NATIONAL CENTER FOR
HEALTH STATISTICS

The National Committee on Vital and Health Statistics, 1991

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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National Committee on Vital & Health Statistics

JUDITH MILLER JONES
CHAIRMAN

GAIL F. FISHER, Ph.D.
EXECUTIVE SECRETARY

The Honorable Louis W. Sullivan, M.D.
Secretary, Department of Health
and Human Services (DHHS)
Washington, D.C. 20201

Dear Secretary Sullivan:

I am pleased to transmit to you the 1991 Annual Report of the National Committee on Vital and Health Statistics (NCVHS), as required by the Committee's Charter.

This has been a very active year for the National Committee, with work accomplished through the full Committee, seven subcommittees, a work group, and several monitors. The Committee completed and approved major reports on the need to collect external cause-of-injury codes in hospital discharge data, on data related to medical indigence, and on inclusion of mental health status measures in national surveys. The Committee also endorsed the report of the Second Workshop on Improving Cause-of-Death Statistics, which NCVHS cosponsored with the National Center for Health Statistics. These reports are all included in the appendixes.

The Committee looks forward to continuing and expanding its activities in the coming year and, as in the past, seeks to be responsive to new health data issues that you and agencies within the Department may identify.

Sincerely yours,

Judith Miller Jones
Chairman

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Foreword

As the country begins to face a new century, it is clear that the nature and extent of current health care financing arrangements and the infrastructure to guarantee access to and delivery of quality health care are very much in question. Policymakers across the land are seeking information to address a myriad of needs, substantive as well as political.

Thanks to the farsightedness and diligence of its past Chairman, Dr. Ronald Blankenbaker, the National Committee is enjoying the resurgence of interest in improved data collection and analysis. With continuing concern for the utility and integrity of data sets pertinent to various domains (hospital inpatient care, ambulatory care, long-term care, and preventive services) and an eye toward research as well as policy applications, the Committee's composition and focus have been changing to reflect emerging needs. I have assumed the chairmanship aware of the immense efforts that preceded my tenure and am rather awestruck by the challenges that lie ahead.

The Committee takes a very broad perspective on data requirements, feeling that as an advisory body, we can and should provide overall guidance as well as technical input. We are aware that decision-makers in the public and private sectors have great concerns about the structure and capabilities of the current delivery system to meet the evolving needs of the U.S. population. We see a rapid rise of health and medical costs, a greater number of people being priced out of the health insurance marketplace, and our general health status measures faring poorly in comparison with other developed countries. For these reasons, we believe there will be an increasing focus on the ability to generate and interpret data regarding the need for care and the adequacy of our responses.

The Committee has spent much effort defining data sets that describe the specific facilities where care is delivered and the nature of that care. This has been an arduous task but one that the Committee believes experience has demonstrated as well worth the effort. With a strong base now in place, we intend to devote energy to the maintenance of these data sets and their evolution over a period of time so that the data sets match changes that are sure to result regarding the locus and the manner in which care is delivered.

It is not sufficient simply to catalogue the services that are provided to patients or where they receive care. We must be mindful that the burden of illness is also changing in response to the rise of new disease entities and to changes occurring in the population as we develop new technologies, reduce the incidence or consequence of some diseases, and face the realities that older age inevitably seems to bring. We believe that much more attention must and will be focused on generating and analyzing data that address the following kinds of concerns:

- What is the changing burden of illness and how does it differ in different regions, age bands, and subpopulations across the country?
- What is the distribution of facilities, services, and providers relative to these needs?
- How much does the receipt of care and health status vary according to income or adequacy of insurance?
- How well does the health care system assess functional abilities and respond to chronic care needs, particularly of the elderly and disabled?
- To what extent does the health care system address preventable illness, injury, and disability?
- How effective are the services being provided relative to outcomes, the sums being expended, and societal priorities, as best as can be determined?

The Committee cannot answer such questions directly, but is aware that answers are lacking and, as a result, our statistical and analytical capabilities are being questioned. Appropriations for data gathering and analysis have not kept pace with the needs over the years, but it is unlikely that appropriations will increase without some better delineation of what we need to know, what is possible to know, and especially what we already know. It is our view that timely and understandable dissemination of information, particularly with regard to health as a function of income and service availability, will help policymakers and the public to understand the power and usefulness of statistical systems. We hope that, with the Committee's assistance, the Department can improve its data collection, management, and dissemination in the future, and provide leadership to assure that necessary data are available for the public and private sectors.

There are a number of areas where the Committee's energies might be focused in the future. First, we have not paid as much attention as we could to the breadth and regularity of large-scale surveys that facilitate an understanding of needs across and within the population and to the unique role that these surveys can play. Lately, funding has not been sufficient to conduct such surveys routinely, especially with enough numbers to examine key demographic or geographic subsets of the population. Moreover, there has been a failure to look at health status in relation to income or insurance availability. Though this is understandable on several grounds, such as the costs and inherent difficulties involved, we believe that the pressures are growing to understand differences in health status—whether they might be attributable to income, lack of insurance, education, behavior, or some other factor. Without such understanding, appropriate policy responses are not possible and too many dollars can be wasted.

Another area of concern is one where the Committee has spent considerable effort, namely looking at the growing reliance on administrative data sets and the capability to link data from several sources, including administrative files. Because it is so costly and time-consuming to construct and conduct surveys de novo, most researchers use readily available data from claims and other administrative files, even when these files are not designed for such use. The Committee has voiced its concern that government agencies, as well as private sector data collectors, should keep research uses in mind when developing administrative health data sets. This is particularly important because these data sets can have a helpful derivative impact within the policy arena as a whole.

We are also mindful of the fact that effectiveness and outcomes studies, in particular, are virtually impossible to conduct unless there is the capability to do longitudinal analyses and to link files across time intervals. Very often this involves linking files created for one purpose to those created for another. In the past, the Committee has advocated use of a uniform patient identifier—the Social Security number for lack of something more convenient and less costly. We are still interested in this issue. Our studies in recent months, and the emergence of a proposed computerized medical record—perhaps with a uniform patient identifier—lead us to believe that this matter bears further watch and study. Issues of privacy and access must be balanced in these discussions.

Finally, we are concerned about the future of coding systems and their ability to accurately reflect and codify not only the disease entities that are ultimately diagnosed and treated, but the symptoms and conditions that patients present as they wend their way through various treatment regimens and locations and with varying results. The implementation of ICD-10 within this country, the evolution of other coding systems that may prove useful, and the adoption of payment schemes that can affect the coding behavior of physicians and other providers are of concern to the Committee.

To many, the relationships between investment in health data systems and health of the population is less than obvious. From the perspective of the Committee, however, this relationship is crucial to the formulation of health policies to carry us through the remainder of the decade and into the 21st century. We must do a better job at simultaneously meeting the health care needs of the population and containing health care costs. We require better data than we currently have to meet this objective.

The need for a comprehensive health statistical system, embracing health care delivery and public health programs at the national, State, and community levels, has never been more critical. It remains the priority role of the National Committee on Vital and Health Statistics to serve as an interface between the public and private sectors, facilitating the necessary interactions among agencies and organizations, encouraging an appropriate balance among different types of data collections, and assuring that the information vital to address the increasingly complex issues in the health care arena will be available.

Judith Miller Jones
Chairman, National Committee
on Vital and Health Statistics

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Executive Summary

During 1991, the National Committee on Vital and Health Statistics (NCVHS), in its advisory capacity to the Department of Health and Human Services (DHHS), accomplished the following activities through the work of the full Committee, seven subcommittees, a work group, and several monitors:

- Developed a comprehensive report on the need to collect external cause-of-injury codes (E-codes) in hospital discharge data. The report strongly recommended inclusion of E-codes in the Uniform Hospital Discharge Data Set (UHDDS) and was submitted to the Assistant Secretary for Health in June 1991, 1 year earlier than the Committee's full report on the UHDDS is due. The report is contained in appendix VI.
- Collaborated with the National Uniform Billing Committee to assure that the revised uniform bill for hospitals will accommodate the recording of an E-code in a separate, labeled field when an injury is the principal diagnosis or directly related to the principal diagnosis for a hospitalized patient.
- Completed a report on data related to medical indigence, which concluded that current data collection and analysis efforts are inadequate to track, understand, and develop solutions to this problem. The report, recommending that the Secretary identify an appropriate group or mechanism to address the data issues related to medical indigence, was transmitted to the Assistant Secretary for Health, who forwarded it to key departmental working groups addressing similar issues. This report can be found in appendix VII.
- Prepared a report on incorporating mental health status measures in national surveys and determined that a measure of depression is the highest priority for inclusion on an annual basis into a national health survey. The National Health Interview Survey (NHIS) was identified as an appropriate vehicle for gathering this needed information, and the National Center for Health Statistics (NCHS) was commended for the steps being initiated to include appropriate mental health status measures in the NHIS. Appendix VIII contains this report.
- Cosponsored with NCHS a Second Workshop on Improving Cause-of-Death Statistics, as a followup to a landmark workshop with public and private sector organizations held in October 1989. The Second Workshop expanded upon a wide range of recommendations for enhancing physician education and quality assurance efforts related to cause-of-death reporting and also laid groundwork for a comprehensive assessment of the current methods and conceptual

framework for certifying cause of death. Endorsed the workshop report, which is included in appendix V, and transmitted it to the Assistant Secretary for Health.

- Sponsored with NCHS and the Association for Vital Records and Health Statistics an educational exhibit addressed to physicians on the importance of accurate cause-of-death reporting. The exhibit was displayed at the annual meetings of several national professional organizations in 1991 and also displayed at additional meetings in 1992.
- Focused at the subcommittee and full Committee levels on issues related to disability data gaps and needs, as well as functional assessment measures in health surveys.
- Continued to monitor and evaluate issues related to medical classification systems, including the implementation of the 10th revision of the International Classification of Diseases, and the progress of activities relating to the development and improvement of classification systems for procedures in the United States.
- Elevated the Work Group on Community Health Statistics to the Subcommittee on State and Community Health Statistics, which initiated its efforts to address the availability of health status and health care data at these levels.
- Participated in a National Workshop on Health Status Indicators for the Year 2000 health objectives and commented on the draft set of indicators, noting concerns on specific issues but expressing overall support for the effort.
- Participated in an NCHS-sponsored meeting on standardization of age-adjusted tabulations by the Department.
- Created a new Work Group on Confidentiality to address issues related to the tabulation and publication of health data, including vital statistics data, and the production of public use data tapes. Broadened the Work Group's scope to explicate current public policy issues surrounding the release and disclosure of health data.
- Followed with interest the newly established NCHS minority health statistics grants program and recommended development of a research agenda. Attended a planning meeting to design an agenda-setting workshop and participated in the workshop sponsored by NCHS in December 1991 to develop guidelines for a research agenda for the grants program.
- Continued efforts to encourage the Health Care Financing Administration and the Social Security Administration to improve the racial and ethnic identifiers in the Medicare administrative data bases.
- Provided comments to the Public Health Service Task Force on Minority Health Data regarding the many concerns the Committee has addressed in this area over the years.
- Continued a systematic review of the UHDDS data elements and definitions, working in collaboration with the Interagency Task Force on the UHDDS and the National Uniform Billing Committee.
- Maintained its role in following the statistical aspects of physician payment systems and other data systems and research concerned with patient-provider encounters.

- Identified the need for a compilation of information on Federal data sources relevant to mentally ill children and adolescents and the services provided to them.
- Received an in depth briefing about the Institute of Medicine Report on the Computer-Based Patient Record and agreed to follow developments in this emerging area.

In 1992, the Committee will continue and expand efforts related to many of the above activities.

Activities, Accomplishments, and Future Plans of the National Committee on Vital and Health Statistics

The National Committee on Vital and Health Statistics (NCVHS) expanded and broadened its assessment of key issues in health data and statistics at the national and subnational levels during 1991. The Committee also continued its collaborative relationships with agencies within the Department of Health and Human Services (DHHS) and other public and private sector organizations.

In 1991, the Committee carried out substantive activities in the following areas through its active subcommittee and work group structure:

- Medical classification systems
- Long-term care statistics
- Ambulatory and hospital care statistics
- Health statistics for minority and other special populations
- Mental health statistics
- State and community health statistics
- Confidentiality

The activities, accomplishments, and future plans of the subcommittees and work group are detailed in the subsequent sections of this report and thus will not be covered here. Membership lists, meeting dates, and charges for the subcommittees are included in appendix IV. The legislative authority, the charter, and the membership list and meetings dates of the full Committee can be found in appendixes I, II, and III.

The full Committee and the NCVHS Executive Subcommittee gave consideration to the variety of issues raised by the subcommittees and work group during the year and also addressed several additional topics, as described below.

A primary focus of the Executive Subcommittee has been communication and dialogue with departmental policymakers and agency staffs to assure NCVHS responsiveness to Department programs and needs. The Assistant Secretary for Health met with the full Committee at its June 1991 meeting and expressed support for the wide range of NCVHS activities and recommendations. The full Committee receives regular reports on major data activities and policies from the National Center for Health Statistics, which provides Executive Secretary support to the NCVHS, and from the Health Care Financing Administration (HCFA), which has a principal liaison working with the Committee and Executive Subcommittee. The Agency for Health Care Policy and Research (AHCPR) also has a principal liaison to the

Committee and Executive Subcommittee. The Agency Administrator briefed the NCVHS in June on the major programmatic emphases of AHCPR and the opportunities for collaboration between NCVHS and AHCPR. Staff from NCHS, HCFA, and AHCPR serve as staff on most of the NCVHS subcommittees and work groups, and the National Institute of Mental Health provides principal staff support to the Subcommittee on Mental Health Statistics. Other appropriate agencies also are represented.

The NCVHS, through the Executive Subcommittee, continued to maintain a strong interest in collaborative activities with NCHS to improve cause-of-death reporting on the death certificate. The Committee and NCHS cosponsored a Second Workshop on Improving Cause-of-Death Statistics on April 21–23, 1991, in Virginia Beach, Virginia—to continue efforts initiated at the landmark workshop held in October 1989 to harness the energies of the public and private sectors in improving the reporting of cause of death by physicians, coroners, and medical examiners.

The Second Workshop brought together 53 individuals from Federal, State, local, and private sector organizations, including representatives of most of the organizations that participated in the first meeting, as well as a number of additional organizations with an interest in improving mortality data. Recommendations expanded upon the 1989 proposals for enhancing physician education and quality assurance efforts related to cause-of-death reporting and also laid groundwork for a comprehensive assessment of the current methods and conceptual framework for certifying cause of death. The participants moved beyond educational and quality assurance responses to the current system and procedures and recommended researching a totally new way of collecting information on cause of death in the future. The new approach would facilitate capturing the multiple causes contributing to death in the majority of decedents, especially the elderly, and should not be limited by either the current paper form or the current format for medical certification of cause of death. The Workshop report and recommendations, which are contained in appendix V, were endorsed by the NCVHS and transmitted to the Assistant Secretary for Health.

The NCVHS and NCHS also developed with the Association for Vital Records and Health Statistics an educational exhibit addressed to physicians on the importance of accurate cause-of-death certification. This exhibit was first shown at the annual meeting of the American College of Physicians in April 1991, and subsequently displayed at the Second Workshop on Improving Cause-of-Death Statistics, and the 1991 annual meetings of the American Academy of Family Physicians, American Society of Internal Medicine, and the American Public Health Association. The exhibit will be taken to additional meetings in 1992.

The Committee has maintained a strong interest in implementation of *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, and had an opportunity to meet with the Deputy Assistant Secretary for Health (Disease Prevention and Health Promotion). The Committee was also represented at an NCHS meeting to examine alternatives and develop proposals for standardizing age-adjusted tabulations in the Department. Major responsibility for following these activities has been assumed by the Subcommittee on State and Community Health Statistics.

The full Committee has developed a growing interest in data needs on disability and functional assessment. The Committee is devoting several sessions to receiving expert testimony in these areas. The Subcommittees on Long-term Care Statistics and Mental Health Statistics are taking the lead in pursuing these data issues.

A Committee member is monitoring the NCHS contract with the National Academy of Sciences (NAS) to provide expert advice on the development of the National Health Care Survey, and the full Committee expects to review the NAS recommendations when they become available in 1992.

The Executive Subcommittee identified emerging recommendations on the need for a computer-based patient record as an area of considerable relevance to several NCVHS subcommittees and the full Committee as well. A half-day session was held at the November 1991 NCVHS meeting to receive a briefing from the Study Director and Staff Officer of the newly released Institute of Medicine report, *The Computer-Based Patient Record: An Essential Technology for Health Care*. The session included broad discussion of the background, objectives, and recommendations of the report and plans for implementing those recommendations. The NCVHS will continue to follow developments in this important area.

Medical Classification Systems

During 1991, the Subcommittee on Medical Classification Systems continued to address issues surrounding the use of the *International Classification of Diseases (ICD)* in the United States focusing on the status, development, and implementation of *ICD-10*; issues concerning implementation and maintenance of the current classification; and activities relating to the development of a classification system for procedures. In November 1991, the Subcommittee proposed revisions to its charge, which were accepted by the full Committee.

Background

The Subcommittee on Medical Classification Systems was established in 1987 as a continuation of the Subcommittee on Disease Classification and Automated Coding of Medical Diagnoses, begun in 1983. Classification systems provide the health care data essential for the formulation of health policy. The NCVHS is committed to addressing the complex issues related to classification systems and the diversity of their application.

Current Year's Activities

The Subcommittee's report concerning issues relating to the coding and classification systems was reproduced by NCHS as Working Paper Series Number 37 and was distributed to the Subcommittee's mailing list. The report was a culmination of 4 years of work by the Subcommittee. The report was sent to Dr. James O. Mason, Assistant Secretary for Health in December 1990. In his response, dated February 6, 1991, Dr. Mason initiated a process under the leadership of the National Center for Health Statistics to ensure that the recommendations from the report receive full attention within the Public Health Service, Health Care Financing Administration and others in the Department of Health and Human Services, and other major Federal agency users of the coding and classification systems.

In June 1991, Karel M. Weigel's appointment as member of the NCVHS expired, and Bruce Steinwald accepted the chairmanship of the Subcommittee. Subsequently, the Subcommittee members held a conference call and a working session to review and revise their charge and to develop their 2-year work plan.

The Subcommittee held one meeting, three working sessions, and a conference call during 1991.

Continuing Work Plan

The Subcommittee's work plan for 1992 will focus on the following areas:

- Continue to provide an open forum for information on the progress of *ICD-10* and its implementation.
- Monitor the development and use of derivative applications of the *ICD*, including specialty-specific compendia.
- Monitor activities relating to the development and improvement of classification systems for procedures in the United States.
- Continue to monitor efforts of the Coordination and Maintenance Committee.
- Monitor the effect of annual changes in diagnosis codes on data quality and research initiatives.
- Monitor progress toward improvement of data quality and coding accuracy, systems for automated coding of medical diagnoses, and patient record documentation.

Long-Term Care Statistics

During 1991, the Subcommittee on Long-Term Care Statistics focused its efforts on the need to improve data collection on disability. The Subcommittee initiated two discussions at the National Committee on Vital and Health Statistics March and November 1991 meetings highlighting issues related to disability data gaps and needs, multiple definitions and functional assessment measures of disability, and the heterogeneity of the disabled population. The Subcommittee revised its charge to reflect a new focus on disability.

Background

The Subcommittee on Long-Term Care Statistics was formed in 1987 as a successor to the Subcommittee on Uniform Minimum Health Data Sets. In 1990, the Subcommittee submitted an interim report on the Health Care Financing Administration (HCFA) resident assessment instrument for nursing homes. The report was approved by the full Committee and submitted to the Assistant Secretary for Health.

Current Year's Activities

The Assistant Secretary for Health forwarded the Subcommittee's interim report to HCFA for comment. The HCFA response essentially acknowledges the need to provide safeguards to assure the quality and reliability of resident assessment data and the need for confidentiality while facilitating the accessibility of data for research and policy formulation. The Subcommittee will continue to monitor HCFA's efforts in exploring how common data elements can be applied across various care settings and its plans for the automation of the resident assessment data collected from the minimum data set.

