health services.

This document provides an overview of the areas that must be part of such a strategy, with comments on specific developments the Committee believes to be necessary. The process should begin with a complete inventory of the issues, progress to date, and major players in each of these areas. Additional areas may emerge during the inventory process.

Attention to Both Benefits and Risks

Clearly, the use of information and communication technologies for health purposes has potential risks as well as benefits, and opinions vary about the relative balance between the two. NCVHS believes that while this balance must be carefully watched, the technologies have decidedly positive applications for health. We envision that increased use of information and communication technology can favorably and dramatically impact upon access, quality and the cost of care by informing treatment decisions, extending service delivery, monitoring health, empowering consumers, facilitating communication between patients and providers, and generating knowledge for clinical care and public health. Finally, such systems can identify and track disparities between groups so that they can be eliminated through action where possible and appropriate. Computerization is already beginning to streamline administrative processes and reduce costs. Each of these developments (which are discussed in more detail below) has the potential to contribute to improved health outcomes, greater cost-effectiveness, and increased satisfaction.

The sensible application of information technology to the health of Americans will only occur if the public is assured that people's health records or other personal health information will not be used to harm them, and that individual privacy will not be abused. The Committee has identified this as a real concern in its hearings and reports relating to privacy and confidentiality as well as the unique personal identifier. NCVHS is on record as supporting a policy of not moving forward to implement any form of unique personal health identifier until federal protections of personal health information are enacted into law. The Committee is pleased that the Administration has announced its decision not to implement a unique personal health identifier until appropriate privacy protections are in place.

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Unless real progress is made in addressing privacy issues legislatively, new health information systems and linkages could exacerbate the existing lack of protections for patients and consequent threats to privacy. For this reason, NCVHS has strongly recommended that the administration assign the highest priority to health privacy policy, and that Congress enact a health privacy law as soon as possible. Legislation is also needed to assure that citizens will not have their personal health information used against them in the context of health care or employment. This means that anti-discrimination legislation is a key component to health information policy reforms relating to privacy, confidentiality, and security. In addition to overarching national confidentiality legislation, each of the technologies and activities listed below must limit data collection and exchange solely to necessary and appropriate uses, and must follow strong security policy and procedural measures.

Another serious risk is associated with the development of information and communication technologies: greater dependence on technology could widen the gap between haves and have-nots in this country. There are already significant differences in access to quality health care among various segments of the population. Some Americans could be put at an even greater disadvantage unless there is a concerted effort to reduce barriers to communication and information technology such as costs of equipment and service and limited health/technology literacy. For this reason, NCVHS recommends that the administration assign high priority to developing and implementing policies to facilitate access to communication and information technologies for all Americans.

While the benefits of the health care information infrastructure generally outweigh the costs and risks, there may be a few situations where the cost burden to invest in automation deserves special consideration. These circumstances might occur in some solo practices or health care settings in rural or isolated areas. It may be in the government's interest to use such actions as tax incentives and enhanced payments to ensure that savings will actually accrue to all health care providers. For those special cases that need help, government assistance should be considered to enable the transition to the health information infrastructure.

An important role for the federal government, therefore, is to support research and strategic planning to determine how to minimize the risks for privacy and address other issues, and to ensure that all Americans will benefit from the NII. The promise of the HII will only be met if there is equitable access for both health care providers and the public. One of the roles NCVHS will assume is monitoring the health component of the NII in the light of these concerns.

Tasks for the Health Information Infrastructure

There is work to be done in each of the following systems, technologies and applications, which together comprise the health information infrastructure (HII).

Population-based data. The health information infrastructure must include population-based data so that public health can be supported at the community, State, and national level. Among other things, this necessitates major improvements in data on populations at special risk, such as people with disabilities and certain racial and ethnic minorities, and

groups that may be too small to register on the radar of existing surveys such as the National Health Interview Survey. Strengthening the population dimension of the infrastructure will make it possible to identify and analyze disparities in health status and care and to track progress on eliminating the gaps. It is at this level that population-based health information can be integrated with data from the other sectors essential to the well-being of the population, including education, business, welfare, housing, justice, and environmental health.

Within the context of rigorous protections for privacy and the confidentiality of personal health information, HIPAA has the potential for introducing major and exciting innovations to population-based data on the health of the American population. The health data reforms enabled by HIPAA could result in the following future benefits: population-based data could be constructed for a wide range of encounters with the health care system in the United States; population-based encounter data on small and difficult to sample populations could become available and offer relevant information regarding interventions in a sufficiently timely manner to evaluate effectiveness; some population-based encounter data could be integrated with population-based survey and public health surveillance data on health status and health outcomes. In time it might be possible to construct population-based health and encounter histories. With a well reasoned HII strategy, the nation should be able to transform its knowledge of the health of the American people and move to optimize the health of individuals and communities through more effective interventions such as targeted educational programs, community services, and evidence-based health care services. Greater knowledge of the population's health and health care services will facilitate both population-based public health and clinical approaches to improve health.

Computer-based health records. Computer-based information on health care and health status can facilitate coordination, research and assessment for both clinical care and public health and permit individuals to participate more closely in their own health care. The nation needs to significantly improve the development and diffusion of computer-based health records (CHRs) of three types: patient, personal, and population. Patient CHRs record clinical care and are used by delivery systems in which doctors, nurses and other health professionals provide an array of hospital, primary care, and other ambulatory and institutional health services. Institutionally focused systems are under rapid development and approaching maturity, but are not widely available. Those focused on the ambulatory setting are much less well developed and in use. Personal CHRs are personal health records for individual use, including assessment of health status and linkage with physicians' records. Some refer to these as consumer-oriented health records. Systems of both types also will facilitate the coordinated management of personal health by the variety of professionals involved in personal health care. The integration of clinical CHRs and personal CHRs could further contribute to continuity of care and informed self-management. The data in population CHRs derive from the health care system and have been made as non-identifiable as possible for public health and research applications. They may also incorporate survey data. Population CHRs are used for monitoring public health and the outcomes of care and also for health services research, including quality assessment.

Integration of data from these three types of CHRs, and especially integration of data from patient CHRs and population CHRs, has the potential to greatly improve our understanding of health needs, health barriers, and health services utilization of the American people. To strengthen these systems, however, they should be driven by patient care and health status, not reimbursement.

Computer-based Health Records Representative Samples of Content		
Personal	**Patient**	**Population**
• Family history • Focussed longitudinal records (e.g., immunizations) • Health maintenance advice • Specific health education • Specific disease manangement	• Medical records (patient care data) • Compliance data • Outcomes data • Records of E-mail to primary care provider and specialists • Scheduling	• Non-identifiable data on care • Primarily non-identifiable data on behaviors, monitoring, risk assessment • Spending

Knowledge management and decision support. The rapid growth of the health knowledge base poses great challenges for both health professionals and the public. Its huge and varied content includes findings from biomedical and health services research, public health data, technology innovations, and policy/legal developments. This knowledge, along with less technical information, is increasingly distributed on the World-Wide Web with potentially universal access and open distribution. These developments warrant action to better serve both professionals and the public.

First, research and development on knowledge management and decision support systems are vital to support the movement toward evidence-based care, cost effectiveness, and quality enhancement. Such systems, especially those available at the point of care, can help clinicians choose evidence-based interventions that are associated with the best health outcomes. While closed systems have been under development for a long time, further attention should be focused on the potential of Internet-based delivery of evidence relating to best health outcomes and also on barriers to acceptance and implementation of that evidence.

Second, the virtual explosion of consumer/patient oriented Web sites and applications, many commercially sponsored, calls for a careful assessment of the roles of the public and private sector in promoting quality and accuracy. Concerns about ''misinformation'' have prompted both the public and private sectors to explore information quality standards, and a consensus on core elements seems to be emerging. The Department is already engaged in these discussions and providing leadership through its own Web sites. Public policy must weigh the risks of inaccurate or fraudulent information against the benefits of public education and the strong demand for such resources, and also consider First Amendment issues. Clearly there is an opportunity for enhanced levels of professional review and assessment of consumer/patient oriented Web sites and applications, particularly for information quality and decision logic. Professionals and ordinary citizens will benefit

from access to a continually updated repository of current knowledge that meets "best evidence" criteria for accuracy and reliability. Some repositories should be linked with consumer input about preferences and satisfaction.

Telemedicine. Telemedicine (care at a distance) can extend the reach of health professionals to remote sites. With proper review and management, integrated clinical and consumer applications can link prevention, health promotion, patient education, and beneficiary/patient services as well as distance care itself. Telemedicine can support the movement toward outpatient and home-based care, foster economically feasible service delivery, and promote the goal of universally accessible health care. The extension of telemedicine services in rural or underserved urban areas has the potential to improve the health of homebound chronically ill and frail elderly persons whose mobility is limited by illness, transportation costs, or other factors. In this area, as in others, it will be important to monitor access to ensure that technology is being used to narrow rather than widen the gap between the haves and have-nots in our nation.

Enabling Cross-Cutting Processes

In addition to protection from unwarranted invasions of privacy and from discrimination, which are discussed above, several other cross-cutting processes are essential to progress in the above domains:

Standards and measures. The standards development process needs to be guided by criteria for prospective standards. Sometimes referred to as "standards for standards," these criteria would facilitate interoperability so that systems can serve multiple functions or at least talk to each other, as in cross-cutting public health and clinical uses. The criteria would be useful when approaching such policy decisions as unique patient identification and the use of "smart cards" for access to services and would help in resolving confidentiality issues and developing appropriate security procedures and technology.

A high priority is the development of standards and nomenclature for capturing the state of knowledge in medicine and health care. Standards of terminology must be developed, maintained, and made accessible at minimal cost to users. These forms of standardization are critical to the linkages and comparisons needed to assess both the quality of care and the health status of the population. The Unified Medical Language System of the National Library of Medicine is a good start for this process, but it is not sufficiently encompassing. In addition to a robust "server" to allow those needing the terms to have access to them on a low-cost basis, a clearer system is needed to constantly review definitions, reach consensus, and then integrate the new terms to older closest synonyms. Clinical records need to reflect primarily clinical realities and not focus on financial and billing procedures and terms. Care will be most easily delivered in a cost-effective and high quality manner if the language used for care delivery and a variety of management purposes most accurately reflects medical conditions and treatments.

Research, education and development. For health information technology to realize its potential, more research, education and development are needed, both within and beyond academic health centers and in other private sector entities, including commercial settings. Agreement on a comprehensive research agenda, with roles for various sectors, would help maximize efforts. Information technology should be an integral part of clinical

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research and professional expertise, a goal that necessitates substantial support for robust information systems and attention to the culture in which the technology is introduced. To address all health care needs, research also must move further to involve patients and practitioners beyond academia as both informed contributors to and consumers of research efforts. Research and education will have key roles in assuring that all Americans have the opportunity to benefit from the HII. Support for basic research is needed as well as for applied research. It should be remembered that most of what we now refer to as the information age had its origins more than two decades ago. The pace of basic research has not kept up, particularly in areas where cross-cutting breakthroughs are needed, including non-technical topics such as cultural and behavioral issues relating to acceptance and optimum use of technology by individuals and institutions.