The Subcommittee held a joint meeting with the Subcommittee on Mental Health Statistics in April 1991 to discuss disability data issues and to review functional assessment instruments from various surveys. The two Subcommittees also held joint working sessions in March and June 1991.

In June 1991, Dr. William F. Bridgers assumed the chairmanship of the Subcommittee. The Subcommittee held two working sessions to revise the charge and to develop a 2-year work plan, which were subsequently approved by the Committee in November 1991. The new charge will focus on identifying the data gaps in disability, particularly as they relate to the elderly, with the long view of improving the coordination and the collection of disability data for policy development.

Continuing Work Plan

The Subcommittee intends to carry out the following work plan in 1992–93:

- Review the adequacy of data on incidence and prevalence of various chronic conditions and their effects on the disabling process, and the need for long-term care within a variety of national surveys.
- Assess the adequacy of Department of Health and Human Services (DHHS) data sources in existing and planned surveys on settings and care givers for long-term care delivery.
- Participate in the Interagency Forum on Aging-Related Statistics and monitor plans for possible longitudinal health and retirement studies and other issues.
- Monitor DHHS plans for a possible national registry of nursing home residents, including employment of the Nursing Home Resident Assessment Minimum Data Set.
- Collaborate with the Subcommittee on Mental Health Statistics on issues related to quality of life assessment, use of ADL's and IADL's as disability measures, mental health related disabilities, and other matters of shared concern.
- Review existing information on the financing of long-term care.
- Monitor status of planning for the Year 2000 census or other information from the U.S. Bureau of Census.
- Explore data requirements of the Americans with Disabilities Act and assess other data sets measuring prevalence of disability and levels of disability.
- Periodically review data availability to track Year 2000 Objectives relevant to disability.
- Review progress of the DHHS Coordinating Group on Disability Data and the Public Health Statistics Task Force on Determination of Disability.

Ambulatory and Hospital Care Statistics

After a year of study and deliberation, in June 1991 the Subcommittee on Ambulatory and Hospital Care Statistics presented its Report on the Need to Collect External Cause-of-Injury Codes (E-codes) in Hospital Discharge Data to the National Committee on Vital and Health Statistics (NCVHS). Extensive written and oral testimony received by the Subcommittee reinforced the need for E-coded data on nonfatal injuries to develop intervention and prevention strategies. The testimony also demonstrated the feasibility of collecting and using the data and the need for a national mandate to facilitate comparability, uniformity, and accessibility of injury information. The Subcommittee report strongly supported inclusion of E-codes in the Uniform Hospital Discharge Data Set (UHDDS). The full Committee concurred and transmitted the report to the Assistant Secretary for Health a year earlier than the Subcommittee's full report on the UHDDS was due. This action was in recognition of the need to move quickly on addressing and overcoming current impediments to E-coding. Positive responses to the report's recommendations were received from the Public Health Service and the Health Care Financing Administration (HCFA), and the report has been widely disseminated to interested organizations and individuals in the public and private sectors. The report was shared with the Interagency Task Force on the UHDDS and the National Uniform Billing Committee (NUBC), as the Subcommittee is collaborating with both groups in its overall review of the UHDDS. In response to the NCVHS recommendations, the NUBC voted at its November 4–5, 1991, meeting to include a separate, labeled field on the revised uniform bill for hospitals to accommodate the recording of an E-code for injury patients.

After completing its report on external cause-of-injury coding, the Subcommittee resumed its systematic review of the UHDDS data elements and definitions. During the year, the Subcommittee maintained its role in following the statistical aspects of physician payment systems and other data systems and research concerned with patient-provider encounters. These activities will continue in 1992.

Recommendations

The Report on the Need to Collect External Cause-of-Injury Codes in Hospital Discharge Data, which was reproduced by NCHS as Working Paper Series Number 38 and is contained in appendix VI, includes the following recommendations:

- Whenever an injury is the principal diagnosis or directly related to the principal diagnosis for a hospitalized patient, there should be an external cause of injury recorded in the medical record.

- When there is an external cause recorded in the record, applicable E-codes should be reported in the hospital discharge data set. A minimum of one E-code should be reported for cause; a second E-code is strongly encouraged for place of occurrence, where appropriate.
- A hospital record or bill should be regarded as incomplete if there is evidence of an injury and no E-code is recorded.
- E-coding should be recommended for all hospitalized patients, in all Department of Health and Human Services programs that deliver and finance care, regardless of the payment source.
- The revised uniform bill (UB-82) for hospitals should accommodate the collection of E-codes. Reporting should be required with the implementation of the revised UB-82.
- Hospitals should be strongly encouraged immediately to improve record keeping on external causes of injury and to begin reporting E-codes voluntarily as one or more of the injured patient's diagnoses as soon as feasible.
- Implementation of this mandate should occur in conjunction with the development of national guidelines and training materials for using E-codes. Training materials are needed for medical records professionals and for physicians.
- Work should begin on improvements to the *ICD-9-CM* classification system for recording external causes of injury, including the alphabetical index for E-codes.
- Adequate resources should be made available to support each of these functions. A budget for conducting training is required to assure accurate and complete recording.

In transmitting these recommendations, the Committee recognized the value of external cause-of-injury information from emergency rooms as well as other ambulatory care settings. The Committee recommended a stepwise approach, beginning in the hospital inpatient setting where the more severe injuries are treated and higher quality data can be obtained. The NCVHS plans to revisit the need for E-coding in outpatient settings after greater experience in using the classification is gained and the value of the data is demonstrated.

Background

The Subcommittee on Ambulatory Care Statistics was formed at the June 1987 NCVHS meeting as a direct outgrowth of the Subcommittee on Statistical Aspects of Physician Payment Systems, which had begun as a work group in 1984. At the November 1989 NCVHS meeting the Subcommittee revised its charge and changed its name to the Subcommittee on Ambulatory and Hospital Care Statistics to reflect an expanded focus on hospital care data. The Subcommittee subsequently recommended to the NCVHS in June 1990 that a thorough and systematic review of the UHDDS should be undertaken, working in close cooperation with the Department and the National Uniform Billing Committee. The Department responded by establishing an Interagency Task Force on the UHDDS, chaired by the HCFA. The Subcommittee began its review of the UHDDS by receiving testimony on E-coding, because during the Subcommittee's informal inquiry into the adequacy of the UHDDS, the additional item most frequently recommended for collection was the E-code associated with an injury diagnosis.

Current Year's Activities

The Subcommittee held three meetings and three working sessions during 1991 to investigate the need for external cause-of-injury data, to pursue its overall review of the UHDDS, and to follow the numerous other health statistical activities covered in its charge. In June 1991, the chairmanship of the Subcommittee changed after the appointment of Dr. William R. Felts, Jr. to the NCVHS expired and Dr. John T. Ashley became chairman.

The Chairman of the Interagency Task Force on the UHDDS reported regularly to the Subcommittee on progress. Subcommittee members and staff attended meetings of the Interagency Task Force on June 12 and July 30, 1991. These meetings included extensive testimony from collectors and users of hospital discharge data on the history and adequacy of the UHDDS. In addition, the Subcommittee was represented at meetings of the National Uniform Billing Committee on March 4–5, July 8–9, and November 4–5, 1991, when revision of the uniform bill for hospitals was discussed.

The Subcommittee's January 16, 1991, meeting continued the receipt of testimony on collection and use of E-coded data that had been initiated at the September 12, 1990, Subcommittee meeting. The Subcommittee received compelling testimony from the Indian Health Service about its effective use of the E-coded data that it had been collecting for 20 years to implement injury prevention and control strategies. Presentations were received on the need for data on occupational injuries and head injuries. Testimony on E-coding was completed at the Subcommittee's May 7, 1991, meeting, which included review of written testimony on legal and liability issues and finalization of the Subcommittee's report. After this meeting, the Subcommittee chairman presented the report's recommendations to the Advisory Committee for Injury Prevention and Control on May 20, 1991. The Advisory Committee was strongly supportive of the Subcommittee's report. The report was approved by the full NCVHS in June 1991.

On September 19–20, 1991, the Subcommittee resumed its overall review of the UHDDS and established a plan for developing recommendations on current and proposed UHDDS data elements and definitions by the June 1992 NCVHS meeting.

The Subcommittee's three meetings also provided opportunities to receive updates from several agencies within the Department on relevant data activities. The HCFA reported regularly on implementation of the revised HCFA-1500, the Unique Physician Identification Number, and physician payment reform. The Subcommittee received an update from the Health Resources and Services Administration on the

National Practitioner Data Bank, which became operational September 1, 1990, and discussed data quality issues and the potential of the Data Bank for assessing quality of care. The National Center for Health Statistics and its contractor described a feasibility study on collecting ambulatory surgery data and the difficulties encountered obtaining certain types of information, including race and ethnicity and charges.

The Subcommittee continued to follow the Department's review and finalization of the Uniform Ambulatory Care Data Set, which was recommended by the Subcommittee and an Interagency Task Force in 1989. After the resolution of all content issues, the Department expects to promote voluntary adoption and to seek reporting from data set users on their experiences in collecting the information.

Continuing Work Plan

The Subcommittee will pursue the following work plan in 1992:

- Complete a thorough and systematic review of the UHDDS in tandem with the Interagency Task Force on the UHDDS.
- Continue to collaborate with the National Uniform Billing Committee on the revision of the uniform bill for hospitals.
- Follow the responses to the recommendations in the Subcommittee's Report on the Need to Collect External Cause-of-Injury Codes in Hospital Discharge Data.
- Work with the Department in finalizing and fostering the use of the recommended Uniform Ambulatory Care Data Set.
- Maintain continuing liaison with the Health Care Financing Administration, National Center for Health Statistics, Health Resources and Services Administration, and Agency for Health Care Policy and Research concerning the statistical aspects of physician payment systems and other data systems and research concerned with encounters between patients and providers and with the outcome of care.
- Follow these data systems and related activities by receiving periodic updates and having an opportunity to react to developments and, where appropriate, framing recommendations concerning their future course.

Health Statistics for Minority and Other Special Populations

During 1991, the Subcommittee on Health Statistics for Minority and Other Special Populations continued its efforts to address the availability of data on the medically indigent population in the United States. The Subcommittee presented a final report on its findings regarding medical indigence to the National Committee on Vital and Health Statistics (NCVHS), which was approved at its February 1991 meeting. The Subcommittee continued in its efforts to encourage the Health Care Financing Administration (HCFA) and the Social Security Administration (SSA) to improve the racial and ethnic identifiers in the Medicare administrative data bases. The Subcommittee followed the activities of the PHS Task Force on Minority Health Data and provided written comments to them regarding the many concerns on minority health data issues that the Subcommittee has addressed over the years. The Subcommittee is very supportive of the newly established National Center for Health Statistics Minority Health Statistics Grants Program and forwarded a letter to the project staff indicating some initial thoughts on the development of priorities and its desire to have an ongoing involvement with the program.

Recommendations

The Subcommittee's report on medical indigence, which can be found in appendix VII, recommended the following:

- The Secretary should identify an appropriate group or develop some other mechanism, such as an interagency task force, to address the statistical and data issues related to medical indigence. The specific charges should include:
    1. To identify the groups and individuals currently involved with developing definitions of data or setting guidelines or standards for definitions of data to be used in measuring medical indigence;
    2. To identify the areas in which these groups are currently focusing their efforts;
    3. To consider fostering cooperative and collaborative efforts among these groups and individuals;
    4. To develop uniform definitions of data to be collected and used in measuring medical indigence, including consideration of a minimum data set;

5. To develop a consensus on the assumptions to be used in measuring medical indigence (such as point compared with period prevalence);
6. To develop common reporting formats and linkages for such data;
7. To develop guidelines for the supplementation of existing data bases, including the collection of new information, to enhance data bases for the purpose of measuring medical indigence, and the design and development of new data bases that would be used in medical indigence-related analyses;
8. To develop standards to assure the security, confidentiality, accuracy, and appropriate maintenance of such data; and
9. To collaborate with other appropriate groups addressing the issue of medical indigence.

- The National Committee on Vital and Health Statistics, through the Subcommittee on Health Statistics for Minority and Other Special Populations, should continue to be actively involved in the implementation of the recommendations.

Background

The Subcommittee on Minority Health Statistics was established by the NCVHS in 1986 after the Secretary's Task Force on Black and Minority Health noted the inadequacy of data on minority populations and identified a need to improve and fully utilize available sources of data.

The Subcommittee recognized the need to expand its focus to include other groups such as the medically indigent, whose health status and health care utilization patterns required special attention that could not be addressed adequately through current data systems. To reflect this expanded focus, the Subcommittee's name was changed in November 1989 to the Subcommittee on Health Statistics for Minority and Other Special Populations.

Current Year's Activities

In April 1991, the Subcommittee's report on medical indigence was forwarded to the Assistant Secretary for Health. The Assistant Secretary forwarded the report to the Department's Data Planning and Analysis Working Group that was established to identify high priority data needs within the Department, including health care utilization and expenditures information, to develop a forward looking strategy to address those data needs during the 1990's, and to help plan surveys more comprehensively. He also forwarded the report to the Counsel to Deputy Secretary Horner and Executive Director of the Department's Task Force on the Uninsured. The Subcommittee has been in contact with both groups to establish a liaison and will continue to follow their activities.

The Subcommittee held four meetings, three working sessions, and three conference calls during 1991 with a primary focus on pursuing various avenues to encourage the HCFA and the SSA to improve the racial and ethnic identifiers in the Medicare administrative data bases. Through several public hearings in past years, the Subcommittee became aware that these data bases have the potential of becoming a rich source of information if racial and ethnic identifiers are included. This information would enable better research on the utilization of health services by minority populations and aid in strategic health planning and treatment. Representatives from both agencies attended all four meetings and, while encouraging, identified some problems in the confidentiality law of the SSA that restricts access and/or release of data to other agencies such as HCFA. The Subcommittee will continue to work with the two agencies to facilitate a process whereby information may be released to HCFA during 1992.

The Subcommittee followed the activities of the PHS Task Force on Minority Health Data through periodic reports made to the Subcommittee by members of the Task Force. The Task Force was established to make specific recommendations to the Assistant Secretary for Health for improving minority health data for public health assessment, policy development, and programmatic purposes. The Task Force invited public comments from data users and other interested parties concerning data policy needs, gaps, uses, and other data issues relating to minority health. The Subcommittee responded with a written document indicating the many concerns on minority health data issues that it has assessed over the years. Some of the concerns were made previously to the Assistant Secretary for Health by the Subcommittee in the form of recommendations, namely:

- All person-based health data systems supported or maintained by the Department of Health and Human Services (DHHS) should make possible racial and ethnic identification in a uniform fashion. This provides the capability for policy analysis and research on health issues related to minority populations.
- DHHS should review newly planned national surveys on health status and health care use to ensure that all considerations are being made to provide adequate sample sizes for minority populations and oversample minorities when appropriate.
- DHHS should continue to support efforts to further analyze existing data that include information about minority populations.
- DHHS should address the recommendations in the Subcommittee's report on medical indigence.

  The following data issues, which were not submitted as recommendations, should be considered by the Task Force.
- The adequacy of data collection efforts specifically related to the aging of subpopulations within the minority populations.
- The need to create a longitudinal data set capable of addressing health issues in minority subpopulations.
- The ability to identify ethnic groups within minority populations. This is relevant for Hispanics and Asians as well as the black population.

- The need to establish mechanisms whereby national data collection techniques and methodologies can be used at the State, regional, and county levels.
- To identify special health care needs of minority populations, data are needed to describe the sources of care for minority groups, and the temporal relationship between ethnicity and patient clinical and functional status with respect to minority "outcomes," that is, what happens to the minority patient.
- Data useful for describing these relationships should be individual-level data and be linkable longitudinally. The data should include information about a treatment, such as surgical and diagnostic procedures and medical management of the conditions, as well as patient outcomes and other factors (such as a patient's existing condition of hypertension or diabetes) that influence the treatments and/or outcomes
- How representative of an identified subpopulation of interest are the minority individuals in the data files? This includes investigating the degree to which the minority individuals are a sample of sufficient size to answer the question.
- How adequate are these minority health data to answering questions regarding minority patient outcomes? Two specific aspects of adequacy include what data are collected and how good these data are for addressing the question.

A request was made to the Task Force that the Subcommittee be allowed to review the final report that is expected in early 1992.

At each of its four meetings, the Subcommittee received reports on the activities of the NCHS Minority Health Statistics Grants Program. The Subcommittee sent a letter to the program expressing its concern on four issues:

- Developing priorities in setting forth a research agenda and the criteria that will be used in selecting grantees.
- Limiting the 1991 grants to projects that analyze existing data sets.
- Establishing an ongoing goal to increase the network of minority investigators.
- Developing guidelines about areas on which researchers should focus.

The Subcommittee Chairman and a member participated in a planning meeting held by NCHS to develop a research agenda-setting workshop for the grants program and participated in the workshop on December 4–6, 1991.

The Subcommittee will continue to follow these activities during the coming year.

Continuing Work Plan

- Continue to pursue various avenues to encourage the Health Care Financing Administration and the Social Security Administration to improve racial and ethnic identifiers in the Medicare administrative databases.
- Continue to monitor the NCHS reauthorization provisions with regard to the mandate to improve minority health statistics and the grants program to public and nonprofit entities for the conduct and/or analysis of special surveys and methodological studies on the health of racial and ethnic populations.

and nonprofit entities for the conduct and/or analysis of special surveys and methodological studies on the health of racial and ethnic populations.
- Maintain liaison with the Department's working groups established to identify data needs within the Department for health care utilization and expenditures information.
- Meet periodically with the Office of Minority Health and collaborating offices.

Mental Health Statistics

In 1991, the Subcommittee on Mental Health Statistics conducted its second year of activities. The Subcommittee continued to pursue key objectives: to achieve the integration of priority mental health topics into national health care surveys; to serve as a forum for mental health statistical concerns within the Department of Health and Human Services (DHHS); and to provide liaison with other committees and activities concerned with data on mental health epidemiology, services, and clients, within and outside of the Department.

A primary accomplishment in 1991 was the achievement of considerable progress in integrating mental health measures into the general health measures of the Nation. Through testimony from expert witnesses, the Subcommittee reached consensus regarding the importance and feasibility of incorporating a measure of depression into the National Health Interview Survey (NHIS). Subsequently, the NHIS staff scheduled a planning meeting to consider mental health and quality of life topics for future surveys. Based upon these developments, the Subcommittee prepared a report to the National Committee that provides a rationale for this work, describes a potential option for incorporating actual measures, and recommends that the NHIS staff be commended for its support of the endeavor. This recommendation was accepted unanimously by the National Committee.

Recommendations

The Subcommittee's report on Mental Health Status Measures in National Surveys is contained in appendix VIII. The report concludes that:

- A measure of depression is the highest priority for incorporation on an annual basis in a national health survey.
- The NHIS is an appropriate vehicle for gathering this needed information.

The report further recommends that:

- The National Committee on Vital and Health Statistics commend the National Center for Health Statistics for the steps being initiated to include appropriate mental health status measures in the NHIS.

Background

The Subcommittee on Mental Health Statistics was formed during 1990 because of concern that the separation of statistical efforts in the areas of physical and mental health limits the ability to monitor changes in the health status of the American population. Psychiatric conditions and symptoms cause great suffering and disability. Such symptoms are frequent among patients treated in primary care and other health care settings. The strong connection between medical and psychiatric morbidity compounds the challenges of care and prevention of disability.

Current Year's Activities

The Subcommittee held three meetings, three working sessions, and a conference call in 1991. The Subcommittee received testimony at two meetings about developments in the area of disability statistics. One meeting was hosted jointly with the Subcommittee on Long-Term Care Statistics. Interest centered on the applicability of disability measures developed for other populations to persons who are mentally ill and the need to develop measures that assess dimensions of functioning specific to mentally ill populations. The Subcommittee noted with interest the activities of the Departmental Work Group on Disability Statistics and the Public Health Service Task Force on Disability Determination, both of which will make important contributions to deliberations on disability statistics for the mentally ill.