Universal access to health information resources. Recent telecommunications reforms promise to make Internet access more affordable for rural health care providers, rural public health agencies, schools, and libraries. But they fall short in ensuring universal access because they only support certain costs for these institutions and do nothing to promote Internet connections to homes and the workplace. To make possible two-way communication and realize the full potential of telehealth, every American should have access to the Internet and intranets at home, at work, and/or in public places such as libraries and community centers. As noted above, telecommunications contact with health care providers permits patients to receive from these providers some forms of care and health status monitoring, as well as education, in their homes. In addition, access to health information resources helps consumers fulfill their responsibilities for self-education and self-care and understand how they can exercise their right to choose their health plans, providers, and care.

International collaboration. The United States is a member of a global society, and we must play an integrative and collaborative role with other countries. Moreover, the United States can learn much from other nations that have taken the lead in some aspects of communications technology. Threats to health, such as emerging diseases and environmental hazards, do not stop at national borders; international collaboration is critical in order to integrate surveillance and warning systems. For all of these reasons, we must ensure that national activities and policies make good sense within the context of a global society. We must promote advancements in the international information infrastructure both through government and private development initiatives and carry our fair share of the effort to create it.

Recommendations for the Federal Government and the NCVHS Role

Building the health information infrastructure and integrating it in the NII[5] will require an aggressive review of federal policies and procedures as well as a major commitment of

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[5]The Information Infrastructure Task Force defined the National Information Infrastructure (NII) as the facilities and services that enable efficient creation and diffusion of useful information. In Putting the Information Infrastructure to Work: Report of the Information Infrastructure Task Force Committee on Applications and Technology. U.S. Department of Commerce, National Institute of Standards and Technology, NIST Special Publication 837, Washington, D.C., 1994. http://nii.nist.gov/pubs/sp857/cover.html

resources from federal and state governments and the private sector. The private sector has been responsible for much of the progress to date in the health information area and in the NII as a whole, and certainly future progress depends on strong private-public partnerships.

As the first step in the process, we suggest that the Data Council determine where multiple agencies can and should coordinate their efforts and where new structures would be more efficient. Achieving sufficient visibility and assuring progress on this crucial national objective may require the appointment of an individual to assure action and monitor progress from within the Secretary's office or at the White House.

Diverse political leadership has supported the development of the NII and the concomitant HII. Vice President Gore has shown important leadership in promoting the development of the NII and in stressing that everyone must have a chance to benefit from it. He has cited the need to bring the economic, health, and educational benefits of the information revolution to all and challenged the country to connect every classroom, library, hospital and clinic to the NII by the year 2000. We welcome the Vice President's strong statements in May and July 1998 about the need for attendant health information privacy protections, and Secretary Shalala's 1997 testimony to Congress on this subject. House Speaker Gingrich has expressed similar goals in a number of pronouncements.

The Committee is ready to respond to requests from the Department to support the leadership of the Data Council in furthering the objectives outlined above. Fortunately, there is already a strong base on which to build. Department staff and members of NCVHS subcommittees and workgroups are already engaged in areas such as standards and security, computer-based patient records, privacy and confidentiality, populations, quality, and health statistics for the 21st Century. These efforts, together with work elsewhere in the Department on the public health information infrastructure, knowledge management, decision-support, consumer health information, and telemedicine can provide core components for an integrated and comprehensive strategy.

Generally, we see our role in terms of four types of activity:
1. Facilitating private-public dialogue and collaboration;
2. Providing expert advice on specific areas such as population-based data, population-specific issues, privacy and confidentiality, and standards and measures;
3. Providing general oversight, and in particular monitoring the impact of the HII on privacy, accessibility, and the disparities between populations; and
4. Supporting progress toward national health privacy legislation.

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NCVHS Workgroup on National Health Information Infrastructure

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Appendix I.
National Committee on Vital and Health Statistics Reports and Recommendations

The most recent reports and recommendations are listed first.

- December 7, 1998, *Letter to the Surgeon General* on "Healthy People 2010 Objectives."
- October 8, 1998, *Letter to the Secretary* transmitting paper, *Assuring A Health Dimension for the National Information Infrastructure.*
- September 23, 1998, *Letter to the Secretary* with recommendations on the use of the SLAITS Survey.
- September 16, 1998, *Comments* on the August 12, 1998, NPRM on Security and Electronic Signature Standards.
- September 16, 1998, *Comments* on the applicability of the Paperwork Reduction Act (PRA) regarding the August 12, 1998, NPRM on Security and Electronic Signature Standards.
- August 31, 1998, *Letter to Secretaries of HHS and Labor* on *Quality First: Better Health Care for All Americans*, final report of the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry.
- August 27, 1998, *Letter to Robert Moore*, former HCFA liaison to the NCVHS.
- August 27, 1998, *Letter to George H. Van Amburg*, former member of the NCVHS.
- June 23, 1998, *Responses to Congressional Questions* received during testimony on Health Information Privacy, March 24, 1998.
- June 23, 1998, *Letter to the Secretary* with findings of the Subcommittee on Privacy and Confidentiality Concerning Identifiability of Health Information and Confidentiality Considerations for Health Registries.
- June 17, 1998, *Comments* on the May 7, 1998, NPRM on National Standard Health Care Provider Identifier.
- June 17, 1998, *Comments* on the applicability of the Paperwork Reduction Act (PRA) regarding the May 7, 1998, NPRM on National Standard Health Care Provider Identifier.
- June 17, 1998, *Comments* on the May 7, 1998, NPRM on National Standards for Electronic Transactions.
- June 17, 1998, *Comments* on the applicability of the Paperwork Reduction Act (PRA) regarding the May 7, 1998, NPRM on National Standards for Electronic Transactions.
- March 10, 1998, *Letter to Secretaries of HHS and Labor* on the Consumer Bill of Rights and Responsibilities.
- February 3, 1998, *First Annual Report to Congress on Implementation of Administrative Simplification.*

- November 24, 1997, *Analysis of Unique Patient Identifier Options*—Report prepared for the NCVHS.
- September 9, 1997, *Letter to the Secretary* with recommendations on security standards to Protect Health Care Information.
- September 9, 1997, *Letter to the Secretary* with recommendations on the standard for a Unique Identifier for Health Plans.
- September 9, 1997, *Letter to the Secretary* with recommendations on the Standard for a Unique Identifier for Individuals for Use in the Health Care System.
- July 3, 1997, *Letter to the HHS Data Council* on the Outcome Assessment Information Set (OAIS) Data Collection Tool.
- July 2, 1997, *Letter to the Secretary* with *Recommendations on Community Health Assessment*.
- June 27, 1997, *Letter to the Secretary* with *Recommendations on Health Privacy and Confidentiality*.
- June 25, 1997, *Letter to the Secretary* with recommendations on standards for Administrative Transaction Messages and Data Content.
- June 25, 1997, *Letter to the Secretary* with recommendations on the standard for a National Provider Identifier.
- August 1996, *Core Health Data Elements Report*.

Appendix II.
Thoughts on the Functions and Form of the National Committee on Vital and Health Statistics

Kathryn Coltin and Lisa Iezzoni
February 18, 1996

Our purpose here is to sketch thoughts on the functions of the National Committee on Vital and Health Statistics (NCVHS) and to suggest how the form or structure of NCVHS might be tailored to best perform these functions in the future. We are motivated by imminent changes in the leadership and membership of the Committee and by a sense that now is a good time to reexamine the way NCVHS identifies its goals and conducts its work.

We focus on a **conceptualization** of the NCVHS' goals, rather than on current, concrete tasks (for example, the core data element project) or specific content areas that NCVHS could address in the future. We intend that this document serve as a vehicle for discussion. **We hope that our suggestions will provoke debate, resulting in counterproposals or alternative formulations that move us all forward**.

Functions of the National Committee on Vital and Health Statistics

As stated in the charge to the Committee, NCVHS has various roles, including monitoring the health of the nation and identifying information needs to perform this role; promoting the availability of data on health and health care services that can be used productively (for example, standard definitions and consistent formats); and encouraging movement toward data systems that address multiple information needs.

Drawing from this charge, we propose a conceptual formulation of the NCVHS functions that suggests specific tasks required of NCVHS; a subcommittee structure to accomplish these tasks; and the types of expertise represented by the NCVHS members. This formulation also suggests where the interest in ''standards'' fits vis a´ vis the focus on questions relating to health and specific populations.

As shown in figure 1, this formulation unfolds as does an old-fashioned camera, starting at the top with the ''viewfinder'' through which the customer or user of information (in this analogy, the ''photographer'') poses questions about the health and health care of the American people (level A). These questions are increasingly focused and the inputs required to produce the picture are disaggregated (for example, separated into the component parts required to actually produce the picture, such as specific data elements and codes) over succeeding levels. Finally, the ''lens'' of data transmission formats and standards (level H), translates the necessary data into a recognizable ''image'' or information, which is meaningfully transmitted to the photographer.

> *The final level (H, data transmission formats and standards) cannot be considered without addressing each of the preceding levels. Otherwise, the camera is unaimed and may transmit useless images to the user. In other*

words, consideration of data elements and technical standards alone is inappropriate unless they relate to specific questions about the health or health care services of the American people.

The first four levels of the camera relate to information and health policy and setting priorities about populations, services, and outcomes. Given the role of NCVHS in advising the Secretary of DHHS, the policy context within which the Committee functions will be largely determined outside the Committee, but ways of addressing these policy areas and ordering of specific Committee priorities should receive substantial NCVHS input. The last four levels involve setting standards, ranging from specifying the data elements required to produce information about persons, populations, and events and definitions of these data elements (level E) to establishing electronic transmission standards (level H).

A. Questions about the health and health care of the American people

B. Populations of particular interest and specific questions about these populations

Information policy

C. Events of interest across populations and within specific populations; events include both person-level clinical and functional outcomes and specific health care interventions

D. Information required to identify individuals, populations, and events

Standards

E. Data elements required to produce this information and definitions of these data elements

F. Sources for the data elements: individuals (e.g., patients) and administrative records

G. Ways of classifying and coding the data elements

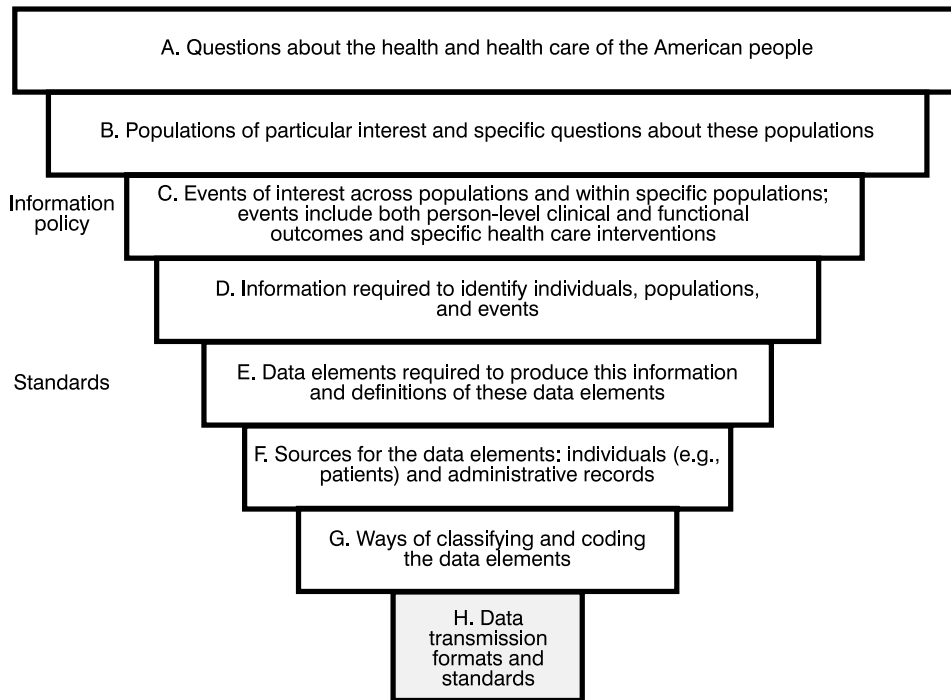H. Data transmission formats and standards