Although the number of mentally ill children and adolescents is very large, mental health statistics on these populations remain underdeveloped. In 1991, the Subcommittee received testimony on the status of epidemiological, service, and client statistics for these populations at two meetings. As a result, the Subcommittee identified content, scope, and data integration gaps that will require attention in the future. The Subcommittee recommended that the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) undertake a compilation of information on Federal data sources relevant to mentally ill children and adolescents and the services provided to them.

In 1992, the Subcommittee will convene Federal representatives of the health, human services, education, and juvenile justice sectors to discuss these topics.

Dr. James O. Mason, Assistant Secretary for Health, DHHS, met with the Subcommittee at the final meeting of 1991 to discuss the proposed reorganization of ADAMHA. His comments on the recommended location and structure of mental health statistical, evaluation, and assessment activities in an Office of Mental Health Services, and services research activities in the National Institute of Mental Health were of particular interest to the Subcommittee. The Subcommittee offered to help Dr. Mason implement the proposed reorganization.

Continuing Work Plan

In 1992, the Subcommittee will continue to pursue unfinished activities initiated in 1991. Particular attention will be given to:

- The identification and development of disability measures for mentally ill persons.
- Development of the statistical field concerning mentally ill children and adolescents.

State and Community Health Statistics

During 1991, the Subcommittee on State and Community Health Statistics initiated its efforts to address the availability of health and health care data at the State and community levels. Testimony received by the Subcommittee and discussions of the Subcommittee focused on data that may currently exist, sources of data, gaps in data, and anticipated future developments. The Subcommittee in its deliberations addressed issues of improving the quantity and quality of health data and access to data at the State and community levels.

Background

The Subcommittee on State and Community Health Statistics was established by the National Committee on Vital and Health Statistics (NCVHS) as a work group in 1990 after review and consideration of the health statistics implications of the Institute of Medicine report on the Future of Public Health and the Nation's Health Objectives for the Year 2000. It was elevated to a subcommittee at the March 1991 NCVHS meeting. Health assessment and surveillance are two of the necessary functions of public health departments. Although assessment is needed at all levels of government, it is at the local or community level where public health issues are identified and solutions effected. Past experience has indicated that at the State and community level, statistics, statistical methodology, and the resources needed to conduct assessment and surveillance are inadequate.

Current Year's Activities

The Subcommittee held three meetings and three working sessions during 1991. At each meeting testimony from various organizations concerning their programs for developing community- and State-level data, as well as their perspective on data needs, was obtained. In particular, the presenters were asked to comment on the following issues that are of major concern to the Subcommittee:

- The incorporation of State- and community-level identifiers in major Federal data sets.
- The ability and commitment of data collection agencies and organizations to tabulate and disseminate community- and State-level health statistics.

- The adequacy of health and population data currently available to carry out assessment and surveillance of health and health care issues and problems at the State and community levels.
- The need to create linkages among data sets to improve their usefulness and power to assess health and health care problems.
- The need to provide resources and technical support to State and local health agencies related to surveillance and monitoring progress on the year 2000 health objectives.

The Subcommittee reviewed the current status of State centers for health statistics and examined three models. In particular, the Subcommittee explored the State centers' abilities to carry out the assessment and evaluation functions at the State and community levels.

The Subcommittee reviewed the draft of the selected Health Status Indicators for the year 2000 health objectives. A letter was sent to Dr. Manning Feinleib, chair of the 22.1 Committee that drafted the health status indicators, expressing the Subcommittee's overall support for the work of the 22.1 Committee. The letter also expressed concerns with several of the proposed indicators and identified areas where indicators need to be developed. In particular, the Subcommittee recommended that wherever possible indicators be specified for minority groups and other special populations in order to monitor progress in reducing disparities. The areas of mental health and functional status (disabilities) were identified as areas where better indicators must be developed.

Continuing Work Plan

The Subcommittee intends to carry out the following work plan in 1992:

- Continue to monitor progress towards achieving the year 2000 objectives.
- Continue to work with Federal and State agencies and organizations to identify gaps in health statistics at the State and community levels.
- Review efforts in establishing mechanisms to share and link data sets at the national, State, and community levels.
- Review and monitor the annual *Prevention Profile* to appear in *Health, United States, 1991*.
- Review alternative methodological approaches for community health assessment.
- Prepare a report, for consideration by the full Committee, that outlines major issues with respect to health data at the State and community levels, and makes recommendations for improvement in the collection, tabulation, analysis, and access to State- and community-level health data.

Confidentiality

The Work Group on Confidentiality was established at the March 1991 meeting of the full National Committee on Vital and Health Statistics (NCVHS) with a charge to the group being approved at the June meeting of the full Committee. The two major objectives for 1991–92 were:

- **The explication of current public policy issues surrounding the release and disclosure of data and**
- **The development of a strategic approach to the long-term management of these critical issues.**

Background

The Work Group on Confidentiality was formed as a result of discussions during the March 1991 meeting of the full Committee regarding issues related to the tabulation and publication of health data, including vital statistics data, and the production of public use data tapes. The Work Group was formed out of the need to provide researchers with the maximum amount of data while still maintaining its confidentiality. During an early Work Group conference call, it became clear that other interagency, interdepartmental, and National Academy of Sciences work underway on confidentiality and privacy may be informative but will not necessarily address the broad questions of concern to the National Committee. The consensus of the group was that the NCVHS is in a unique position to assist specific agencies in their deliberations, and to heighten awareness of the advantages of proactive policy positions on data linkage, access, security, and the role of the Social Security number or other unique identifiers.

Current Year's Activities

The Work Group held three working sessions and two conference calls during 1991. The primary purpose of the first meeting was to produce a work plan and charge for the group.

The second and third working sessions discussed and finalized plans for a public hearing to be held in January 1992. Invited representatives of public and private agencies will respond to a series of questions on access and privacy, data security, data release, and the use of unique identifiers.

A review was undertaken of recently prepared and published documents in the areas of data linkage and data confidentiality prepared by the National Research Council Panel on Confidentiality and Data Access; the Agency for Health Care Policy and Research; the National Center for Health Statistics; and the General Accounting Office.

During the year, various Work Group and staff members attended the following:

- A session of the Public Health Conference on Records and Statistics (July 1991) devoted to public use data tapes and data confidentiality.
- A meeting with Joan Turek-Brezina, Chair, DHHS Task Force on Privacy of Private Sector Health Records (October 1991).

Continuing Work Plan

During 1992, the Work Group will carry out the following work plan:

- Conduct a public hearing on January 15 to receive input from invited participants.
- Prepare syntheses of information from January hearings and documents and present results to NCVHS in March 1992.
- Prepare draft report for June 1992 meeting with strategic recommendations for ongoing role of NCVHS in relation to data confidentiality.

Appendix I.
Legislative Authority for the National Committee on Vital and Health Statistics From the Public Health Service Act

Section 306, subsection (k) of Public Health Service Act

(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 sixteen members.

(2) (A) The members of the Committee shall be appointed by the Secretary from among persons who have distinguished themselves in the fields of health statistics, health planning, epidemiology, and the provision of health services. Except as provided in subparagraph (B), members of the Committee shall be appointed for terms of four years.

(B) (i) In the case of membership terms on the Committee under this subsection (as in effect prior to January 1, 1988) which expire in calendar year 1988, the appointments to three such terms in such calendar year shall be for a period of four years and the appointments to two such terms in such calendar year shall be for a period of three years, as designated by the Secretary.

(ii) In the case of membership terms on the Committee under this subsection (as in effect prior to January 1, 1988) which expire in calendar year 1989, one such term shall be extended for an additional consecutive one-year period, as designated by the Secretary.

(iii) In the case of membership terms on the Committee under this subsection (as in effect prior to January 1, 1988) which expire in calendar year 1990, two of such terms shall each be extended for an additional consecutive one-year period, as designated by the Secretary.

(3) Members of the Committee shall be compensated in accordance with section 208(c).

(4) It shall be the function of the Committee to assist and advise the Secretary—

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

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

(C) 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 Veterans' Administration, the Department of Defense, and other Federal agencies concerned with health and health services;

(D) 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)(i);

(E) 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;

(F) 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; and

(G) 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.

(5) 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.

Appendix II. Charter

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

CHARTER

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

PURPOSE

The Secretary is charged under Section 306(k) of the Public Health Service Act, as amended, 42 U.S.C. 242k(k), with the responsibility to collect, analyze and disseminate national statistics on vital events; the extent and nature of illness and disability of the population of the United States; the impact of illness and disability of the population on the economy of the United States, and on other aspects of the well-being of its population; environmental, social, and other health hazards; determinants of health; health resources and the supply of services by health institutions; utilization of health care; health care costs and financing; family formation, growth, and dissolution; to undertake research, demonstrations, and evaluations respecting new or improved methods for obtaining current data on the matters referred to above; to undertake epidemiological research, demonstrations, and evaluations on such matters; to provide selected technical assistance to State and local jurisdictions; to coordinate health statistical and epidemiological activities of the Department; and to engage in cooperative endeavors with other countries to foster research consultation and training programs in statistical activities.

This Committee shall provide advice, consultation, and assistance and make recommendations to the Secretary through the Assistant Secretary for Health on policies and plans in developing major national systems of health data collection in the Department, on coordination of Federal health data requirements, and on analysis over a wide range of questions relating to general health problems of the population, health care resources, the use of health care services and health care financing and expenditures. In these matters, the Committee shall consult with the Health Care Financing Administration and other components of the Department, other Federal entities and non-Federal organizations as appropriate.

AUTHORITY

Section 306(k) of the Public Health Service Act, as amended, 42 U.S.C. 242k(k). The Committee is governed by provisions of Public Law 92-463 (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:

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

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

(C) 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; 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;

(D) with respect to the design of and approval of health statistical and health information systems concerned with collection, processing, and tabulation of health statistics within the Department of Health and Human Services, 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);

(E) 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;

(F) 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;

(G) in the development of a report on the state of the Nation's health, its health services, their costs and distributions, to make proposals for improvement of the Nation's health statistics and health information systems, at such intervals as may be required by the Congress;

(H) in establishing standards to assure the quality of health statistical and epidemiological data collection, processing, and analysis; and

(I) with respect to data on the effects of the environment on health.

STRUCTURE

The Committee shall consist of 16 members, including the Chair. The members of the Committee shall be appointed by the Secretary from among persons who have distinguished themselves in the fields of health statistics, health planning, epidemiology, and the provision of health services. The Secretary shall appoint the Chair for a one-year period, renewable at the discretion of the Secretary.

Members shall be invited to serve for overlapping four-year terms. 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 expiration of the term for which their predecessor was appointed shall be appointed only for the remainder of such term. A member may serve after the expiration of their term until a successor has been appointed.

Subcommittees composed of members of the parent Committee may be established 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 Chair shall appoint ad hoc subcommittees, composed solely of members of the parent Committee, as necessary to address specific issues for consideration. The subcommittees shall make their recommendations to the parent Committee. Timely notification of the subcommittees and ad hoc subcommittees, including charges and membership, shall be made in writing to the Department Committee Management Officer by the Executive Secretary of the Committee.

Management and support services shall be provided by the National Center for Health Statistics, Centers for Disease Control.

MEETINGS

Meeting 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.

Meeting 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 meeting 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 the rate of $188 per day, plus per diem and travel expenses in accordance with the Standard Government Travel Regulations.

ANNUAL COST ESTIMATE

Estimated annual cost for operating the Committee, including compensation and travel expenses for members but excluding staff support, is $126,054. Estimated annual man-years of staff support required is 2.5, at an estimated annual cost of $113,171.

REPORTS

An annual report shall be submitted to the Secretary through the Assistant Secretary for Health, not later than January 31 of each year, 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

The duration of the National Committee on Vital and Health Statisitics is continuing, and a new charter shall be filed no later than July 23, 1992, the date of the expiration of the next two-year period following the date of the statute establishing this advisory committee, in accordance with Section 14(b)(2) of Public Law 92-463.

APPROVED

7/26/90
Date

Louis W. Sullivan, MD
Louis W, Sullivan, M.D.
Secretary

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

NOTICE OF RECHARTERING OF THE NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

This Committee was established by statute and has functions which are of a continuing nature so that its duration is not governed by Section 14(a) of the Federal Advisory Committee Act but is otherwise provided for by law. The Committee is rechartered in accordance with Section 14(b)(2) of said Act.

7/26/90
Date

Louis W. Sullivan, MD
Louis W. Sullivan, M.D.
Secretary

Appendix III. Roster of the National Committee on Vital and Health Statistics

Department of Health and Human Services
Office of the Assistant Secretary for Health

Chairman

Judith Miller Jones (1992)
Director
National Health Policy Forum
2021 K Street, NW., Suite 800
Washington, DC 20052

Ex Officio

Manning Feinleib, M.D., Dr.P.H.
Director, National Center for
Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782

Executive Secretary

Gail F. Fisher, Ph.D.
Associate Director, Office of
Planning and Extramural Programs
National Center for Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782

Current Membership

(Date Appointment Expires)

John T. Ashley, M.D. (1994)
Executive Director
University of Virginia Hospitals
Box 148
Charlottesville, VA 22908

Laurence G. Branch, Ph.D. (1992)
Director of Long-term Care Research
Abt Associates Inc.
55 Wheeler Street
Cambridge, MA 02138

William F. Bridgers, M.D. (1994)
Professor of Public Health
School of Public Health
University of Alabama at Birmingham
University Station
Birmingham, AL 35294

Nancy L. Cannon, Ph.D. (1993)
Senior Consultant
Private Health Care Systems
20 McGuire Road
Lexington, MA 02173

Frederick A. Connell, M.D. (1992)
Acting Director
Maternal & Child Health Program
School of Public Health and
Community Medicine
University of Washington, SC-37
Seattle, WA 98195

Paul Y. Ertel, M.D. (1994)
Clinical Professor
Department of Pediatrics
University of Michigan
400 Maynard Street, Suite 11A
Ann Arbor, MI 48104

Donna Ganzer (1995)
Vice President
Health Care Management and
Patient Services
American Hospital Association
840 North Lake Shore Drive
Chicago, IL 60611

Sister Irene V. Kraus (1993)
President
Daughters of Charity National
Health System
11775 Borman Drive
St. Louis, MO 63146-6905

Risa J. Lavizzo-Mourey, M.D. (1993)
Chief, General Internal Medicine
Philadelphia VA Medical Center
University and Woodland Avenues
Philadelphia, PA 19104

David Mechanic, Ph.D. (1992)
Institute for Health, Health Care
Policy, and Aging Research
Rutgers University
30 College Avenue
New Brunswick, NJ 08903

Carlos A. Moreno, M.D. (1994)
Associate Professor
Department of Family Practice
University of Texas Health Science
Center at San Antonio
7703 Floyd Curl Drive
San Antonio, TX 78284

Byron C. Pevehouse, M.D. (1995)
135 Mountain Spring Avenue
San Francisco, CA 94114–2119

Bruce Steinwald (1995)
Vice President
Health Technology Associates
Columbia Square
555 Thirteenth Street, NW.
Washington, DC 20004–1109

George H. Van Amburg (1993)
State Registrar and Chief
Office of the State Registrar and
Center for Health Statistics
Michigan Department of Public Health
P.O. Box 30195
Lansing, MI 48909

Thomas T.H. Wan, Ph.D. (1995)
Professor and Director
Williamson Institute for Health Studies
Medical College of Virginia
Virginia Commonwealth University
Box 206
Richmond, VA 23298

Members Retired During 1990

Ronald G. Blankenbaker, M.D. (1991)
Vice President for Medical Affairs
St. Vincent Hospital
and Health Care Center
2001 West 86th Street
Indianapolis, IN 46260

William R. Felts, Jr., M.D. (1991)
Professor of Medicine
George Washington University
Medical Center
2150 Pennsylvania Ave., NW.
Washington, DC 20037

Karel M. Weigel, R.R.A. (1991)
Division of Administrative Services
Mayo Clinic
200 SW., First Street
Rochester, MN 55905

Meeting Dates

All meetings held in Washington, DC

March 6–7, 1991
June 5–7, 1991
November 6–8, 1991

Appendix IV. Subcommittees of the National Committee on Vital and Health Statistics

Executive Subcommittee

Current Roster

Chairman

Judith Miller Jones (1992)
Director
National Health Policy Forum
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Meeting Dates

Meetings held in Washington, DC

March 6, 1991 (working session)
April 4, 1991

Meeting held in Shepherdstown, WV

August 14–16, 1991

Functions and Process for the Executive Subcommittee, National Committee on Vital and Health Statistics

Background

At the November 8, 1985, meeting of the NCVHS, based upon the recommendations of the Ad-hoc Subcommittee on Policy and Directions, there was established an Executive Subcommittee of the NCVHS.

Purpose

The Executive Subcommittee was established to assist the Chairman, NCVHS, in administering the activities of the NCVHS to facilitate and expedite accomplishment of policies determined by the full Committee, and in providing liaison with governmental and non-governmental organizations. The functions and procedures governing the Executive Subcommittee are subject to approval and modification by the full Committee.

Composition

The Chairman of the NCVHS is the Chairman of the Executive Subcommittee. Additionally, the Chairman, NCVHS shall appoint, subject to ratification of the full Committee, three members to the Executive Subcommittee on an annual basis, with the option of reappointment, if appropriate. When appropriate, the three members will be selected one member each from those who have 1, 2, or 3 years remaining in their terms of appointment to the NCVHS. The NCVHS Executive Secretary, or designee, will be an ex officio member of the Executive Subcommittee.

Functions

Specific responsibilities of the Executive Subcommittee are to:

- Identify and recommend issues for full Committee and Subcommittee attention.
- Develop Committee agendas with a view towards planning several agendas in advance.
- Develop annual NCVHS Report.
- Coordinate and facilitate Subcommittee activities.
- Advise National Center for Health Statistics (NCHS) or other appropriate agencies on allocation of annual NCVHS budget and on resource needs for future years.
- Conduct other business delegated to it by the full Committee.

Procedures and Process

The Executive Subcommittee is empowered to act between full Committee meetings on those activities delegated to the Subcommittee, their actions subject to ratification by the full Committee.

Specific activities include:

- In interim periods between the full Committee meetings of the NCVHS, the Executive Subcommittee will monitor, through telephone calls, mail, and/or meetings, the progress of work and other activities relevant to the current approved program of the full Committee. Working with staff and subcommittee Chairmen, activities will be facilitated, and problems and issues identified and resolved to accomplish the planned program.

- The Executive Subcommittee will review work plans developed by the subcommittees and make recommendations to the full Committee.
- The Subcommittee may confer with Chairmen of other subcommittees or others to consider particular problems or issues impacting on the work of the full Committee. These may include senior personnel in the Department and other public and private agencies with interest in considerations appropriate to the responsibilities of the Committee.
- Minutes of any meetings of the Subcommittee will be prepared and mailed to the full Committee membership or presented at the next full Committee meeting. If work progresses by mechanisms other than meetings, appropriate reports will be made to the full Committee membership.
- The Chairman of the NCVHS or designee will report on the activities of the Subcommittee at each full meeting. This report will include an outline of the areas of concern of the Subcommittee and proposed plans for subsequent followup and activity.
- In unusual events where some actions, previously not approved by the Committee, may be required by the NCVHS and a meeting has not been scheduled, the Subcommittee may consider alternatives and make recommendations to the full Committee by mail or telephone. With concurrence, approved actions may be taken by the Chairman or other formally appointed representatives of the Committee.
- In the absence of the Chairman at an Executive Subcommittee or full Committee meeting, the Executive Subcommittee member with the most seniority on the NCVHS would act as Chairman.