Figure. Schematic representing functions of the National Committee on Vital and Health Statistics: An old-fashioned camera, increasingly focusing on the image of interest

Appendix III.
National Committee on Vital and
Health Statistics Subcommittee and
Workgroup Structure

The NCVHS working structure consists of an Executive Subcommittee and three subcommittees that have been created to do substantive work in their respective areas. Subcommittee and Workgroup charters, work plans, meeting schedules, agendas, and work products as they are completed are all posted on the NCVHS Web site. The Committee adopted the following structure and leadership in June 1998:

- Subcommittee on Standards and Security
  Chair: Simon P. Cohn, M.D. (4/99)
  - Workgroup on Computer-based Patient Records
    Chair: Jeffrey S. Blair, M.B.A.
- Subcommittee on Privacy and Confidentiality
  Chair: Kathleen A. Frawley, J.D.
- Subcommittee on Populations
  Chair: Lisa I. Iezzoni, M.D.
  - Workgroup/Project on Health Statistics for the 21st Century
    Chair: Daniel J. Friedman, Ph.D.
  - Workgroup on Quality
    Chair: Kathryn L. Coltin, M.P.H.
- Executive Subcommittee (planning and implementation)
  Chair: John R. Lumpkin, M.D. (4/99)
  - Workgroup on National Health Information Infrastructure
    Chair: John R. Lumpkin, M.D. (4/99)

Evolution of Subcommittees and Workgroups Since 1996

The Committee had the following Subcommittees and Chairs for most of 1996 (the numbers will be used to track them through the reorganization):

Group I.
Medical Classification Systems (Bruce Steinwald)
Ambulatory and Hospital Care Statistics (John T. Ashley, M.D.)
State and Community Health Statistics (George H. Van Amburg)

Group II.
Health Statistics for Minority and Other Special Populations (David R. Williams, Ph.D.)
Mental Health Statistics (Nicholas Zill, Ph.D.)
Disability and Long-Term Care Statistics (Judith D. Kasper, Ph.D.)

Group III.
Monitor for Confidentiality (James W. Thompson, M.D.)

Group IV.
Executive Subcommittee (Judith Miller Jones and Don E. Detmer, M.D.)

In November 1996, NCVHS adopted a new structure, assigning the portfolios of the preexisting groups and new functions as follows:

- Subcommittee on Health Data Needs, Standards and Security (Barbara Starfield, M.D.)
    - Workgroup on Data Standards (''K2'') (John R. Lumpkin, M.D.)
    - Workgroup on Population-Based Data (Lisa I. Iezzoni, M.D.)
- Subcommittee on Populations at Risk (Thomas A. LaVeist, Ph.D.)
  (This subcommittee was later renamed the Subcommittee on Population-Specific Issues and Chaired by Lisa I. Iezzoni, M.D.)
- Subcommittee on Privacy and Confidentiality (Robert M. Gellman, J.D.)
- Workgroup on Planning and Implementation created within Executive Subcommittee (Kathryn L. Coltin)

Appendix IV.
Members' Comments

Commentary by John Lumpkin

NCVHS is at an important crossroads in its work. This report highlights the significant progress that has been made over the last 3 years. Important decisions have set the stage for the transformation of the health care system. In 1996 Congress significantly changed the charge of the National Committee on Vital and Health Statistics to transform it into the leading U.S. Department of Health and Human Services advisory committee on health and health care information. The membership of the Committee as well as the scope of the charge was also changed. The Committee began to work in three broad arenas to advise the Department of Health and Human Services (DHHS) on health information policy: health care transaction standards, privacy and confidentiality standards, and population-based information.

In response to HIPAA, NCVHS participated in an aggressively open and inclusive process with DHHS and public and private organizations and agencies. Over a short period of time numerous hearings were held to provide for full discussion of the availability of standards and the appropriateness of adoption of those standards. Hours of testimony from providers, payers, clearinghouses, and standards development organizations provided the basis for the decisionmaking process. As a result, the recommendations from NCVHS reflected a broad public consensus on which administrative transaction electronic data interchange standards should be adopted. During the hearing process, it became very obvious that many entities were concerned about their ability to meet the deadlines established in the act for implementation. This was of particular concern because of the close temporal proximity of the implementation deadlines for HIPAA and the year 2000. Many organizations were contemplating the significant expenditures of time and money that were required to assure that their systems were Y2K compliant. Others raised concerns about changes in coding systems that had been in use for years. As a result recommendations were made concerning a more prolonged transition period for the HIPAA requirements for electronic data interchange than was originally anticipated.

Other hearings were held to discuss issues of privacy and confidentiality. This included separate hearings by the Subcommittee on Privacy and Confidentiality and joint hearings with the Subcommittee on Standards and Security. At these hearings testimony was taken concerning a broad range of subjects. It was clear that an important segment of the public was very concerned about the potential for electronic health records to make it more difficult for individuals to maintain their privacy and the confidentiality of their data. Security experts noted that significant concerns existed in the current paper-based system. Many noted that electronic systems had the potential to enhance the protection afforded to

health records. Through the course of the testimony it also became clear that issues of privacy went beyond concerns about unauthorized access. Therefore, the Privacy and Confidentiality Subcommittee focused its recommendations on issues related to who should have access to personal health information.