Subcommittee on Medical Classification Systems

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Meetings held in Washington, DC

February 4, 1991
March 6, 1991 (working session)
June 6, 1991 (working session)
October 1, 1991 (conference call)
November 6, 1991 (working session)

Charge to the Subcommittee on Medical Classification Systems

It shall be the charge to this Subcommittee to monitor, evaluate, and formulate recommendations as appropriate in the following areas:

- The progress of decisions regarding *International Classification of Diseases, 10th Revision* with particular attention to the feasibility of, and necessity for, development of an *ICD-10-CM*, including alternative mechanisms and suggested time tables for a clinical modification.
- The progress towards implementation of *ICD-10* including ongoing dissemination of information; the development and dissemination of educational materials; the implementation of operational systems and programs to serve the whole of the user community, providers (physicians, hospitals, and ambulatory care), payers, researchers, and so forth.
- The development and use of derivative applications of the ICD, including specialty-specific compendia.
- The continuing process of the *ICD-9-CM* Coordination and Maintenance Committee and related activities since they are expected to serve as the

prototype for ongoing maintenance of *ICD-10*, including national and international activities.

- The progress of activities relating to the development and improvement of classification systems for procedures in the United States.
- The ongoing refinement of Diagnosis Related Groups (DRGs), including non-Medicare applications.
- The progress towards improvement of data quality and coding accuracy, systems for automated coding of medical diagnoses, and patient record documentation.

Subcommittee on Long-Term Care Statistics

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Meeting Dates

Meetings held in Washington, DC

March 6, 1991 (working session)
April 18, 1991
June 6, 1991 (working session)
September 10, 1991 (working session)
November 7, 1991 (working session)

Charge to Subcommittee on Long-Term Care Statistics

The multifaceted universe of chronic or long-term care of interest to the Subcommittee consists of those therapeutic and preventive health services and social and personal services required to compensate for or preclude losses in independent functioning resulting from physical or cognitive impairments. These services take place in a wide range of institutional, community, and residential settings. These services are provided by various kinds of professionals as well as lay persons and are paid for by a number of federal, State, and local public and private sources, and sometimes are provided without compensation. All of these factors make consideration of data adequacy a complex undertaking.

There is a link between disability and long-term care, and the causes of disability are varied: developmental, injury-related, chronic disease-related including mental health conditions, related to aging or frailty, or to conditions secondary to a primary disability. Disabilities often dictate the need for assistance in the activities of daily living (ADLs) or instrumental ADLs (IADLs). However, care of the disabled or those at risk in the disabling process is not limited to that resulting from ADL and IADL limitations; rather, it requires a complete and integrated system of longitudinal care.

The Subcommittee's charge is to describe and assess the adequacy of statistical information on needs, access, utilization, effectiveness, financing, and eligibility for long-term care as broadly defined. Projections suggest that this challenge will become greater in the future; as the Baby Boom generation ages and mortality rates continue to fall, the number of older persons will increase. The prevalence of some chronic, debilitating conditions and co-morbidities will increase, and the complexities of assuring equitable and effective financial and geographic access to appropriate care will expand. An increasing capability for therapeutic and preventive intervention technologies and strategies, such as deinstitutionalizing many with disabilities, may lead to further fragmentation of services and their financing and further complicating data adequacy. The work plan of this Subcommittee will need to evolve in response to all of these factors; this will be a multiyear undertaking.

Subcommittee on Ambulatory and Hospital Care Statistics

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Meetings held in Washington, DC

January 16, 1991
March 6, 1991 (working session)
May 7, 1991
June 6, 1991 (working session)
September 19–20, 1991
November 7, 1991 (working session)

Charge to Subcommittee on Ambulatory and Hospital Care Statistics

- Conduct a thorough and systematic review of the Uniform Hospital Discharge Data Set (UHDDS) for the purpose of recommending any revisions needed to meet current and anticipated needs. Carry out this review in tandem with the Department of Health and Human Services (DHHS) and in close cooperation with the National Uniform Billing Committee. As part of the review process, receive appropriate input from other governmental agencies, the research community, and the private sector. Report preliminary results of the UHDDS review by the February 1992 NCVHS meeting and present a final report by the June 1992 NCVHS meeting.

- Monitor the responses within DHHS to the final report on the Uniform Ambulatory Care Data Set, which was submitted to the Assistant Secretary for Health by the NCVHS and the Interagency Task Force. Monitor any implementation plans that are developed by the agencies.
- Follow the efforts of the Uniform Claim Form Task Force for the Health Care Financing Administration (HCFA) 1500 to seek greater standardization of the definitions in use for place or site of health care services.
- Provide continuing liaison with the HCFA, the NCHS, and other relevant agencies concerning the statistical aspects of physician payment systems and other data systems and research and development projects concerned with patient-provider encounters.
- Follow these data systems and related activities by receiving periodic updates, having an opportunity to react to developments and, where appropriate, framing recommendations concerning their future course. Among those activities for which data policy, data coordination, and data quality issues will be reviewed are a) progress towards implementing the Medicare Common Working File, b) status of the revision of the HCFA 1500, c) progress towards implementation by the Medicare program of the unique physician identification number (UPIN), d) status of research and demonstration projects on prospective payment methodologies for ambulatory care, e) Medicaid data development, and f) development of the National Practitioner Data Bank.
- Follow plans for implementing the requirement for physician coding of diagnoses on the HCFA 1500. Examine issues of data quality and coordination.
- Follow the status of relative value scale research, development, and implementation through physician payment reform legislation and the associated data requirements.
- Consider the importance of emerging and projected quality of care activities for relevance to existing data systems and implications for revisions to those systems. Examine data quality issues related to measurement of the effectiveness and quality of care. Provide liaison with the Agency for Health Care Policy and Research for these types of activities.

Subcommittee on Health Statistics for Minority and Other Special Populations

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Meeting Dates

Meetings held in Washington, DC

January 22–23, 1991
March 6, 1991 (working session)
March 8, 1991
June 4, 1991
June 6, 1991 (working session)
October 17, 1991
November 7, 1991 (working session)

Charge to Subcommittee on Health Statistics for Minority and Other Special Populations

Recognizing the importance to the Department of Health and Human Services of collecting and disseminating valid and reliable health data on minority and other special populations, it shall be the Subcommittee's charge to:

- Review and make recommendations on the uniformity and adequacy of the collection, analysis, and dissemination of minority health data.
- Work with and support the Office of Minority Health and collaborating offices in their data-related minority health activities.
- Examine health data issues related to the medically indigent, including the medically underserved, uninsured, and underinsured to determine whether DHHS systems adequately address these issues, and make recommendations.

Subcommittee on Mental Health Statistics

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Meeting Dates

Meetings held in Washington, DC

February 7, 1991
April 18, 1991
June 6, 1991 (working session)
October 18, 1991
November 7, 1991 (working session)

Charge to Subcommittee on Mental Health Statistics

The Subcommittee will serve to identify important mental health statistical issues for the full Committee and to facilitate the integration of general health and mental health statistical systems. More specifically, it will

- Identify major gaps in mental health statistics.
- Explore the feasibility of filling existing gaps with ongoing data collection efforts; to explore how ongoing efforts might be supplemented.
- Examine areas of measurement development necessary to meet national goals or priorities.
- Work with the Public Health Service (PHS) and other DHHS agencies to identify areas of needed initiatives and opportunities for coordination of efforts and to bring in other relevant federal agencies.

- Examine how major data sources (that is, Medicare and Medicaid data) can be used to help meet mental health data needs.
- Explore opportunities for data linkage relevant to data bases collected by NCHS, HCFA, and other Federal agencies.
- Increase the availability, quality, and utility of data dealing with mental illness including the provision of public use data tapes.
- Coordinate the NCVHS review of the biennial publication, *Mental Health, United States.*

Subcommittee on State and Community Health Statistics

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Meetings held in Washington, DC

March 6, 1991 (working session)
April 19, 1991
June 6, 1991 (working session)
September 11–12, 1991
November 7, 1991 (working session)
December 11–12, 1991

Charge to Subcommittee on State and Community Health Statistics

Background

The Institute of Medicine Report *The Future of Public Health*[1] identifies health assessment as one of the necessary core functions of public health departments. To quote from the report:

> The committee recommends that every public health agency regularly and systematically collect, assemble, analyze, and make available information

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[1] Institute of Medicine, The future of public health. National Academy of Sciences. Washington National Academy Press. 1988.

on the health of the community, including statistics on health status, community health, needs, and epidemiologic and other studies of health problems.

Health assessment is necessary at all levels of government. However, it is at the local or community level where public health issues are identified and solutions effected. Unfortunately, the resources (people, money, accepted methodologies, and statistics) to conduct such assessments at the community level are often inadequate.

Healthy People 2000,[2] the Year 2000 Health Objectives, underscores the need for assessment at the community level. Priority area 22, Surveillance and Data Systems, addresses the public health problems and evaluates solutions. The National Center for Health Statistics (NCHS), as lead agency for implementing priority area 22, must work with public and private agencies to track the objectives, identify data gaps, and build statistical capacity at the State and local levels. As the Year 2000 process proceeds, many of the general concerns related to community health assessment will become focal points of Year 2000 initiatives.

The process of setting the Year 2000 objectives has brought together many individuals and organizations from the public and private sectors. These groups will be instrumental in implementing intervention strategies and evaluating success toward meeting the objective targets. The National Committee on Vital and Health Statistics (NCVHS) has the opportunity to complement these activities by utilizing its broad advisory role to assist the Public Health Service in policy development related to data availability and need.

The charge of the Subcommittee shall be to:

- Monitor progress toward achieving the Year 2000 Health Objectives 22.1–22.7.
- Work with NCHS, other Federal and State agencies, appropriate private agencies, and other subcommittees of the NCVHS to review and identify gaps in current health statistics including social, environmental, mental health, social economic, health care, and disease statistics.
- Review efforts to link national, State, and local data sets including data collected and compiled by the private sector for use in evaluating the effectiveness of disease and injury prevention and therapeutic intervention strategies.
- Participate with other groups in a process to recommend any necessary action to improve the comparability and compatibility of health statistics collected and published through various government and private agencies.
- Identify and review current alternative methodological approaches to community health assessment.
- Review and monitor the annual *Prevention Profile*, which will appear with *Health, United States* throughout the 1990's.

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[2] Department of Health and Human Services. Healthy people 2000: National health promotion and disease prevention objectives for the Nation. Washington: Public Health Service. U.S. Government Printing Office. 1990.

Work Group on Confidentiality

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Meetings held in Washington, DC

May 22, 1991 (conference call)
June 5, 1991 (working session)
September 12, 1991 (working session)
November 7, 1991 (working session)

Charge to Work Group on Confidentiality

The Work Group on Confidentiality has two objectives for 1991–92: the explication of current public policy issues surrounding the release and disclosure of data, and the development of a strategic approach to the long-term management of these critical issues.

In setting the course of the Work Group, the basic assumption was that the National Committee members have a common goal. Health care data should be made available to researchers and policy analysts (at the appropriate levels of disaggregation), *with* the correct safeguards in place to protect confidentiality.

Background

The Work Group on Confidentiality was formed as a result of discussion during the March 1991 meeting of the National Committee. The members of the Work Group held a conference call in May 1991. In the discussion, it became clear that other interagency and interdepartmental and NAS work underway on confidentiality and privacy may be informative but will not necessarily address the broad questions of concern to the National Committee. The consensus of the group was that the NCVHS is in a unique position to assist specific agencies in their deliberations, and to heighten awareness of the advantages of proactive policy positions on data linkage, access, security, and the role of the Social Security number or other unique identifiers.

Proposed Activities 1991–92

The Work Group on Confidentiality will try to describe the delicate balance between data access and privacy that is being tested by increasing pressure for release of sensitive information at the same time that technology makes data transfers and disaggregation easier than ever before. To evaluate the methods and assumptions currently in place, the Work Group proposes to undertake the following activities:

- Representation at the Public Health Conference on Records and Statistics July 1991 meeting.
- Meeting of Work Group in late September 1991, to design a series of questions about how other Federal, State, and local agencies set policy on access and privacy, definitions of "use" of data associated with levels of disaggregation, conditions tied to data release and their practical application, who "controls" public data, and possible changes now underway or planned that may impact the access and privacy equilibrium.
- Open meeting in late 1991 to which Federal, State, local, private sector, and Health and Human Services representatives will be invited to respond to the Work Group questions. At this session the Work Group will invite discussion of specific data concerns recently raised with the NCHS related to release of vital statistics data.
- Specifically, the Work Group will solicit input from Social Security Administration, Department of Defense, Veterans Administration, NCHS, HCFA, AHCPR, and State and local organizations, will look at current policies related to social security number, the benefits to merged/linked/longitudinal files; and the obstacles to maintaining these files.
- Working sessions, winter 1991–92, to prepare an analysis of the problems found and strategic approach to the longer term resolution of problems arising from maintaining an appropriate balance between data access and privacy.

Appendix V. Report of the Second Workshop on Improving Cause-of-Death Statistics

Executive Summary

Information on mortality patterns is a major resource for health policy and research. Much of this information is based on the causes of death reported on death certificates. Participants in the Second Workshop on Improving Cause-of-Death Statistics, held April 21–23, 1991, in Virginia Beach, Virginia, developed a wide range of recommendations for enhancing physician education and quality assurance efforts related to cause-of-death reporting and also laid groundwork for a comprehensive assessment of the current methods and conceptual framework for certifying cause of death.

The second workshop, cosponsored by the National Center for Health Statistics (NCHS) and the National Committee on Vital and Health Statistics, was held to continue efforts initiated at a landmark workshop in October 1989 to harness the energies of the public and private sectors in improving the reporting of cause of death by physicians, coroners, and medical examiners. Participants included 53 representatives of Federal, State, local, and professional organizations.

Foremost among the 1989 recommendations was the need for a broad-based educational effort, with primary focus on the physician. Recommendations for physician education at the second workshop again emphasized the need to seek multiple opportunities for training on the importance of accurate certification and on the mechanics for achieving it. The second workshop further stressed the need for feedback to physicians on the information obtained from death certificates and feedback from physicians on the problems they encounter certifying cause of death.

Participants endorsed the recommendations of the 1989 workshop for improved quality assurance and quality control of death records and encouraged the States to implement as many of them as possible. These recommendations, which were viewed as actions States can take now, included development and dissemination of a model quality assessment program that incorporates primary on-site review at point of origin of the death certificate, querying by State registrars, periodic audit through review of source documents (that is, medical records), and amendment of records when more information becomes available.

However, the group moved beyond quality assurance procedures that can be applied to the current system to recommend researching a totally new way of collecting information on cause of death in the future.

The new approach would respond to the multifactorial nature of death in the majority of decedents, especially the elderly, and should not be limited by either the current paper form or the current format for medical certification of cause of death. Investigation and development of electronic and *interactive* techniques for training physicians, for guiding physicians in completing the medical certification, and for transmitting information were proposed. Software development was recommended to support the new approach.

Specific workshop recommendations included the following:

Physician Education

- It is essential to convey the importance of cause-of-death information and to provide an overview of the process during medical school training. Educational materials should be tied to the appropriate and relevant clinical topics and linked with research on mechanisms of disease and death.
- Residency is considered the key time for educating physicians on cause-of-death reporting. Educational efforts should begin at the orientation of new residents and should be focused on the resident's first completion of a death certificate.
- Continuing medical education, either through self-study or other course work, on completion of the death certificate should be considered as a requirement for relicensure and/or medical society membership.
- Continuing medical education modules should be developed for practicing physicians. These modules should be tied to clinical research and problem areas.
- Training should be targeted to physicians who complete a significant number of death certificates in their practice. A study should be undertaken to determine which physicians certify deaths.
- Medical examiners and coroners are a resource for training on cause-of-death certification in medical schools and can also serve as a resource to State registrars and hospitals by serving as consultants, reviewing death certificates, and providing feedback to certifiers.
- Local health officers also can serve as a resource to States for querying cause of death.
- Assuring accurate completion of the death certificate is part of continuous quality improvement in the hospital. There should be one or more focal points in the hospital for assuring proper completion of death certificates.
- The role of the medical records department in fostering accurate cause-of-death reporting in the hospital should be increased.
- Completion of training in cause-of-death certification should be a requirement for staff privileges.
- Hospitals should facilitate submission of amendments to death certificates after autopsy findings are received.
- The usefulness of death certificate information for individual programs and specialties, from both a clinical and research perspective, must be marketed to the physician community. A medical media "blitz" is needed.

- States should develop action plans for improving cause-of-death certification and convene planning meetings with the interested parties in their respective States.

Evaluation and Software Development

- There should be a total reevaluation of how medical information is collected through the death certificate. This would include evaluation of alternative designs for the medical certification of cause of death and for the order of reporting underlying and contributing causes.
- Uniform software for completion of the death certificate, for use by all jurisdictions, should be developed. The new software should be interactive and user (physician) friendly. Although aimed at proper completion of the certificate, the new software should also be educational.
- Software should be developed for completing the entire death certificate. Several modules should be considered to meet needs of various users and producers of death certificates.
- The first module undertaken should be the medical module, focusing on the cause-of-death certification by the physician.
- Hospital autopsy data should be incorporated into the process.
- System design requirements for the medical module should be developed within 2 years; the medical module should be operational by 1996.
- The National Center for Health Statistics should coordinate the development of the interactive approach and software. Medical examiners and coroners, physician organizations, the National Funeral Directors Association, States, and the Association for Vital Records and Health Statistics are all key players in development and implementation of the medical module.
- The model State vital statistics act and regulations, which currently are undergoing review and revision by the States and NCHS, should take into consideration collection and issuance of death information through electronic means.

Second Workshop on Improving Cause-of-Death Statistics

April 21–23, 1991
Virginia Beach, VA

Introduction

The Second Workshop on Improving Cause-of-Death Statistics on April 21–23, 1991, in Virginia Beach, Virginia, brought together 53 individuals from Federal, State, local, and private sector organizations for 3 days of intense discussion on approaches for improving the quality of cause-of-death information. The workshop was cosponsored by the National Center for Health Statistics (NCHS) and the

National Committee on Vital and Health Statistics (NCVHS) as a followup to the landmark workshop held on this topic in October 1989. Attendees at the second workshop included representatives of most of the organizations that participated in the first meeting, as well as a number of additional organizations with an interest in improving mortality data. A copy of the agenda and a list of participants by organization are included in appendixes A and B.

The second workshop was held to continue efforts initiated at the October 1989 workshop to harness the energies of the public and private sectors in improving the reporting of cause of death by physicians, coroners, and medical examiners. Cause-of-death information is widely used by health policymakers and researchers in examining mortality patterns and establishing priorities for future actions. The 1989 workshop produced a number of significant recommendations that guided subsequent policy and research for improving mortality statistics. Foremost among the 1989 recommendations was the need for a broad-based educational effort, with primary focus on the physician. A second major recommendation was for the development and dissemination of a model quality assessment program. These two broad areas were the focus of the second workshop.

Summary of Recommendations

Participants in the second workshop developed a wide range of recommendations for enhancing physician education and quality assurance efforts and also laid groundwork for a comprehensive assessment of the current methods and conceptual framework for certifying cause of death. Investigation and development of electronic and *interactive* techniques for training physicians, for guiding physicians in completing the medical certification, and for transmitting information were proposed. As in the first workshop, recommendations for physician education emphasized the need to seek multiple opportunities for training on the importance of accurate certification and on the mechanics for achieving it. However, this second workshop also stressed the need for feedback to physicians on the information obtained from death certificates and feedback from physicians on the problems they encounter certifying cause of death.

Progress Reports

The workshop began with a review of the progress achieved in implementing the recommendations from the 1989 meeting. Dr. Manning Feinleib, Director of NCHS, reported on initiation of an evaluation of the format, procedures, and cognitive processes associated with completing the medical certification of the death certificate; plans for continuing medical education modules; development of two exhibits to educate the public health community and physicians on the importance of accurate completion of cause-of-death information, and development of a two-sided laminated sheet containing instructions for completing the cause-of-death section of the death certificate. Dr. Feinleib solicited the assistance of physician groups with the planned evaluation study, which will involve structured interviews with physicians in specialties frequently responsible for completing a death certificate.

George Van Amburg, representing the Association for Vital Records and Health Statistics (AVRHS), described the current status of activities at the State level to improve reporting of cause of death. The majority of States responding to an AVRHS survey had conducted training sessions for physicians since the first workshop, and many had increased querying of questionable causes of death or improved edits of the death records. Approximately half of the States responding felt these efforts had improved quality of the data.

Dr. Ronald Blankenbaker, NCVHS Chairman, reported on the Committee's strong support of the recommendations from the first workshop, its transmittal of the workshop report and recommendations to the Assistant Secretary for Health for policy consideration within the Department and publication of the document in the Committee's 1990 annual report, and the sponsorship with NCHS and AVRHS of the educational exhibits.

A summary of all of the progress reports is contained in appendix C.

Challenge to Participants

Dr. Joanne Lynn, Director of the Division for Aging Studies and Services at The George Washington University Medical Center, challenged the group to address the implications for cause-of-death reporting for the elderly population, where the majority of decedents will have multiple conditions, any of which could have caused the death. Contrasting this to the beginning of the 20th century, Dr. Lynn asserted that, "Once you make it past war, violence, and auto accidents, your death will be multifactorial." She maintained that physicians often are presented with a "fundamentally incoherent task" in certifying a chain of causation for death and urged that the system be made more user friendly to promote recording of accurate and meaningful information. As an alternative to the current format, Dr. Lynn suggested that the physician list all significant established diagnoses and star the one-three conditions that actively contributed to dying "at this time and in this way." Dr. Lynn further expressed her concerns that nonphysicians should be able to pronounce death outside of the hospital and that, in the majority of cases, it should not be necessary to include the cause of death on the certified copies of the death certificates used by the decedent's family for numerous legal and financial purposes.

Mr. Charles Sirc, State Registrar in New Hampshire, followed Dr. Lynn's remarks by providing information about specific activities in New Hampshire. He described a dual certification process and a recent law that enables nurses to pronounce death in certain situations. The State of New Hampshire also can issue death abstracts that do not contain the cause of death. Mr. Sirc further reported on his various activities in New Hampshire to reach physicians on the importance and mechanics of accurate cause-of-death certification. These efforts include participation in grand rounds through the auspices of the continuing education coordinator at Dartmouth Medical School, provision of packets of information to new physicians and to relicensees in the State, publishing articles in medical society journals and newsletters, and working collaboratively with medical records personnel and funeral directors.

Dr. Feinleib concluded that use of the death certificate is in a transitional stage and that it is necessary to define better what health policymakers and researchers actually need from the death certificate. Citing cause-of-death information as one of the most useful public health resources available, Dr. Feinleib encouraged working within the current system while initiating efforts to consider more fundamental changes to the format and approach.

Workshop Recommendations

Following these presentations, participants divided into four breakout sessions: two devoted to physician education and two to quality assurance and control programs. After discussing issues and recommendations in these four small sessions, the two groups focusing on physician education combined and the two working on quality assurance and control combined. The resulting recommendations from these combined efforts follow.

Education of Physicians

Participants addressed each of the recommendations from the first workshop and considered how they could be advanced and extended. They reconfirmed that there should be multiple points of training at various times in the physician's education and practice and through as many disciplines as possible.

Medical School

- Although residency is considered the key time for educating physicians on cause-of-death reporting, it is essential to convey the importance of the information and to provide an overview of the process during medical school training. Clinical faculty should be targeted for initial training so that educational materials can be tied to the appropriate and relevant clinical topics and linked with research on mechanisms of disease and death. Disciplines most likely to have a direct interest in cause-of-death reporting are epidemiology, preventive medicine, and biostatistics; pathology; geriatrics; internal medicine; family practice; and oncology.
- Medical school faculty can be approached through the division directors, who determine curricula in the medical schools, or through professional societies.
- Medical students also can be reached through national student organizations and the student section of the American Medical Association (AMA).

Residency

- Educational efforts should begin at the orientation of new residents and should be focused on the resident's first completion of a death certificate. International medical graduates who have not received training on cause-of-death reporting in medical school may need supplemental training on the topic. Training should emphasize accurate reporting of both causes of death and manner of death.
- The residency director should be well versed in the proper completion of the medical certification and should review the death certificates of his or her residents and provide constructive feedback.
- Other opportunities for training during the residency program include grand rounds, clinical pathology conferences, and hospital morbidity and mortality conferences. Residents also can be reached through the residents section of the AMA and physician specialty groups.
- The Accreditation Council for Graduate Medical Education (ACGME) could be approached about making education in completion of the death certificate a requirement for residency.

Licensure and Board Certification

- Continuing medical education, either through self-study or other course work, on completion of the death certificate should be considered as a requirement for relicensure and/or medical society membership. This requirement may be particularly appropriate for specialties that complete substantial numbers of death certificates.
- The first workshop recommended that a question on cause-of-death certification be added to part 3 of the National Boards. This recommendation was expanded to include part 1 of the National Boards and specialty board exams. This should be pursued through professional organizations or by personal contact. Even if a question is not always included on each of these exams, the study book for the respective exam should include sample questions on the subject.

Practicing Physicians

- The workshop endorsed the development of continuing medical education modules for practicing physicians. These modules should be tied to clinical research and problem areas, with a case-oriented approach.
- Consideration should be given to use of "training decks" to provide physicians experience in completing medical certifications for a wide variety of case histories. Training decks are used effectively by NCHS in developing the proficiency of medical coders.
- Interactive technology should be applied to the training of physicians and to the actual completion of the death certificate. A user-friendly system would allow the physician to enter pertinent medical information into a personal computer, would query the certifier about causation and contributing factors, and would walk him or her through proper completion of the medical certification. Such a system could provide immediate feedback to and elicit feedback from the

certifier, overcoming much of the frustration that physicians currently experience in completing the death certificate.

- Nonpecuniary incentives should be considered for proper completion of the death certificate. Incentives and feedback are essential for changing attitudes and behavior.
- Physicians need encouragement and incentives to file amendments to death certificates when additional information becomes available.
- The availability of a short-form certified copy of the death certificate, which does not include cause of death, for use by the family might make physicians more comfortable in recording sensitive causes of death.
- Consideration should be given to revision of the death certificate format and instructions for cause of death to make them more compatible with physician training and the practice of medicine. This would include evaluation of alternative designs for the medical certification of cause of death and for the order of reporting underlying and contributing causes. The current format is standardized by international agreement with the World Health Organization (WHO).
- Training should be targeted to physicians who complete a significant number of death certificates in their practice. This is likely to include house officers, medical examiners, oncologists, cardiologists, geriatricians, and physicians practicing in nursing homes and hospices. The training should be tailored to the different settings.
- A study should be undertaken to determine which physicians certify deaths and whether a relatively few physicians are certifying a large proportion of the deaths in particular jurisdictions. It was noted that 30 States collect the physician identification number on the death certificate and that this could provide the basis for such a study.

Medical Examiners and Coroners

- Medical examiners and coroners are a resource for training in medical schools and can also serve as a resource to State registrars and hospitals for cause-of-death certification by serving as consultants, reviewing death certificates, and providing feedback to certifiers.
- Separate training materials should be developed for medical examiners and coroners.
- Results of a medical examiner autopsy should be fed back to the decedent's physician and the hospital, where appropriate.

Hospitals

- Assuring accurate completion of the death certificate is part of continuous quality improvement. Feedback is an essential element.
- There should be one or more focal points in the hospital for assuring proper completion of death certificates. Appropriate individuals include the director of continuing medical education, the quality assurance coordinator, or the director of medical records.

- The role of the medical records department in fostering accurate cause-of-death reporting in the hospital should be increased.
- Completion of training in cause-of-death certification should be a requirement for staff privileges.
- Hospitals should facilitate submission of amendments to death certificates after autopsy findings are received.
- The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) should require peer review of the death certificate for in hospital deaths.

States

- The querying program by State registrars should be viewed as a training tool. To the extent possible, physicians should be used to query other physicians about questionable cause-of-death certifications.
- Local health officers also can serve as a resource for querying cause of death.
- States should develop action plans for improving cause-of-death certification and convene planning meetings with the interested parties in their respective States.

Information Dissemination

- Physicians' newsletters and journals should be used to convey the value of cause-of-death information. A medical media "blitz" is needed.
- Whenever the mortality data are published, there should be a specific source citation that the information was obtained from the death certificates filed in State vital statistics offices.
- The *Morbidity and Mortality Weekly Report* (*MMWR*) published by the Centers for Disease Control could be used to highlight the importance of accurate cause-of-death reporting.
- While recognizing the sensitive nature of the annual release of hospital mortality information by the Health Care Financing Administration, this release provides an opportunity for parallel educational messages in the printed media about completion and uses of the death certificate.
- Medical cable television is an educational resource for the public and physicians.
- Science writers should be interested in the subject of mortality data and trends. The AMA sponsors an annual Science Writers Conference. It was noted that information dissemination is most effective when there is a human interest component.
- *Healthy People 2000* is a vehicle for educating the health care field about the importance of mortality data.
- The educational exhibit developed by NCHS, NCVHS, and AVRHS for physicians should be used at several professional meetings and evaluated.

- Training and other educational approaches must be evaluated to determine their effectiveness in improving cause-of-death certification.

Marketing

- The usefulness of death certificate information for individual programs and specialties, from a clinical and research perspective, must be marketed to the physician community.
- Specific examples should be provided of how allocation of resources and setting of program priorities are based upon mortality statistics.
- Influential organizations in the medical community should champion better reporting of cause of death on the death certificate. Such organizations include the AMA, the JCAHO, medical specialty societies, the Institute of Medicine, Physicians for Social Responsibility, and religious physician groups.

Quality Assurance

Participants endorsed the recommendations of the 1989 workshop for improved quality assurance and quality control of death records and encouraged the States to implement as many of them as possible. These recommendations, which were viewed as actions States can take now, included development and dissemination of a model quality assessment program that incorporates:

- Primary on-site review at point of origin of the death certificate.
- Querying by State registrars.
- Periodic audit through review of source documents (that is, medical records).
- Amendment of records when more information becomes available.

However, building on several of the recommendations for education of physicians, the group moved beyond quality assurance procedures that can be applied to the current system and presented a more radical set of recommendations for the future:

A Totally New Approach

- There should be a totally new way of approaching collection of information on cause of death.
- The new approach should not be limited by either the current paper form or the current format for medical certification of cause of death.
- The approach should use electronic, interactive means to achieve its goal of improved cause-of-death information.
- By necessity, such an approach requires considerable study and evaluation. The first step is a total reevaluation of how medical information is collected through the death certificate. As stated in the education recommendations, this would include evaluation of alternative designs for the medical certification of cause of death and the order of reporting underlying and contributing causes.
- This approach should promote greater uniformity, accuracy, and timeliness of cause-of-death information.

Model State Vital Statistics Act and Regulations

- The model State vital statistics act and regulations, which are currently undergoing review and revision by the States and NCHS, should take into consideration collection and issuance of death information through electronic means.

Software Development

- Software development should support the new approach.
- Uniform software for completion of the death certificate, for use by all jurisdictions, should be developed.
- The new software should be interactive and user (physician) friendly. Although aimed at proper completion of the certificate, it will be educational.
- Software should be developed for completing the entire death certificate. Several modules should be considered to meet the needs of various users and producers of death certificates.
- The first module undertaken should be the medical module, focusing on the cause-of-death certification by the physician.
- The software should contain feedback features, including prompts and an ad hoc report generator. The prompts would aid in determining the proper sequencing of medical conditions. These prompts could differ for physicians and medical examiners and/or coroners, as well as for different age groups.
- The module should use standard definitions for manner of death and injury at work.
- Hospital autopsy data should be incorporated into the process.
- System design requirements for the medical module should be developed within 2 years; the medical module should be operational by 1996.
- Practical issues, such as variation across hospitals in their capacity to adopt an interactive model, must be studied and evaluated.
- The National Center for Health Statistics should coordinate the development of the interactive approach and software.
- Medical examiners and coroners, physician organizations, the National Funeral Directors Association, States, and the Association for Vital Records and Health Statistics are all key players in development and implementation of the medical module.

Action

Participants articulated action steps to carry out the workshop recommendations and identified responsible groups. The organizational representatives suggested ways in which their respective organizations could play a role in achieving the recommended actions.

Action	Responsible Organizations
Publicize meeting and importance of improving quality of cause of death	All participants
Develop training materials	NCHS, with input from AMA, NMA, AVRHS, AMRA, physician speciality groups, NAME, IACME, AAMC, AAHC, NIH, ACGME, SMCDCME, and other CME groups
Disseminate and carry out educational activities	AAMC, ACGME, SMCDCME, AAHC, AMA, NMA, NAME, RWJF, AAFP, and States
Query certifiers as a training tool	States
Evaluate "how certifiers think"	NCHS and physician organizations
Evaluate "who certifies"	NCHS, AVRHS, and States
Evaluate reversing order of cause-of-death certification and alternative design of certificate and instructions	NCHS, NAME, AVRHS, States, physician organizations and specialty groups, and RWJF
Require review of death certificate quality within hospitals	JCAHO
Add questions to parts I and III of National Boards	National Board of Medical Examiners
Encourage making training in death certificate completion a requirement for residency and hospital staff priviliges	ACGME, physician specialty organizations, and JCAHO
Encourage use of medical examiners as resources to States and hospitals	NAME
Assign full-time staff at NCHS to address and coordinate recommendations	NCHS
Develop State action plans and convene State planning meetings	States, in association with State and local health officers, medical examiners and coroners, and funeral directors

Action	Responsible Organizations
Take into consideration collection and issuance of death information through electronic means	Model State Vital Statistics Act and Regulations Revision Committee, NCHS, AVRHS, and States
Develop system design requirements for an interactive death certificate	NCHS (coordinator), NAME, IACME, and physician organizations, National Funeral Directors' Association, AVRHS, States, and RWJF

Dr. Blankenbaker closed the meeting by congratulating the participants for their "very courageous" efforts to assess the situation in which the medical and statistical communities find themselves with respect to cause-of-death certification and to offer some very constructive and innovative ideas on how to improve the situation. He stressed the importance of nonpunitive and educational approaches to improving the quality of medical care and the quality of health data. Finally, he suggested first using the media to disseminate information about the workshop and its recommendations and next using the media to educate the physician community and the public at large on the importance of improving cause-of-death information.

Appendixes

Appendix A. Workshop agenda
Appendix B. List of participants by organization
Appendix C. Summary of progress reports

Appendix A

Second Workshop on Improving Cause-of-Death Statistics

April 21–23, 1991
Virginia Beach, VA

Agenda

Sunday, April 21

7:30 p.m.	Welcome - Manning Feinleib, M.D., Dr.P.H., Director, National Center for Health Statistics, and Ronald G. Blankenbaker, M.D., Chairman, National Committee on Vital and Health Statistics
8:00 p.m.	Reports from all attending organizations on recent activities related to improving cause-of-death reporting
9:30 p.m.	Adjourn

Monday, April 22

8:30 a.m.	Plenary session Explanation of format of breakout groups and what they are expected to accomplish Presentations on issues related to death certification: Physician - Joanne Lynn, M.D., M.A., FACP, Director, Division for Aging Studies and Services, The George Washington University Medical Center State Registrar - Charles Sirc, State Registrar, New Hampshire
9:30 a.m.	Breakout sessions (4) Two groups will focus on physician education, and the other two will focus on quality assurance programs.

12:00 Noon	Lunch
1:30 p.m.	Breakout sessions (4)
3:30 p.m.	Breakout sessions (2) The two groups focusing on physician education will combine, and the two working on quality assurance will combine. They will begin working on combined presentations to make to all attendees
5:00 p.m.	Adjourn
5:30 p.m.	Social

Tuesday, April 23

8:00 a.m.	Breakout sessions (2)
10:00 a.m.	Plenary session Presentation and discussion of recommendations related to physician education and quality assurance
1:00 p.m.	Adjourn

Appendix B
Attendees for the Second Workshop on Improving Cause-of-Death Statistics

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Appendix C
Summary of Progress Reports

National Center for Health Statistics (NCHS), Centers for Disease Control (CDC)

The National Center for Health Statistics (NCHS) reported on a variety of activities undertaken in response to the recommendations of the first workshop, many in cooperation with other organizations.

- NCHS disseminated the workshop findings and recommendations widely through the final report of the workshop, a news release to participating and other interested organizations, and an action plan. Articles and notices about the report were carried in *Public Health Reports*, the *American Journal of Public Health*, and *Statistical Bulletin* of the Metropolitan Life Insurance Company; these articles stimulated many requests for copies of the final report.
- NCHS reached out to new audiences through development of two exhibits. The first, sponsored by NCHS, the National Committee on Vital and Health Statistics (NCVHS), the Association for Vital Records and Health Statistics (AVRHS), and the Health Care Financing Administration (HCFA), was entitled "Improving the Quality of Mortality Statistics," and was exhibited at the 1990 annual meeting of the American Public Health Association (APHA). It highlighted several efforts to improve the quality of mortality statistics, including the 1989 workshop.

  The second exhibit, which was sponsored by NCHS, NCVHS, and AVRHS, was an educational exhibit addressed to physicians on the importance of accurate cause-of-death certification. It was shown at the annual meeting of the American College of Physicians in April 1991 and was on display at the Second Workshop on Improving Cause-of-Death Statistics. The exhibit, which emphasizes the many uses of mortality data for policy and research purposes, is available for use by associations, medical societies, and various educational and information programs. Plans were announced to display the exhibit at the 1991 annual meetings of the American Academy of Family Physicians, American Society of Internal Medicine, and the APHA. In 1992 the exhibit will be taken to meetings of the American College of Cardiology, American Society of Clinical Oncology, and the National Medical Association.
- Other educational efforts included development of a one-page laminated handout, "How to Complete Medical Certification of Cause of Death," as a quick reference for physicians. This handout is distributed at professional meetings and is available in quantity to interested groups. Copies also have been

provided to State Health Departments for further distribution. The handout can be of particular utility to interns and residents.

- NCHS is awarding a contract for an evaluation study to systematically derive information on the cognitive and situational aspects of the process by which physicians certify cause of death. The study will examine the effect of the certificate's format on the quality of information provided by the physician certifying death, the physician's general understanding of the medical certification portion of the death certificate and of the statistics that result, the physician's attitude toward completing the certification, and the conditions under which physicians complete the certification. The results are expected to be used for designing more effective educational programs and for suggesting modifications to forms or procedures in order to improve the quality of cause-of-death information.
- NCHS will be working with a major association in Continuing Medical Education (CME) to develop a training module that would provide instruction to the physician on how to complete the cause-of-death certification and on why accurate reporting is important. The CME module hopefully will be endorsed and accredited by ongoing programs in CME and will be a resource to States for use in settings where physicians routinely obtain CME.
- NCHS is supporting a committee process for evaluating and revising the Model State Vital Statistics Law and Regulations. The 1989 workshop suggested that this committee could be an appropriate vehicle for a broader discussion of issues related to confidentiality and access to death records. The committee has received testimony on this topic from a variety of experts, including ethicists, lawyers, and members of the media, and is considering the impact of open versus restricted aspects of the death record on cause-of-death reporting. In order to guide the committee, NCHS undertook a study, which suggested that there is little, if any, substantively meaningful difference in reporting sensitive causes of death between the open and restricted record States. The above-mentioned evaluation study on the medical certification process will assess whether, nonetheless, the physician's perception of open compared with restricted registration is a factor.
- A methodological study conducted by NCHS demonstrated that a mail survey may be feasible for conducting an evaluation of the quality of information on the death certificate if augmented by telephone and personal interviews to increase response rates. Costs of conducting a national survey on the quality of medical certification, however, were found to be substantial. The study showed considerable variation among physician panelists in determining correct cause of death. Variation seemed to be based, in part, on physician specialty and training. Only one-quarter of sample physicians reported having received training in medical school on medical certification and approximately one-quarter reported having received no training in medical certification from any source. The majority used no reference materials, such as the *Physician Handbook* developed by NCHS.
- The instructions for completing the cause-of-death portion of the death certificate were placed on the back of the standard certificate, which was

adopted in total or in part by 1989 in virtually all States. Some 23 States chose to include the instructions on the death certificate. The immediate effects of this form of instruction were clear and beneficial. For example, reported deaths from diabetes nationwide rose significantly in 1989 when physicians were more informed of the need to fully identify the chain of events that led to death.