The issue of unique identifiers also occupied the Committee's attention. Unique identifiers for health plans, payers, and providers generated discussion concerning the format and character of the identifiers. However, it was the personal unique identifier that stirred the most controversy. When NCVHS adopted the Core Health Data Elements report, it recommended that a modified social security number be used as a unique identifier. At the time of the adoption of that recommendation few concerns were raised. With the mandate from Congress in the Administrative Simplification provisions of HIPAA, NCVHS reviewed its earlier recommendation. Hearings were held that indicated significant opposition to the earlier recommendation as well as to the designation of any future personal unique health identifier. Despite disagreement, the majority of the Committee agreed to move forward and comply with the Congressional mandate to make recommendations to the Secretary of the Department of Health and Human Services. However, after extensive debate NCVHS also urged that no action be taken until the privacy and confidentiality provisions of HIPAA were implemented. After a joint hearing by the Privacy and Confidentiality Subcommittee and the Standards and Security Subcommittee, it became clear that neither the Administration nor Congress wanted further consideration of a personal unique identifier until the privacy and confidentiality issues were resolved.

At the same time that the Subcommittees on Privacy and Confidentiality and on Standards and Security were engaged in the HIPAA hearings, the Subcommittee on Populations was also fully occupied. Hearings related to data issues of Puerto Rico and the insular areas were a major activity. In addition, hearings were held related to data needs for Medicaid-managed care and quality assessment. The formation of the Quality Workgroup facilitated a closer examination of data and information issues related to the measurement of quality in health care. Recommendations were also made in regards to the designation of race and ethnicity in Federal data sets. Through the work of the Subcommittee on Populations, it became apparent that work needed to be done to evaluate the current health statistics system and make recommendations for the next century. The Workgroup on Health Statistics for the 21st century was formed to lead the efforts in that area.

With the leadership of Dr. Don Detmer, a workgroup was formed to address the application of the National Information Infrastructure initiative to health. The workgroup produced a document articulating a clear vision for the development of an overarching National Health Information Infrastructure (NHII). This has become a very important part of the work of NCVHS because it became a unifying vision for the technical health care-related standards and privacy work and the population focus that has been a central part of the work of the Committee since its inception.

The next few years will be challenging and exciting for NCVHS. At the center of the efforts will be the refinement of the National Health Information Infrastructure vision. Continued work on electronic data interchange standards and the electronic patient record will provide the basis for the enabling technology for NHII. The review of the privacy and

confidentiality implications of this and other work will be a major activity for the Committee. Finally, we will have to find new and innovative ways to address data and information needs to key health issues of racial and ethnic disparities in health and health care, access to health care, long-term care, and measurement of quality.

Additional Views of Robert Gellman

The discussion in the report about the unique health identifier for individuals offers a misleading impression about the activities of the Committee. What the Committee really did in its 1997 recommendation was to decide that a unique patient identifier was a desirable goal. The Committee expressly voted on this specific issue, and it insisted on affirming support for an identifier despite opposition from some Committee members who argued that any decision on the patient identifier issue was unwise and precipitous.

The Committee adopted its recommendation for a unique patient identifier in advance of public hearings and in the absence any formal analysis of the costs or benefits of a patient identifier. Indeed, in its zeal, the Committee even voted to proceed with hearings on the issue before the Department's promised white paper was to be publicly available.

It is very nice that the Committee wants to see privacy legislation before an identifier is adopted. But this is the only qualification to the Committee's support for a health identifier. The Committee expressed no reservation about the costs of an identifier, about any possible negative consequences for the availability of health care, or about the nature of privacy controls that might be needed. In my opinion, none of the health privacy proposals offered to date would prevent a health identifier from becoming a universal national identifier for all governmental and private purposes. Neither these concerns nor the lack of evidence about them deterred the Committee from prematurely taking a position in favor of a health identifier.

Reflections by Barbara Starfield

NCVHS has made great strides in its work in the most recent 2 years, as well documented in its report. The efforts prompted by the requirements of the Administrative Simplification provisions of the HIPAA have propelled the Committee into the arena of clinical records—a facet of health data that heretofore has not been much in the sights of the Committee. Apart from its prior efforts to develop core data elements for administrative transactions deriving from the clinical record, the Committee has not until now had to deal with the specifics of clinical encounters, at least not in their great specificity and detail.

This new imperative will soon prove a major challenge to individual Committee members. Very few people, even Committee members, have expertise in both population data needs and clinical data needs. As population health is not merely the sum of individual health, there will be increasing need for Committee members to develop at least an appreciation of the differences. As managed care becomes increasingly population-oriented, and as public health increasingly takes on clinical challenges never before in its purview (as, for example, Health Objectives for the Nation that involve meeting of goals for specific clinical conditions), the work of the Committee will change to incorporate the dual perspectives as two sides of the same coin. The newly emerging literature on ecological

determinants of health that involve characteristics of the social environment that are not derivable by aggregating individual social characteristics makes it clear that the country can no longer rely solely on information on health obtained from individuals, whether it be specific surveys or practitioner-patient interactions. New techniques such as geocoding, will propel the science of information gathering, analysis, and interpretation into new realms and open a much wider range of possibilities for understanding causation of ill health and its responsiveness to interventions. Electronic communication that makes it possible to link data from different sources, including traditional public health and clinical settings, will expand the horizons of understanding at the same time as they provide challenges for the maintenance of individual privacy and confidentiality.

The Committee is at a critical juncture in this transition in its development. How well it succeeds in charting new waters is still unclear. At the very least, its members will have to be increasingly appreciative of differences in viewpoints and expertise of its members, and willing to learn from each other perspectives that we did not bring with us when we agreed to become members.

Appendix V.
Charter

CHARTER

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

PURPOSE

Collection, analysis and dissemination of health and health-related information is a crucial aspect of the responsibilities of the Department of Health and Human Services. The Department also plays a national leadership role in health data standards and health information privacy policy, and is charged with the responsibility for implementation of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996. In addition, the Department engages in cooperative efforts with other countries and the international community to foster health data standards, comparability and cross-national research.