National Committee on Vital and Health Statistics (NCVHS)

- The NCVHS endorsed the final report from the first workshop and submitted it to the Assistant Secretary for Health for policy consideration in the Department of Health and Human Services.
- The final report from the first workshop was published in the appendix to the 1990 NCVHS annual report.
- The NCVHS has worked with NCHS in developing the educational exhibits on improving cause-of-death certification and cosponsored both.

Association for Vital Records and Health Statistics (AVRHS)

In preparation for the second workshop, the AVRHS surveyed all registration districts to determine what, if any, actions had been taken by the registration areas in response to the first workshop on improving cause-of-death statistics.

- Thirty-eight registration areas, or 70.3 percent, responded. Of those responding, over half indicated they had conducted physician or medical examiner (ME) and/or coroner training programs since the first workshop. The 12 conducting physician training sessions had a mean physician attendance of 24. The ME and/or coroner training tended to be individualized. Eight districts had prepared write-ups or articles for State or county association newsletters or journals.
- A number of districts indicated the following additional activities to help improve reporting in their areas: legislation to increase filing time, promulgating regulations on who may certify, formalized procedures for adding supplemental data, establishing a death registration advisory meeting, displaying exhibits at professional meetings, adding prompts for risk factors, returning records to facilities for their mortality review panel, and distributing packets of instructional material to new licensees.
- Twenty-three of the respondents (60.5 percent) reported that they had increased their query levels or improved their edits. Most important, 47.4 percent of the respondents felt that the activities they initiated had resulted in improvement, with another 21.5 percent indicating that it was too early to tell. Only 10.5 percent stated that their efforts had not resulted in improvement.
- Districts noted a wide range of specific problem areas with respect to cause-of-death reporting. The two most frequently mentioned were deaths in the elderly, particularly nursing homes, and deaths due to external causes. When asked to indicate barriers to improvement, registration districts most frequently (44.7 percent) mentioned that the medical professionals had little interest or

time for training. The second most frequent barrier was lack of resources. Registration districts (63.2 percent) felt that medical schools should be more actively involved in training and that NCHS should develop better training material, including training software for physicians.

American Hospital Association (AHA)

The AHA reported that an article was published in *Medical Staff Affairs* following the first workshop. The Association looks forward to supporting specific strategies for improving cause-of-death certification that will be implemented in hospital settings.

American Medical Association (AMA)

The AMA's Council on Scientific Affairs prepared a report on "Improvement in the Accuracy of Death Certificates: Physician Education and Quality Assurance." The report was to be considered by the AMA House of Delegates in December 1991. The AMA approved a resolution to cooperate with NCHS to improve and encourage collection of risk factor data, including tobacco use, on the death certificate.

American Medical Record Association (AMRA)

An article was published in the AMRA *Journal*, reporting on the recommendations from the first workshop and encouraging members to ensure that, at the facility they serve, certificates are complete and accurate.

Association of American Medical Colleges (AAMC)

The AAMC reported to the Council of Teaching Hospitals on the recommendations of the first workshop.

Data available from the Association's faculty roster system could be used to develop an inventory of biostatistics and epidemiology instructors at State medical schools, as recommended at the first workshop.

Association of State and Territorial Health Officials (ASTHO)

The ASTHO disseminated information to the States about the first workshop. Its affiliate, the AVRHS, is playing the lead role for ASTHO in this effort.

College of American Pathologists (CAP)

The CAP reported on a new population-based pilot project in El Paso County, Colorado, which may lead to development of a national autopsy data bank.

An analysis performed of 545 deaths over a 6-month period revealed a consistent failure to use autopsy information in the completion of the cause-of-death certification. Although 28 percent of the decedents had received autopsies, in no cases was the information used.

International Association of Coroners and Medical Examiners (IACME)

The IACME provided news releases from the first workshop to its membership and local medical societies.

Joint Commission on Accreditation of Healthcare Organizations (JCAHO)

The JCAHO included a notice on the final report from the first workshop in its publication, *Quality Review Bulletin.*

The JCAHO reported on the development and testing of hospital performance measures and confirmed the importance of accurate cause-of-death reporting for continuous quality improvement. It was noted that death certificates could be reviewed as part of the surveying process. The JCAHO has observed a renewed interest in performing autopsies.

Metropolitan Life Insurance Company

An article on cause-of-death reporting was published in the January 1991 issue of *Statistical Bulletin*.

National Association of County Health Officials (NACHO)

The NACHO, which represents 3,000 counties, recognizes the importance of mortality statistics for community assessment and committed itself to better support reporting of cause of death on the death certificate through its newsletters and meetings with the medical community.

National Association of Medical Examiners (NAME)

The NAME has an ad hoc committee on death certification and has plans to field a survey on concerns of medical examiners. The Association is interested in working with local health officers and supports promoting greater consistency through development of guidelines, along the lines of those developed for reporting suicide.

National Medical Association (NMA)

The NMA representative to the first workshop submitted resolutions to both the NMA and AMA on the importance of improving cause-of-death information. Mortality conferences and clinical pathological conferences should include completion of the death certificate. Residents and physicians who care for patients in nursing homes and hospices should be the focus for training in proper cause-of-death certification. The decreasing tendency to perform autopsies represents a problem in obtaining accurate information.

Society of Medical College Directors of Continuing Medical Education (SMCDCME)

The Society represents 135 medical colleges. Recommendations from the two workshops will be presented to the Executive Committee and membership at the Society's annual meeting. The SMCDCME will continue to work with NCHS on developing a CME module on cause-of-death certification.

Robert Wood Johnson Foundation (RWJF)

The RWJF will make planning grants to 10 States in early 1992 to improve information for health policy. The Foundation is interested in working with the workshop participants to improve cause-of-death information.

U.S. Conference of Local Health Officers (USCLHO)

The USCLHO recognizes the importance of improved cause-of-death statistics for assessing the health of communities and believes that *Healthy People 2000* can be a vehicle for educating the health care field about the importance of mortality data.

Agency for Health Care Policy and Research (AHCPR)

The AHCPR plays a leadership and coordination role in developing standards for an electronic patient record; this is relevant for research on electronic death records.

Health Care Financing Administration (HCFA)

The annual release of Medicare hospital mortality data by HCFA is an opportunity to call attention to the importance of accurate cause-of-death reporting.

National Center for Environmental Health and Injury Control (NCEHIC), CDC

The NCEHIC has put together a directory of medical examiners and coroners for use in disseminating information about cause-of-death reporting. The directory contains a section on information resources. Efforts are being made to compare data from ME's and coroners with the relevant death certificates, and autopsy rates are being examined. The latter indicate tremendous variation geographically and on specific causes of death.

National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), CDC

The NCCDPHP maternal mortality study group is working closely with States, AVRHS, the Health Resources and Services Administration, and the American College of Obstetricians to review maternal and infant deaths through mortality review panels.

National Institute for Occupational Safety and Health (NIOSH), CDC

The NIOSH is working on a standardized definition for injury at work.

The National Heart, Lung, and Blood Institute (NHLBI), National Institutes of Health (NIH)

The NHLBI would like to conduct diagnostic validation studies using standardized algorithms to evaluate and promote improved reporting of cardiovascular deaths.

National Institute on Aging (NIA), NIH

The NIA supports conducting additional studies of deaths in the elderly, using the National Mortality Followback Survey. Further research is needed on mechanisms of disease and dying, particularly in the elderly.

Appendix VI.
Report on the Need to Collect External Cause-of-Injury Codes in Hospital Discharge Data

National Committee on Vital and Health Statistics

Subcommittee on Ambulatory and Hospital Care Statistics

Executive Summary

Each year, one out of every four persons in the United States is injured. Unintentional injuries constitute the fourth leading cause of death, killing approximately 100,000 people each year and accounting for 2.3 million years of life lost. Another 45,000 persons die from homicide or suicide, with the United States ranking first among industrialized nations in violent death rates. Additional millions are incapacitated by injuries. For every death from an injury, there are 16 persons hospitalized and another 380 persons who seek medical attention or have restricted activity due to an injury. Occupational injuries in this country exceed those of Sweden, Japan, Norway, and the United Kingdom. In 1991, the total lifetime cost of all injuries sustained in 1985 was estimated to be $200 billion. Productivity losses from injuries are far greater than those for cardiovascular diseases and cancer combined. Trauma patients represent 6.9 percent of all health expenditures, and trauma care makes up approximately 12 percent, or $1 billion, of the overall cost of uncompensated care.

No nationwide system exists for recording information on nonfatal injuries, which represent 99 percent of all injuries in the United States. Recognizing the enormous human and economic costs of injury and the need to improve the collection of data on nonfatal injuries for the development of intervention and prevention strategies, the Subcommittee on Ambulatory and Hospital Care Statistics of the National Committee on Vital and Health Statistics (NCVHS) concludes that the NCVHS should make the following recommendation to the Secretary of the Department of Health and Human Services (DHHS):

Whenever an injury is the principal diagnosis or directly related to the principal diagnosis for a hospitalized patient, there should be an external cause of injury recorded in the medical record. When there is an external cause recorded in the record, applicable E-codes should be reported in the hospital discharge data set. A minimum of one E-code should be reported for cause; a second E-code is strongly encouraged for place of occurrence, where appropriate. A hospital record or bill should be regarded as incomplete if there is evidence of an injury and no E-code is recorded.

The Subcommittee further advises:

- E-coding should be recommended for all hospitalized patients, in all DHHS programs that deliver care, regardless of the payment source.
- The revised Uniform Bill (UB-82) for hospitals should accommodate the collection of E-codes. Reporting should be required with the implementation of the revised UB-82, tentatively scheduled for October 1992.
- Hospitals should be strongly encouraged immediately to improve recordkeeping on external causes of injury and to begin reporting E-codes voluntarily as one or more of the injured patient's diagnoses as soon as feasible. This will be facilitated when the fields reserved for reporting secondary diagnoses codes on the UB-82 are expanded, projected for October 1991.
- Implementation of this mandate should be in conjunction with the development of national guidelines and training materials for using E-codes. Training materials are needed for medical records professionals and for physicians.
- Concurrently, work should begin on improvements to the *ICD-9-CM* classification system for recording external causes of injury, including the alphabetical index for E-codes.
- Adequate resources should be made available to support each of these functions. A budget for conducting training is required to assure accurate and complete recording.

A national mandate is needed to facilitate comparability, uniformity, and accessibility of injury information. Voluntary reporting results in inconsistent recording, skewed data, and inadequate information for addressing problems at the county and community level. Identifying the causes for the most severe injuries will help target high-risk activities and occupations and maximize use of limited resources. Compelling evidence presented by the Indian Health Service, States, and private nonprofit organizations demonstrates that effective intervention strategies can be implemented in response to available data on external causes of injury.

The Subcommittee on Ambulatory and Hospital Care Statistics is conducting a thorough and systematic review of the Uniform Hospital Discharge Data Set (UHDDS) for the purpose of recommending any revisions needed to meet current and anticipated needs. This review is being conducted in close cooperation with the National Uniform Billing Committee (NUBC), which maintains the Uniform Bill (UB-82) for hospitals, and in tandem with a DHHS Interagency Task Force on the UHDDS. In its informal inquiry into the adequacy of the UHDDS, the additional item of information most frequently recommended for collection was the external cause of injury associated with an injury diagnosis. Extensive written and oral testimony subsequently received by the Subcommittee from August 1990–May 1991 reinforced the need for E-coded data and the feasibility of collecting it.

The Subcommittee has examined impediments to E-coding. These include insufficient space on the billing form; incomplete medical records; inadequacies in the E-coding classification system; lack of rules, national guidelines, and instructional materials;

costs; and potential liability issues. Each was found to require attention, but none was found to be insurmountable. Suggestions for addressing and overcoming these impediments are contained in the report.

The Subcommittee learned that five States recently have mandated E-coding, and others are considering doing so. This has increased the possibility that, absent national guidelines on E-coding, uniformity and comparability across States will not be encouraged or occur. The Subcommittee also believes the impediments to collecting E-codes require immediate attention if accurate and useful data are to be available in the future. Finally, the Subcommittee is cognizant of plans by the NUBC to recommend changes to the UB-82 in the coming year.

Therefore, the Subcommittee has decided to issue this report to the NCVHS, a year earlier than its full report on the UHDDS is due, recommending the inclusion of E-codes in the hospital discharge data set. It is hoped that this report will provide guidance to the States and insurers considering mandates on E-coding, furnish an impetus to the injury control and disease classification communities to address the problems identified with the system and environment for E-coding, and give the NUBC sufficient notice of its recommendations so that E-codes can be accommodated in a revised UB-82.

The Subcommittee recommends that mandatory E-coding begin in the inpatient hospital setting, paving the way for collection in emergency rooms and ambulatory sites once greater experience is gained in using the classification, and the value of the data is further demonstrated. The Subcommittee defers to the NUBC to decide whether there should be a separate field for E-codes on the revised UB-82 or whether E-codes should be recorded as one of the patient's diagnoses. Preliminary feedback from the NUBC favors a separate dedicated field, and the Subcommittee concludes that, in the long run, one or more separate fields are most desirable and should be the goal for all systems. Based on the findings and experiences of several States, the Subcommittee recommends not including misadventure codes (E870–E876) as part of required reporting of E-codes.

National guidelines for recording E-codes must be developed before a national mandate to include E-codes in the UHDDS is implemented. The Subcommittee recommends that this should be undertaken by the Morbidity Classification Branch of the National Center for Health Statistics (NCHS), in cooperation with the Center for Environmental Health and Injury Control, Centers for Disease Control, and the Editorial Advisory Board of the Coding Clinic. Concurrently, work should begin immediately on improving the E-code supplemental classification and alphabetical index in *ICD-9-CM*. The Subcommittee encourages the Morbidity Classification Branch, NCHS, to take the lead in collaboration with other interested parties.

In mandating recording of E-codes, the intent is not to expand data collection responsibilities, but to make clear that E-codes, as part of the disease classification system, are a high priority for inclusion in hospital discharge data. Hospitals are an important component of our Nation's public health infrastructure and must respond to the health problems in their communities, of which intentional and unintentional injuries represent a significant share. By gathering information about the causes of injury in the populations they serve, hospitals will be in a better position to care for patients and reduce health care costs. The Subcommittee is concerned that, without strong financial incentives or sanctions, the mandate to report E-codes may not succeed nationally. The Subcommittee will continue to watch the experience in the States that have required E-coding and to monitor implementation.

Report on the Need to Collect External Cause-of-Injury Codes in Hospital Discharge Data

National Committee on Vital and Health Statistics
Subcommittee on Ambulatory and Hospital Care Statistics

I. Introduction

The National Committee on Vital and Health Statistics (NCVHS) Subcommittee on Ambulatory and Hospital Care Statistics was charged in November 1989 to develop a recommendation on the need to reexamine the Uniform Hospital Discharge Data Set (UHDDS) and the major mechanisms used to collect it. The Subcommittee subsequently proposed a thorough and systematic review of the UHDDS in June 1990. This recommendation was approved by the NCVHS, with a target date of June 1992 for completion of the review and any necessary revisions.

During the Subcommittee's informal inquiry into the adequacy of the UHDDS, the additional item of information most frequently recommended for collection was the external cause of injury associated with an injury diagnosis. In response to this interest, the Subcommittee devoted the majority of its efforts from June 1990–June 1991 to an exploration of the value and feasibility of collecting external cause-of-injury codes (E-codes) as part of the hospital discharge data set. The Subcommittee is impressed by the enormous human and economic costs of injury and the passion and commitment of the injury prevention and control community to improve the collection of injury data for the development of intervention and prevention strategies. The Subcommittee is further persuaded of the current and potential utility of E-codes in hospital discharge data for needs assessment, program design, and evaluation of intervention and prevention strategies.

The Subcommittee also has taken note that several States have recently mandated E-coding and others are considering doing so. This has created a natural experiment for assessing the feasibility of incorporating E-codes into the UHDDS but also has increased the possibility that, absent national guidelines, uniformity and comparability across States will not be encouraged or will not occur. The Subcommittee has received considerable testimony about the impediments to collecting E-codes, all of which require immediate attention if accurate and useful data are to be available in the future. Finally, the Subcommittee is cognizant of plans by the National Uniform Billing Committee (NUBC) to recommend changes in the coming year to the Uniform Bill (UB-82) for hospitals.

Therefore, the Subcommittee has decided to issue this report to the NCVHS on the need for collecting E-codes as part of the UHDDS a year earlier than its full recommendations on the UHDDS are due. It is the Subcommittee's hope that this report will provide guidance to the States and insurers considering mandates on E-coding, furnish an impetus to the injury control and disease classification communities to address the problems identified with the system and environment for E-coding, and give the NUBC sufficient notice of its recommendations so that E-codes can be accommodated in a revised Uniform Bill.

II. Background

A. Charge to Subcommittee

In June 1990, the NCVHS approved the proposed charge of the NCVHS Subcommittee on Ambulatory and Hospital Care Statistics to assess and reexamine the data elements and definitions contained in the UHDDS. The full charge of the Subcommittee, as well as a roster of the Subcommittee membership and staff, are contained in appendixes A and B.

The UHDDS was first promulgated in 1974 by the Secretary of the Department of Health, Education, and Welfare as a minimum, common core of data on individual hospital discharges in the Medicare and Medicaid programs, with the purpose of improving the uniformity and comparability of hospital discharge data. The data set was revised in 1984 and published in the July 31, 1985, issue of the *Federal Register.*

In accepting its new charge, the NCVHS Subcommittee on Ambulatory and Hospital Care Statistics committed itself to conducting a thorough and systematic review of the UHDDS for the purpose of recommending any revisions needed to meet current and anticipated needs. The Subcommittee further agreed to carry out its review in close cooperation with the National Uniform Billing Committee, which maintains the Medicare Uniform Bill (UB-82), a principal vehicle for collecting the UHDDS elements. At the same time, the NCVHS recommended to the Department of Health and Human Services (DHHS) that an Interagency Task Force be developed to review the UHDDS in tandem with the Subcommittee. A report on the preliminary results of the UHDDS review is scheduled for February 1992, and a final report is due by June 1992.

B. National Uniform Billing Committee

The National Uniform Billing Committee (NUBC) meets regularly to maintain the UB-82 and is chaired by the American Hospital Association (AHA). The NUBC consists of equal representation of provider organizations (that is, AHA, the Healthcare Financial Management Association, and the Federation of

American Health Systems) and payer organizations (that is, the Health Care Financing Administration [HCFA], Medicaid, CHAMPUS, Blue Cross Blue Shield Association, and the Health Insurance Association of America). The NUBC hopes to recommend changes in the UB-82 by the fall of 1991, with implementation of a revised bill in October 1992.

C. Interagency Task Force

In response to the recommendation of the NCVHS, the Assistant Secretary for Health established an Interagency Task Force, chaired by the HCFA to review the UHDDS from the perspective of the programmatic needs of the Department. The Task Force is operating under the same time frame as the NCVHS Subcommittee for the overall review of the UHDDS and expects to issue a final report in the summer of 1992.

III. Process

A. Subcommittee inquiry

The Subcommittee began its UHDDS inquiry by informally contacting collectors and high users of hospital discharge data in the public and private sectors and asking them to comment on the adequacy of the UHDDS. The majority of comments received suggested that it was time to take a fresh look at the UHDDS and the major mechanisms used to collect the information in the data set. Before making a recommendation to the NCVHS, on April 18, 1990, the Subcommittee convened a meeting of a variety of DHHS staff to determine the urgency and optimal approach for undertaking a review and any revision of the UHDDS. This meeting raised a number of issues related to the adequacy, completeness, and comparability of current hospital discharge data and confirmed the key role the UHDDS can play in encouraging greater uniformity of data collection.

During the Subcommittee's informal inquiry into the adequacy of the UHDDS, the additional item of information most frequently recommended for collection was the external cause-of-injury associated with an injury diagnosis. In response to this interest, the Subcommittee held two meetings and informational hearings on September 12, 1990, and January 16, 1991, that focused on the collection and use of external cause-of-injury data. A wide variety of individuals and organizations representing governmental agencies, the research community, and the private sector, presented their views on the need for external cause of injury data and the feasibility of collecting injury data through the UHDDS. Although most of the testimony received was highly in favor of the recommendation that E-codes be a required element in hospital discharge reporting, a number of possible obstacles also were identified and will be addressed in detail in this report.

B. Letters of Testimony and Support

In addition to formal oral testimony presented at Subcommittee meetings, letters were sent to the Subcommittee by city and State health departments, university affiliated groups, representatives from Federal programs, health and/or medical-related academic and professional organizations and associations, and not-for-profit groups. Among this group, there were no detractors. The vast majority of those who wrote were strongly in support of the mandatory inclusion of E-codes in the UHDDS.

The theme that ran through all of the letters received was that E-codes are a "missing link" without which researchers, policymakers, and health professionals cannot plan, implement, or evaluate programs designed for injury prevention and control. The experiences and insights of those who sent letters, as well as those who made presentations at the two Subcommittee meetings, are discussed throughout this report and were invaluable to the preparation of the report. A matrix that cites every letter sent to the Subcommittee and depicts the variety of groups in support of E-coding, can be found in appendix C of this document.

C. National Uniform Billing Committee (NUBC)

The NUBC began its inquiry into the adequacy of the UB-82 in 1989. In August 1990, the Committee sent a survey to all State Uniform Billing Committees requesting their comments on the current form. Although respondents to the NUBC survey did not address the need for external cause-of-injury data, the Injury Control Section of the North Carolina Department of Environment, Health and Natural Resources and the North Carolina Medical Society approached the NUBC in July 1990 about their interest in having a dedicated field on the UB-82 for collection of E-codes.

The NUBC met in Chicago, Illinois, March 4–6, 1991, to review the results of the survey and to consider future design changes to the UB-82 form. The NCVHS Subcommittee Chairman and key staff have been attending the meetings of the NUBC, and the NUBC Chairman or representative attends the Subcommittee meetings. The minutes from the March 4–6, 1991, NUBC meeting, during which the Subcommittee Chairman and staff reported on the Subcommittee's investigation into the need for collecting external causes of injury in hospital discharge data, report that "NUBC members recommended that one dedicated field be established on the new UB-82 for the purposes of E-code reporting. The recommendation was subject to comment by State Uniform Billing Committees and final prioritization of space on the new form."

D. Interagency Task Force

The Interagency Task Force held an organizational meeting on January 31, 1991, and subsequently met on March 14 and April 17, 1991. Its next meeting is scheduled for the second week in June. In the first several meetings, reports have been made by the Task Force members, as well as representatives of the Department of Veteran Affairs and the Department of Defense about the experiences within their respective agencies in collecting and using the UHDDS. Interest in E-coding has been noted by several representatives.

The Chairman of the Interagency Task Force attends the meetings of the NCVHS Subcommittee, and the key staff person to the Subcommittee is a member of the Task Force. The Subcommittee Chairman or his designee also is invited to Task Force meetings.

IV. Overview of the impact of injuries

It is estimated that each year one out of every four persons is injured (1). Approximately two-thirds of all injuries that result in death are unintentional (2). Researchers report that, generally, the leading causes of injury fatality are motor vehicles, falls, and firearms. What the injury prevention and control field is unable to provide is detailed information about the etiology of nonfatal injuries, which represent 99 percent of all injuries in the United States (1). Such information could facilitate injury case identification, provide descriptive information about the injury problem of a population, allow targeting of high-risk activities and occupations, and underpin the development, implementation, and evaluation of intervention and prevention strategies.

The lack of causal data on nonfatal injuries has vast implications in terms of human and economic costs. These costs are economic, in the forms of medical payments and disability, but also personal and societal. The field of injury research has considerable data on mortality because certifiers are expected to record external causes of injury on death certificates. In the following discussion much of the data used are related to mortality figures, highlighting the fact that there is little information available on the impact of nonfatal injury on the health system or economics of the United States.

A. Impact of injuries on health

Unintentional injuries constitute the fourth leading cause of death in the United States, killing approximately 100,000 people each year. During the first four decades of life, unintentional injuries claim more lives than infectious or chronic diseases. In 1987, 2.3 million years of life were prematurely taken by unintentional injuries, more than from any other cause. Additional millions are incapacitated by unintentional injuries, with many suffering lifelong disabilities. These events occur disproportionately among the young and older people (3).

At least 2.2 million people are victims of violent injury each year; approximately 40,000 persons die annually from intentional injury. The United States ranks *first* among industrialized nations in violent death rates, and deaths caused by violent and unintentional misuse of firearms exceed in number the combined total of the next 17 nations. Together, suicide and homicide constitute the fourth leading cause of years of potential life lost to people before age 65 years in the United States. Suicide is the third leading cause of death among people aged 15–24 years, and homicide is the leading cause of death for the black population aged 15–34 years (3). Preliminary data released by the Federal

Bureau of Investigation show that violent crimes—murder, rape, robbery, and aggravated assault — increased by 10 percent in the United States last year, the largest annual increase since 1986 (4).

Occupational injuries also impose severe costs. During 1987, permanent impairments suffered on the job grew from 60,000 to 70,000 and total disabling injuries numbered 1.8 million (3). Approximately 6 percent of all jobs in the United States are in the "construction" category, yet this occupation is responsible for more than 20 percent of injuries which result in job-related deaths. The U.S. workers' death rate is four times that of Sweden, Japan, Norway, and the United Kingdom (5).

Injury has particular bearing on young people because it is the leading killer of individuals under 44 years of age (6). The rate of child injury mortality in the United States was compared to that of Canada, England and Wales, France, Netherlands, and Norway by Williams et al. Child injury death rates overall were greater in the United States than rates of other countries studied for every year from 1980 to 1986. These findings, reported in a recent issue of *Pediatrics*, included the fact that in every age group, for each category, drowning, firearms, homicide, poisonings, and fire, U.S. death rates are among the highest. Homicide now accounts for more infant deaths in the United States than any other type of injury (7). Overall, the rates of mortality for the largest racial subgroups in the United States are each greater than the overall rates in the other study countries (7).

B. The economic costs of injuries

Injuries are expensive for the health care system and for individuals.

1. The Nation

Injury imposes hardship on the economic structure of the country by negatively impacting worker productivity. This adverse effect is growing. The rate of serious injury and the number of lost work days are substantially higher today than when the U.S. Occupational Safety and Health Administration was created in 1970 to solve these problems. As of 1988, 6.3 million work days were lost, compared with 2.5 million in 1972 (5). Overall, estimated lifetime costs of all injuries incurred in 1985 exceeded $158 billion, and costs estimated by 1991 are $200 billion. Unintentional injuries account for about two-thirds of these costs. The cost is almost evenly divided between costs related to direct medical care expenses, loss of productivity due to death, and loss due to disability (1). In fact, the burden of disability and other nonfatal outcomes may show a proportional increase as mortality declines (7). In addition, the costs associated with disability due to injury are not one time events. The economic impact is sustained for years following the initial trauma.

2. Families

Injuries affect family economics as well. Labor union health and welfare records from 1988–89 reveal that the highest fatality rate was among those aged 45 to 54 years. Married men represented 77 percent of these deaths, thereby leaving at least one dependent (5).

3. Health care system

The staggering effects of injury on the health care system are beginning to be recognized. The costs are greater than the costs of cancer and cardiovascular disease combined. Fully 2.3 percent of this country's gross national product is spent on trauma care (6). Representing 6.9 percent of all health expenditures, trauma patients occupy 12 percent of the hospital beds in the United States (6). Using 1985 data, it has been estimated that for every 1 death due to injury, there are 16 hospital admissions and an additional 380 persons who either receive medical attention or have restricted activity due to an injury (1) (Based on NCHS mortality data, the National Hospital Discharge Survey, and the National Health Interview Survey.) For childhood injuries, researchers estimate that for each death there are an estimated 45 persons hospitalized and 1,300 who visit emergency rooms (8). Nonfatal injuries account for 1 in every 10 hospital admissions, or approximately 3.3 million admissions to short-term hospitals per year (1) (National Hospital Discharge Survey data). A study of injuries in Maryland estimated per case 1-year treatment charges related to the receipt of health care and rehabilitation services ranged from an average of $8,100 for those sustaining minor injuries to $105,350 for those with severe head or spinal cord injuries (9).

More than 70 percent of the cost burden of injury is borne by the private sector through workers' compensation (17.2 percent), private insurance (33.5 percent), uninsured care (16.6 percent), and self-payment (4.9 percent) (1). Costs to the public sector, through Medicare and Medicaid payments and public hospital expenditures, are significant. Public funds expended in 1985 for the medical costs of injury were estimated at $11.6 billion; Federal funds covered $8.9 billion of these costs. The Federal Government also pays $13 billion in disability and death benefits under Social Security Disability Insurance, Supplemental Security Income, and the Veterans Administration (1).

One of the consequences of a growing number of uninsured and underinsured trauma victims is the loss of millions of dollars to trauma centers and other hospitals treating these patients. Based on a study of 16 acute care hospitals that maintain a trauma center, the American Trauma Council found that the loss to hospitals and trauma centers associated with care for self-paying patients ranges from 40 to 60 percent of total charges (10).

Nationally, the overall cost of uncompensated care has been estimated at $8.3 billion per year. Trauma care makes up approximately 12 percent ($1 billion) of this cost (11). Other data show that the percentage of discharges and total estimated charges for self-pay and no-charge patients is higher for unintentional injuries than for any other diagnostic category, with the exception of deliveries (12). Trauma patients are typically young adults who are least likely to have commercial insurance or to be eligible for public assistance programs. This group is expected to grow as the number of people who cannot afford health insurance continues to grow (13).

V. Lack of causal data on injuries

Researchers, policymakers, and health providers agree that there is a serious lack of information available on causes of injury, especially nonfatal injury. No nationwide system for recording information on nonfatal injury exists. Hospital discharge data systems offer the potential for obtaining uniform, timely, representative, and specific injury information. Four recent reports, *Injury in America* (1988), *Injury Control* (1988), *Cost of Injury* (1989), and *Injury Prevention Meeting the Challenge* (1989) concur that inadequate data exist to address the epidemiology and prevention of nonfatal injuries. The Committee of Trauma Research of the National Academy of Science, Institute of Medicine, responsible for *Injury in America*, states clearly that the scientific study of injury is dependent upon the gathering of data on which to base the research. Each report attests that E-coding of hospital discharge data would fill the data gap.

Cost of Injury, a study in which public program participation in covering the costs of injuries was examined, was inhibited in its investigations because of the lack of coded information about injury.

Healthy People 2000, recently published by DHHS as the blueprint for disease prevention and health promotion activities in this decade, also recognizes the need for data on nonfatal injuries. The recommendations on surveillance and data needs in the unintentional injuries priority area recommends establishing and refining existing State-level data systems for injury morbidity using the State Uniform Hospital Discharge Data Set and implementing external cause-of-injury coding in hospital records as high priorities. In the Objectives for the Year 2000 there are not only a number of health status goals that are related to injury morbidity, but also a number of non-health status goals that are actually intervention activities. It will be impossible to evaluate the trends in injury morbidity or the efficacy of the intervention strategies without the availability of E-code information.

Limitations of other data sources are as follows:

A. Mortality data

Fewer than one percent of all injuries are fatal. Thus, mortality data cannot provide an adequate measure of the injury problem. Also, the numbers of deaths in small geographic areas usually are inadequate to provide reliable information on distribution of causes by age, sex, race, and ethnicity.

B. Trauma data

Public Law 101–590, entitled the Trauma Care Systems Planning and Development Act of 1990, is an amendment to the Public Health Service Act that requires that States receiving Federal assistance must establish and operate a central data reporting and analysis system for trauma care data, including data on the nature and cause (E-codes) of injury. At a minimum, these data are to be obtained from each designated trauma center in the State, of which there are approximately 300 nationwide. The bill also requires the Secretary of DHHS to establish a national advisory council on the trauma care system within the Department. This council will probably be involved with linkage to States. The Health Resources and Services Administration (HRSA) has been designated as the lead agency for implementation of the Act.

Further, there has been discussion about developing a national uniform trauma care data set, including process and outcome measures for prehospital, hospital, and rehabilitation services, and guidelines for standardized analysis and reporting of trauma care data that would be appropriate for use by all acute care hospitals. This effort would promote the development of regionalized trauma care data systems to provide standardized data elements useful for quality of care assessment and epidemiologic research of traumatic or severe injuries.

Trauma centers and trauma registries already provide some information on nonfatal injuries, but the majority of injured persons are not treated in trauma centers and do not get included in trauma registries. Again, only the most serious injuries are captured, and availability of data varies widely from State to State. In order to be useful a trauma registry must be population-based, and creation of such registries is quite expensive. The Missouri Department of Health, which has a number of sources of data, informed the Subcommittee that "(although) Missouri has a wealth of data about injuries, including mandated ambulance run reports, a head and spinal cord injury registry, and a trauma registry for designated trauma centers..., we are unable to use these records to effectively pinpoint the impact of injuries on any given county or community. The numbers are too small and do not reflect in a timely and accurate fashion what prevention strategies might be applied in any given locale (14)." E-coded data from all the hospitals in Missouri could rectify this problem.

C. Occupational injuries

As is the case for injury in general, data on nonfatal occupational injuries are very poorly documented. While union and labor leaders attest that an adequate system for surveillance of traumatic fatalities exists, nonfatal injury surveillance remains a problem. These leaders report that employees often are discouraged from revealing that their injuries are work-related when they seek care, and, thus, the appropriate category on the billing form is not checked at admission.

Subsequently, the actual causes of the injury are likely to be obtained by the physician or nurse and will appear in the hospital record (15).

Neither the workers' compensation system, the workers' compensation carriers, the National Safety Council, employers, unions, nor the Secretary of Labor are exploring the epidemiology of workplace injury. Neither the Bureau of Labor Statistics annual survey nor its supplementary data systems provide data that are specific enough to develop injury intervention or prevention programs. There is a great deal of variability in State Workers' Compensation laws, which not only differ from State to State but often are subject to change in a single State. As a result, no national work place injury surveillance system exists.

Proposals for the establishment of a national sample of serious occupational injuries have been made for over a decade. One such proposal was made by the National Academy of Sciences in 1987 in its report, *Counting Injuries and Illnesses in the Workplace*. In this report, the lack of such a data base was recognized, and a specific endorsement was made for the collection of "detailed data on severe occupational injuries categorized as injuries resulting in death, hospitalization or outpatient surgery (16)."

Labor groups would like occupation-specific data to be accessible in order to target occupational work groups, unique industrial problems, and geographic trends.

D. Police records

Police records can provide some information about the more serious motor vehicle injuries as well as injuries from interpersonal violence, but these records are most useful when linked with hospital discharge records, which contain details on the nature and severity of such cases and the treatment costs. A serious limitation of police records for motor vehicle injuries is that information usually is only provided about the drivers of the vehicles involved.

VI. Value of E-codes

Advocates of E-coding report that the information on injury that could be gathered through the use of E-codes would be invaluable. For example, it is critically important in studying head injuries and developing preventive measures to know whether these injuries are from falls, motor vehicle crashes, bicycle or motorcycle riding, or sports.

Research based on injury data would allow targeting of high-risk activities and occupations, identification of industry-specific problems, and would justify the development, implementation, and evaluation of intervention and prevention strategies. Ultimately, these strategies could lead to decreased death, disability, and injury, as well as lower compensation insurance premiums and medical costs. E-codes, routinely included in hospital discharge data, would bridge the gap between mortality and morbidity data.

Over the past several years, the Division of Injury Control, Center for Environmental Health and Injury Control, Centers for Disease Control, has provided funding for the development of injury prevention programs and staffing at the State and county levels, as well as for the establishment of eight injury control research centers. These programs have expressed the need for E-coded hospital discharge data in their injury prevention work and should be a mechanism for analyzing the data once they are collected.

A. Prevention

Experts in the field of injury adhere to the belief that injuries are events that occur in patterns and are therefore preventable. The primary obstacle to identifying high-risk groups and activities is the lack of adequate data on the etiology of nonfatal injuries.

Some well-known examples of preventive action taken in response to high rates of associated injury or death are the promotion of installation of seat belts and air bags in cars; requiring bicyclists and motorcyclists to wear helmets; offering child-proof caps on prescription drug bottles; and banning three-wheel motorbikes by the Consumer Product Safety Commission. These programs have demonstrated the effectiveness of using data for injury prevention. In Seattle, Washington, for example, helmet use among children riding bicycles increased from 5.5 percent before a public awareness campaign to 15.7 percent afterward (17). Two programs especially, air bags and requiring helmets on motorcycles, have been cited as effective at preventing fatality. The estimated savings per year as a result of the use of air bags is approximately $4.7 billion. For bicycle-helmet promotion activities, a savings of $1.8 million is realized. And motorcycle helmet use laws save an estimated $97 million each year in hospital admissions and other related costs (18). The Indian Health Service (IHS) estimates that providing each new baby leaving an IHS hospital with a child restraint seat costs approximately $20 per baby, whereas treating one child seriously injured in a motor vehicle crash costs up to $75,000–$80,000 (19).

B. Specific Uses of E-code Data

1. National Safe Kids Campaign

The National Safe Kids Campaign provides an example of how information on nonfatal injuries translates into prevention programs. By using E-codes from the Children's Hospital of Alabama hospital discharge summaries, the Alabama Safe Kids Coalition detected an area of Birmingham with a greater concentration of bicycle-related injuries than any other part of the city. In response, the group held a bike "rodeo" in that area of the city, focusing on bike safety, including helmet use. Alabama Safe Kids plans to use E-code data again to evaluate the effectiveness of the safety program (20). Nationally, according to the American Academy of Pediatrics, only 5 percent of child cyclists use bike helmets. Research shows that wearing a bike helmet reduces the risk of head injury by 85 percent (21).

2. Indian Health Service

The Indian Health Service (IHS) has had over 20 years of experience in using E-coded information on the causes of injury to direct agency prevention activities. The IHS, the agency primarily responsible for delivering services to the Nation's approximately one million native Americans, has 45 hospitals and several hundred outpatient centers around the country. (The IHS also uses non-Federal hospitals, especially in the Northwest region of the country.) The IHS has an electronic E-code and N-code (nature of injury) triggered system that automatically notifies the IHS injury prevention coordinators in each of the 12 IHS regional areas of any hospitalized injury. This system is in place in IHS hospitals, and its contract medical care hospitals are paid to provide these data. E-coding has allowed the IHS, working with the American Indian Tribes and Alaskan Native villages, to develop community-specific injury profiles. For example, the IHS discovered, through the analysis of E-coded information, that drowning is a specific problem for Alaskan Natives, while burns appear prominently in the upper tier of the United States.

Three specific examples of how the availability of cause-of-injury information allowed the IHS' injury surveillance system to identify and address serious injury problems were reported to the Subcommittee by Richard J. Smith, Manager of the Injury Prevention Program within the IHS, and are described below:

The White Mountain Apache Reservation—Pedestrian injuries were a significant problem on the White Mountain Apache Indian reservation in Eastern Arizona. Sixty-seven percent of these injuries were occurring at night on a 1-mile stretch of road. Based on this information, the IHS presented its findings to the State and the tribal council and were able to get $39,000 to put lighting up on the stretch of road, successfully preventing additional injuries. Thus, with good injury data, the IHS was able to quantify the problem and could specifically target the prevention effort.

The Cherokee Reservation—Pedestrian injuries were also a problem on the Cherokee reservation in Cherokee, North Carolina. Tourists to the Cherokee reservation were regularly hospitalized with severe injuries. Using E-code data, pin maps, and the local police department, the IHS identified a very narrow area of roadway where people were getting hit by motor vehicles. In response, they were able to find the resources necessary to put in a pedestrian walk path that virtually eliminated the problem.

Blackfeet, Montana—In the final example, the "Other" category of cause of injury was investigated and it was discovered that there was a significant problem of sports-related injuries in the high schools on the reservation in Browning, Montana. This information allowed the community to address the problem directly through sports safety education efforts.