The National Committee on Vital and Health Statistics is the Department's statutory public advisory body on health data, statistics and national health information policy. This Committee shall serve as a national forum on health data and information systems. It is intended to serve as a forum for the collaboration of interested parties to accelerate the evolution of public and private health information systems toward more uniform, shared data standards, operating within a framework protecting privacy and security. The Committee shall encourage the evolution of a shared, public/private national health information infrastructure that will promote the availability of valid, credible, timely and comparable health data. With sensitivity to policy considerations and priorities, the Committee will provide scientific-technical advice and guidance regarding the design and operation of health statistics and information systems and services and on coordination of health data requirements. The Committee also shall assist and advise the Department in the implementation of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act, and shall inform decision making about data policy by HHS, states, local governments and the private sector.

AUTHORITY

42 U.S.C. 242k(k), Section 306(k) of the Public Health Service Act, as amended. The Committee is governed by provisions of Public Law 92-463, as amended, (5 U.S.C. App. 2), which sets forth standards for the formation and use of advisory committees.

FUNCTION

It shall be the function of the Committee to assist and advise the Secretary through the Department of Health and Human Services Data Council, on health data, statistics, privacy, national health information policy, and the Department's strategy to best address those issues.

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Specifically, the Committee shall advise the Department in the following matters:

(A) Monitor the nation's health data needs and current approaches to meeting those needs; identify emerging health data issues. including methodologies and technologies of information systems, databases, and networking that could improve the ability to meet those needs.

(B) Identify strategies and opportunities to achieve long-term consensus on common health data standards that will promote (i) the availability of valid, credible, and timely health information, and (ii) multiple uses of data collected once; recommend actions the federal government can take to promote such a consensus.

(C) Make recommendations regarding health terminology, definitions, classifications, and guidelines.

(D) Study and identify privacy, security. and access measures to protect individually identifiable health information in an environment of electronic networking and multiple uses of data.

(E) Identify strategies and opportunities for evolution from single-purpose, narrowly focused, categorical health data collection strategies to more multi-purpose, integrated, shared data collection strategies.

(F) Identify statistical, information system and network design issues bearing on health and health services data which are of national or international interest; identify strategies and opportunities to facilitate interoperability and networking.

(G) Advise the Department on health data collection needs and strategies; review and monitor the Department's data and information systems to identify needs, opportunities, and problems; consider the likely effects of emerging health information technologies on the Departments data and systems, and impact of the Department's information policies and systems on the development of emerging technologies.

(H) Stimulate the study of health data and information systems issues by other organizations and agencies, whenever possible.

(I) Review and comment on findings and proposals developed by other organizations and agencies with respect to health data and information systems and make recommendations for their adoption or implementation.

(J) Assist and advise the Secretary in complying with the requirements imposed under Part C of Title XI of the Social Security Act;

(K) Study the issues related to the adoption of uniform data standards for patient medical record information and the electronic interchange of such information, and report to the Secretary not later than August 21 2000 recommendations and legislative proposals for such standards and electronic exchange;

(L) Advise the Secretary and the Congress on the status of the implementation of Part C of Title XI of the Social Security Act;

(M) Submit to the Congress and make public, not later than one year after the enactment of the Health Insurance Portability and Accountability Act, and annually thereafter, a report regarding the implementation of Part C of Title XI of the Social Security Act. Such report shall address the following subjects, to the extent that the Committee determines appropriate:

> - The extent to which persons required to comply with Part C of the Act are cooperating in implementing the standards adopted under such part;
>
> - The extent to which such entities are meeting the security standards adopted under such part and the types of penalties assessed for noncompliance with such standards.
>
> - Whether the federal and State Governments are receiving information of sufficient quality to meet their responsibilities under such part.
>
> - Any problems that exist with respect to implementation of such part.
>
> - The extent to which timetables under such part are being met.

(N) Assist and advise the Secretary in the development of such reports as the Secretary or Congress may require.

In these matters, the Committee shall consult with all components of the Department, other federal entities, and non-federal organizations, as appropriate.

STRUCTURE

The Committee shall consist of 18 members, including the Chair. The members of the Committee shall be appointed from among persons who have distinguished themselves in the fields of health statistics, electronic interchange of health care information, privacy and security of electronic information, population-based public health, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Members of the Committee shall be appointed for terms of

up to four years. The Secretary shall appoint one of the members to serve a two year, renewable term as the Chair.

Of the members of the Committee, one shall be appointed by the Speaker of the House of Representatives after consultation with the minority leader of the House of Representatives; one shall be appointed by the President pro tempore of the Senate after consultation with the minority leader of the Senate, and 16 shall be appointed by the Secretary.

Membership terms of more than two years are contingent upon the renewal of the Committee by appropriate action prior to its termination. Any member appointed to fill a vacancy occurring prior to the expiration of the term for which his or her predecessor was appointed shall be appointed only for the remainder of such term. Members may serve after the expiration of their terms until successors have been appointed.

Standing and ad hoc subcommittees, composed solely of members of the parent Committee, may be established to address specific issues and to provide the Committee with background study and proposals for consideration and action. The Chair shall appoint members from the parent Committee to the subcommittees and designate a Chair for each subcommittee. The subcommittees shall make their recommendations to the parent Committee. Timely notification of the subcommittees, including charges and membership, shall be made in writing to the Department Committee Management Officer by the Executive Secretary of the Committee. The HHS Data Council, through the Assistant Secretary for Planning and Evaluation, shall oversee and coordinate the overall management and staffing of the Committee. Professional, scientific, and technical staff support shall be provided by all agencies of the Department. The National Center for Health Statistics shall provide executive secretariat and logistical support services to the Committee.

MEETINGS

Meetings shall be held not less than annually at the call of the Chair, with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all meetings.

Meetings of the subcommittees shall be held at the call of the Chair, with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all subcommittee meetings. All subcommittees shall report their findings to the Committee. Meetings shall be open to the public except as determined otherwise by the Secretary; notice of all meetings shall be given to the public. Meetings shall be conducted, and records of the proceedings kept, as required by the applicable laws and departmental regulations.

COMPENSATION

Members who are not full-time Federal employees shall be paid at a rate not to exceed the daily equivalent of the rate in effect for an Executive Level IV of the Executive Schedule for each day they are engaged in the performance of their duties as members of the Committee. All members, while so serving away from their homes or regular places of business, may be allowed travel expenses, including per diem in lieu of subsistence, in the same manner as such expenses are authorized by Section 5703, Title 5, U.S. Code, for employees serving intermittently.

ANNUAL COST ESTIMATE

Estimated annual cost for operating the Committee, including compensation and travel expenses for members but excluding staff support, is $363,768. Estimated annual person-years of staff support required is 4.0, at an estimated annual cost of $268,897.

REPORTS

In the event a portion of a meeting is closed to the public, a report shall be prepared which shall contain, as a minimum, a list of members and their business addresses, the Committee's functions, dates and places of meetings, and a summary of Committee activities and recommendations made during the fiscal year. A copy of the report shall be provided to the Department Committee Management Officer.

TERMINATION DATE

Unless renewed by appropriate action prior to its expiration, the charter for the National Committee on Vital and Health Statistics will expire on January 16, 2000.

APPROVED:

April 1 1998		Secretary
Date		
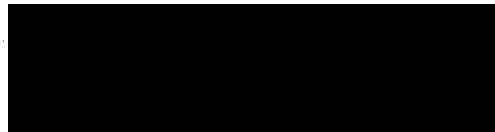
Appendix VI.
Legislative Authority
United States Code
TITLE 42-THE PUBLIC HEALTH AND WELFARE
CHAPTER 6A-PUBLIC HEALTH SERVICE
SUBCHAPTER II - GENERAL POWERS AND DUTIES
Part A - Research and Investigations

Sec. 242k. National Center for Health Statistics

...

(k) National Committee on Vital and Health Statistics; establishment; membership; term of office; compensation; functions; consultations of Secretary with Committee and professional advisory groups.

> (1) There is established in the Office of the Secretary a committee to be known as the National Committee on Vital and Health Statistics (hereinafter in this subsection referred to as the "Committee") which shall consist of 18 members.

> (2) The members of the Committee shall be appointed from among persons who have distinguished themselves in the fields of health statistics, electronic interchange of health care information, privacy and security of electronic information, population-based public health, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Members of the Committee shall be appointed for terms of 4 years.;

> (3) Of the members of the Committee—

>> (A) 1 shall be appointed, not later than 60 days after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996, by the Speaker of the House of Representatives after consultation with the Minority Leader of the House of Representatives;

>> (B) 1 shall be appointed, not later than 60 days after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996, by the President pro tempore of the Senate after consultation with the Minority Leader of the Senate; and

>> (C) 16 shall be appointed by the Secretary.;

(4) Members of the Committee shall be compensated in accordance with section 210(c) of this title.

(5) The Committee—

   (A) shall assist and advise the Secretary—

      (i) to delineate statistical problems bearing on health and health services which are of national or international interest;

      (ii) to stimulate studies of such problems by other organizations and agencies whenever possible or to make investigations of such problems through subcommittees;

      (iii) to determine, approve, and revise the terms, definitions, classifications, and guidelines for assessing health status and health services, their distribution and costs, for use (I) within the Department of Health and Human Services, (II) by all programs administered or funded by the Secretary, including the Federal-State-local cooperative health statistics system referred to in subsection (e), and (III) to the extent possible as determined by the head of the agency involved, by the Department of Veterans Affairs, the Department of Defense, and other Federal agencies concerned with health and health services;

      (iv) with respect to the design of and approval of health statistical and health information systems concerned with the collection, processing, and tabulation of health statistics within the Department of Health and Human Services, with respect to the Cooperative Health Statistics System established under subsection (e), and with respect to the standardized means for the collection of health information and statistics to be established by the Secretary under subsection (j)(1);

      (v) to review and comment on findings and proposals developed by other organizations and agencies and to make recommendations for their adoption or implementation by local, State, national, or international agencies;

      (vi) to cooperate with national committees of other countries and with the World Health Organization and other national agencies in the studies of problems of mutual interest;

      (vii) to issue an annual report on the state of the Nation's health, its health services, their costs and distributions, and to make proposals for improvement of the Nation's health statistics and health information systems; and

      (viii) in complying with the requirements imposed on the Secretary under part C of title XI of the Social Security Act;

(B) shall study the issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information;

(C) shall report to the Secretary not later than 4 years after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996 recommendations and legislative proposals for such standards and electronic exchange; and

(D) shall be responsible generally for advising the Secretary and the Congress on the status of the implementation of part C of title XI of the Social Security Act.; and

(6) In carrying out health statistical activities under this part, the Secretary shall consult with, and seek the advice of, the Committee and other appropriate professional advisory groups.

(7) Not later than 1 year after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996, and annually thereafter, the Committee shall submit to the Congress, and make public, a report regarding the implementation of part C of title XI of the Social Security Act. Such report shall address the following subjects, to the extent that the Committee determines appropriate:

(A) The extent to which persons required to comply with part C of title XI of the Social Security Act are cooperating in implementing the standards adopted under such part.

(B) The extent to which such entities are meeting the security standards adopted under such part and the types of penalties assessed for noncompliance with such standards.

(C) Whether the Federal and State Governments are receiving information of sufficient quality to meet their responsibilities under such part.

(D) Any problems that exist with respect to implementation of such part.

(E) The extent to which timetables under such part are being met.