E-codes have also have been used by the IHS in a number of other ways. In preparing grant applications, the mental health and social services branches used the data for identifying specific methods of self-inflicted injuries. The agency was able to discover that a significant number of crushing injuries were due to the use of old-fashioned wringer washing machines.

Availability of E-codes assures that resources are targeted to the real cause of injury. In one community, a large number of poisonings were occurring among children. The community wanted to implement a MR. YUK campaign, complete with stickers for home cleaning products. The IHS Prevention Program was able to determine that prescription drugs, not under-the-sink type products, were the cause of poisonings, requiring an entirely different prevention effort.

3. Massachusetts Statewide Childhood Injury Prevention Program

   By using E-coded hospital discharge data, the Massachusetts Statewide Injury Prevention Program was able to increase the number of cases available for analysis by 40-fold over deaths and to describe the epidemiologic characteristics of the important causes of nonfatal childhood injuries. Whereas deaths were caused primarily by motor vehicles, burns, and intentional injuries, injuries resulting in the highest proportion of hospitalizations had other causes. These included drowning, intentional injuries that were self-inflicted or of undetermined intent, poisonings, and crashes involving motorcycles, motor vehicles-pedestrians, and motor vehicles-bicycles. Falls and sports-related injuries were found to account for about the same proportion of emergency room visits and inpatient care (22).

4. Rhode Island Department of Health

   Rhode Island has analyzed the E-coded data submitted to the State voluntarily prior to the mandate in 1989 and has used the results to support seat belt and motorcycle helmet legislation (as yet unsuccessful) and increased resources for injury prevention and control (23).

5. Washington State Department of Health and Harborview Injury Prevention and Research Center

   The State of Washington mandated E-coding in 1989 (see below) and has begun to analyze the 1989 data tape with the Harborview Injury Prevention and Research Center in Seattle. The data have been particularly useful in conjunction with other available data sets. For example, hospital discharge data on motorcycle-related injuries have been analyzed for costs of hospitalization and severity of injury and then linked with police reports to determine whether the injured party was wearing a helmet. In another study suicide data from vital records for persons 15–30 years of age have been linked with the hospital records to see if any of the victims were hospitalized for any kind of injury (for example, motor vehicle injury) before the suicide; the results showed a two- to threefold increase in suicides among persons with such hospitalizations and has provided the basis for an intervention program. Finally, a study is underway examining the cost of care for fall-related injuries in the elderly, focusing on patients who were admitted from home but discharged to nursing homes (24).

C. State experiences in collection of E-codes

Although 34 States have legislative mandates to gather hospital-level data and 28 States have mandatory Uniform Hospital Discharge Reporting Systems, most hospitals do not routinely code external causes of injury on their billing instruments or discharge abstracts. Because voluntary reporting of E-coding is inconsistent, five States have mandated reporting E-codes in their hospital discharge data systems, and a sixth, Arizona, has mandated recording E-codes in hospital records. The five States mandating E-coding are California (1990), New York (1990), Rhode Island (1989), Vermont (1990), and Washington (1989). In New York, Washington, Vermont, and Rhode Island, the change was made through regulation. In California, a law was passed in 1988, but regulations were not finalized until 1990. Although a few of the States already had reasonably high voluntary reporting, not all five did. A number of other States have expressed similar interest in mandating E-codes, and several have promoted voluntary reporting, such as Colorado, Massachusetts, Virginia, and Wisconsin, with varying success.

Two States (Rhode Island and Vermont) require reporting E-codes as one of the patient's diagnoses. The other three designate one or more separate fields on the hospital discharge abstract for recording E-codes. (California has room for up to five; New York and Washington, up to two). The winter 1990 issue of *Leadership Quarterly*, a publication of the National Safe Kids Campaign, provides a brief description of how each of the five States achieved a mandate for E-coding. In summary, the States were able to build coalitions among the representatives from all of the affected parties, including physicians, hospitals, business, insurance, and labor and to provide evidence that inclusion of E-coding in hospital records would not be unduly expensive nor time-consuming and would be more practical and less costly than other alternatives, such as statewide trauma registries. A study by Dr. Frederick P. Rivara, Director of the Harborview Injury Prevention and Research Center, which reported relatively modest implementation and ongoing costs, was key in several States (18). (See discussion of costs below.)

VII. Potential impediments and solutions

The high value of external cause-of-injury coding in hospital discharge data for injury prevention and control activities and the lack of a national requirement that the data be collected lead to a recommendation to mandate E-coding. However, such a recommendation often prompts objections, especially by hospital personnel and administrators, about the burden that a mandate would cause. This section of the report details the information obtained by the Subcommittee on the most common reasons why E-codes currently are not being more widely reported and suggests how these impediments should be addressed and overcome:

A. There is no national requirement to record E-codes.

Except for a very small range of codes describing adverse reactions to drugs nationally, hospitals are not required to record E-codes. Some hospitals use E-codes in describing all injuries; some do not use them at all. This results in deficiency and inconsistency in the quantity and quality of information pertaining to cause of injury for hospitalized patients. Currently, coders often limit their reporting to a few select E-codes, relying heavily on general codes, such as E928.9, "Unspecified accident." Mandating E-codes with guidelines and training would promote more specific recording of codes.

Most advocacy groups agree that E-codes must be required, not simply suggested for inclusion. A voluntary system, it has been found, results in inconsistent recording and skewed data. Analysis by the State of Rhode Island of data obtained under voluntary reporting shows that injury discharges with E-codes include different types of injuries than injury discharges without E-codes and therefore cannot be taken as representative of all hospitalizations with injuries. The experience of the State of Wisconsin bears out the necessity of mandating the reporting of E-codes. The Center for Health Systems Research and Analysis at the University of Wisconsin reports that in 1989 only 10 percent of Wisconsin hospitals reported E-codes on all injured patients. On July 1, 1990, the Office of Health Care Information (OHCI) expanded its data base to provide a separate field reserved for E-codes and stated in the inpatient data base manual that E-codes were to be reported. However, no further awareness efforts were taken regarding the new plans. The medical records community has failed to comply with the new guidance without a requirement by HCFA or State statute or more aggressive tactics by OHCI. The current lack of requirement means that E-coding is erratic and thus, little useful data are generated (25).

B. E-codes are not part of and do not affect the current reimbursement system.

Currently, E-codes do not affect hospital reimbursement. They are not part of the prospective payment system and, therefore, carry little impact with hospital administrators and insurers.

However, as has been demonstrated, injuries do have important cost implications. Analysis of E-coded records would provide important information about the actual costs associated with trauma, making clear the implications of injury on health costs and reimbursements. In many cases, more thorough diagnosis coding can lead to higher reimbursement levels, and, although E-codes are not generally related to reimbursement, it is not inconceivable that the information provided could be factored into the reimbursement system at some future time. As an example, during its inquiry, the Subcommittee learned that the Maryland Health Services Cost Review Commission (HSCRC), which administers Maryland's Medicare waiver, recognizes the value of programs that are aimed at controlling health risk factors, including injury, in the community. The HSCRC offers competitively available funding, in the form of short-term rateadjustments, to health care organizations that implement prevention programs based upon "proven" interventions (26).

E-coding also can offer information of considerable interest to public and private insurers by pointing to other possible sources of insurance and secondary claims recovery. Currently, the UB-82 provides for Medicare "occurrence codes" to report an auto accident that involves liability insurance or auto medical and/or no-fault insurance, an accident that may involve a civil court process, an employment-related accident, or any other accident for which no casualty-related payers have been developed. Medicare edits records to see if certain codes are present that signal the fiscal intermediary to check if Medicare should be the secondary, rather than the primary payor. Thus, external causes of injury already are being tied to the billing mechanism.

C. There is not enough room on the UB-82 for E-codes.

Space is limited on the current paper format of the Uniform Bill. Only five spaces are available for diagnosis codes, and an E-code, opponents say, would occupy space that might go to a reimbursable diagnosis. Space is especially an issue with elderly patients because they normally have more conditions to report, and, consequently, the E-code gets "bumped." Similarly, injuries of greater severity require more diagnostic reporting space, thus leaving no room for an E-code. Again, when there is a case of multiple traumas, such as suffered in motor vehicle crashes, less room is available for E-codes. The same holds for patients with longer lengths of hospital stay. Yet in the interest of cost containment, the elderly and patients with severe and multiple injuries would logically seem to be the ones to study for cause-of-injury information.

Although 11 of the States that mandate hospital discharge reporting systems do not use the UB-82 as their collection document, there is general agreement that the data collected on the UB-82 typically drive other hospital discharge data.

HCFA had plans to accept up to 10 diagnosis codes beginning in October 1990, but implementation was delayed because the HCFA intermediaries needed time to upgrade their billing systems to accept the additional diagnoses. The most current information is that intermediaries will be expected to accept up to nine diagnoses (one principal and eight other) as of October 1, 1991. Hospitals using paper forms will be instructed to use the remarks section of the billing form for this expanded reporting until the UB-82 is revised. This modification will open up space to report at least one E-code whenever an injury is the principal diagnosis. Data from the National Hospital Discharge Survey indicate that up to two million patients nationally have more than seven diagnoses;

however, in the case of an injury patient it would seem reasonable to allocate at least one of the eight positions for other diagnoses codes to an E-code. In the future, more extensive electronic billing will alleviate the problem of adequate space on the form.

Even when additional space becomes available for E-codes, most injury prevention and control advocates believe that a separate data element is desirable for recording E-codes as it ensures no confusion or competition with the clinical diagnoses (27). There is concern that as reimbursement becomes more complicated and as the elderly and other surviving injury victims increasingly have multiple conditions and complications, even nine diagnosis spaces will get filled, once again pushing E-codes out.

Those who support inclusion of E-codes within the spaces designated for *ICD-9-CM* diagnoses generally do so because they believe this approach is more likely to be adopted relatively quickly. They also point out that most hospitals have the ability, through computerized programs, to select the diagnoses that impact on the patient's reimbursement and will not need all nine fields. Further, a separate item creates the added challenge of matching injury codes with the E-codes if there are several injuries or causes. However, this could be a problem even if reporting is within the diagnosis fields.

As noted above, the States that have mandated E-coding initially have taken different approaches on this issue.

A related question concerns the number of E-codes that should be used. One space may not be enough because there is often more than one E-code related to an injury. Most injury prevention experts suggest that spaces for two E-codes, one for the cause of injury (E850–869.9 and E880–928.9) and the other for the place of occurrence (E849), are optimal. Because the E849 category includes only 10 options (.0 –.9), it has been suggested that one six-digit field, with five digits for the first E-code and the sixth digit reserved for place of occurrence, could be an acceptable compromise (28).

D. Often there is inadequate information in the medical record from which to code the external cause of injury.

Many times inadequate information in the patient's medical record prevents high-quality and accurate coding of injury. Dr. Philip Fine, Director of the University of Alabama at Birmingham Injury Prevention Research Center, informed the Committee that even when hospitals attempt to document E-codes, they often do so incorrectly. For example, they do not use the maximum number of allowable (and necessary) digits and they use general, rather than specific, categories. He attributed these problems, in part, to poor physician documentation in the medical records and the lack of incentives for physicians and medical records personnel to adopt E-coding in a voluntary environment.

Some States and researchers have found better chart documentation than others. Before E-coding was implemented in New York State, the State Health Department conducted a study at five hospitals that routinely used E-codes and five that did not in order to determine how much training would be needed. The study revealed that in 90 percent of the injury cases, regardless of the type of hospital, the records contained enough information for E-coding. In this study the best sources of cause-of-injury information were nurses' notes taken on the second or third day of patients' stays (29).

The responsibility for accurate E-coding is shared by the medical records professionals who do the coding, the medical staff who record descriptive information in patient charts, and the hospitals that support their responsibilities.

Hospitals should consider accurate and complete recording of external causes of injury in the medical record as an important part of their quality improvement program for injury patients. The desired information, if not in the hospital medical record, is often found in emergency room records or ambulance records. Assurance that relevant records from the hospital emergency room are included in the patient's hospital medical record is a quality issue. Hospital quality improvement committees may be able to impact the quality of recording in medical charts through their ability to influence whether a physician continues to have privileges in the institution. These committees, within the hospitals, often have more clout with the medical staff than medical societies or professional associations.

The IHS recognized that successful E-coding depended on quality information in the chart and accurate translation into codes. A study of E-codes from IHS hospital records found that E-codes for unknown or unspecified causes were used for 25 percent of records. At two hospitals, 63 percent of E-codes assigned by independent coders agreed; another 18 percent matched on general cause-of-injury groups (30). After these findings, the IHS began working with their medical records people and medical staff to improve the quality of E-coding.

The State of Rhode Island is undertaking a study to evaluate the sources of documentation of external cause of injury within the hospital medical record and to identify measures that can be taken to improve the completeness of the record. They plan to look at in-hospital deaths due to injuries and to link them with records from the medical examiner to see whether intent is being documented in emergency rooms.

Several groups have recognized the need for physician training to promote better reporting and have offered to play a role. The American College of Emergency Physicians (ACEP) specifically offered to be active in providing training for physicians on the importance of reporting external causes of injury, as well as the need for accuracy and consistency. The ACEP conducts a number of educational programs each year (31).

E. The *ICD-9-CM* Supplemental Classification for E-codes and its alphabetical index are difficult to use and understand.

The *International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM)* volume I (tabular list) contains codes used to describe diseases and the nature of injuries. There is a Supplemental Classification of External Causes of Injury and Poisoning, in which the codes are preceded by the letter E and are in the range of 800 to 999. These E-codes were developed as companion codes to be used with the nature of injury codes in volume I, in order to describe the circumstances, including location, of an injury. They are used most frequently with codes from chapter 17, the chapter on injury and poisonings.

Although the rest of *ICD-9-CM* has regularly been refined and updated, the E-codes and their alphabetical index have not. The E-code Supplement is characterized as cumbersome, duplicative, and sometimes archaic. The index does not include main entries for some very common external causes, thus requiring considerable searching for the correct code. A basic sports term like "bicycling," for example, is inexplicably not included. Because the E-code supplement and index are difficult to use, coders become frustrated and assign nonspecific codes (32).

Other problems identified with the classification are E-codes that call for rendering a judgment on complex legal matters, such as "criminal intent," or codes necessitating factual determinations that are likely to require more information than a hospital record will contain (33).

There is consensus that the E-code classification should be evaluated and modified, as needed, and that the index needs to be revised for definitional clarity. The Morbidity Classification Branch of the Division of Health Care Statistics, National Center for Health Statistics (NCHS), which has responsibility for updating the *ICD-9-CM* diagnoses and modifying the *ICD* for morbidity uses, has expressed an interest in assuming the lead to evaluate and recommend changes to the tabular list and alphabetical index for E-codes. The process that exists for formally modifying the *ICD-9-CM*, which includes E-codes, involves the *ICD-9-CM* Coordination and Maintenance (C&M) Committee. The Committee meets three times a year, cochaired by HCFA and NCHS, and reviews recommendations to expand and change the codes. Proposed changes are announced in the *Federal Register* before being printed in the *ICD* book and the Supplement. Expert advice, through written and public testimony, is sought by the C&M Committee in making its recommendations to the HCFA Administrator and NCHS Director. A representative of the committee reported that the C&M Committee has not received any formal requests for E-code modifications, although concerns with the E-code supplement have been expressed. Nonetheless, the C&M Committee, in conjunction with recommendations from the Morbidity Classification Branch, NCHS, affords the mechanism for an approach to revising the classification.

F. There are no national guidelines or rules for E-coding.

In addition to revisions in the *ICD-9-CM*, guidelines are needed that delineate for hospital coders how to incorporate E-codes into their data systems. Currently, there are no clear sequencing guidelines for E-coding on hospital discharge forms. For example, should the E-code be placed beside the nature of injury diagnosis code, simply in one of the diagnosis blocks, or as a completely separate data element? Another issue to be addressed is whether the hospital continues to code the E-code on a readmission. Dr. Jane Gordon, Deputy State Epidemiologist in the Oregon Department of Human Resources, reports a high proportion of injury patients being counted multiple times in hospital discharge reporting when they are transferred from one level of care to another or are readmitted for rehabilitation and late effects of injury. Costly matching programs must be used to sort out the duplicates (34). The State of California addressed this problem by mandating the collection of the patient's Social Security number in the hospital discharge record at the same time that E-coding was mandated. In the absence of a unique patient identifier in the hospital discharge data set, a yet unrealized data need in most data systems, guidelines must be developed to deal with multiple counting. The Subcommittee will address this issue in its overall review of the UHDDS.

Due to the lack of national leadership, some States are beginning to develop their own guidelines. Many people in States already implementing E-codes feel that if there is a national mandate it would spur the development of national guidelines, making the data more comparable. National guidelines should be developed through a consensus process including all groups involved in reporting and coding injuries. The American Medical Record Association (AMRA) Council on Coding and Classification is currently working to develop such guidelines. The Advisory Committee for Injury Prevention and Control recommended that the Division of Injury Control of the Center for Environmental Health and Injury Control (CEHIC), Centers for Disease Control, should participate with the NCHS in developing national guidelines. The Morbidity Classification Branch, NCHS, cited above, is prepared to develop and promulgate coding guidelines for the use of E-codes, in conjunction with activities to modify and improve the classification. A coordinated effort is needed on a national level to assure the comparability of information collected.

G. Limited instructional materials are available to train coders in the proper assignment of E-codes and physicians in the reporting of external cause of injury in the record.

The lack of instructional materials parallels the lack of guidelines and must be remedied in the same process. Training programs for medical records personnel should be developed that allow for continuing education. Instructional materials also must be developed for physicians. Currently, States implementing E-coding are relying on several well-respected consultants in this area or are having to develop their own materials. Although reporting requirements in individual States may differ somewhat, national instructional materials based on national guidelines and drawing on the experiences of the States, will play a major role in promoting comparability. The combination of guidelines and ongoing training will improve the coding and collection of cause-of-injury data.

H. The cost of E-coding is perceived to be prohibitive.

The potential cost of adding E-coding to the hospital discharge form is another barrier to widespread support, especially from hospital groups. Some argue that the costs of requiring E-coding would be prohibitively expensive for hospitals; and hospitals object to being asked to report any new data if there is no recognition of the increased cost of doing so and if it will not influence hospital reimbursement.

However, none of the organizations that wrote to the Subcommittee concerning E-coding felt that the additional cost would be significant. When the issue of mandating E-codes in the hospital discharge data system was raised in Washington State, the State hospital association expressed tremendous concern about the costs to hospitals of such an addition. The State health department commissioned a study by an independent financial consultant, who surveyed hospitals, information system vendors, and medical records experts to estimate potential costs. The study concluded that one-time implementation costs, which include modification of the computerized data base and the coding guidelines used by medical record personnel, would average $600 per hospital. Annual costs resulting from increased operating expenses to include E-codes were estimated at an average of another $600 per hospital, because of the increased workload of coding and entry of the additional data. According to the consultant, it would take a medical record coder only about 3 minutes per chart to add E-codes (18). The study convinced the Washington State Hospital Commission to add E-codes to the data system, and subsequent experience in the State has not contradicted the consultant's study (24).

Several of the other States that have mandated E-coding currently are studying the cost and ease of implementation, but in each case the process seems to be going relatively smoothly. Before implementation, the State of New York estimated that E-codes would add 2 percent to the total volume of coding activity in the State's hospital medical record departments (35). The wide use of software for computer-assisted coding was expected to keep the additional costs to a minimum.

With technological changes, many insurance companies will adopt an electronic claim base that will make the capture of data easier, more accurate, and less costly than in the past with paper claims. Reporting on an informal survey of member companies, the Health Insurance Association of America informed the Subcommittee that E-codes are considered useful, and member companies would accept them when the UB-82 is revised (36).

The Subcommittee is cognizant of the cost issues for hospitals and feels that costs should be monitored and mechanisms for minimizing the costs and any additional burden to hospitals should be encouraged. However, the

Subcommittee considers E-coding for injury patients part of standard coding practice and the hospital's responsibility to code medical records. The fact that these codes currently do not affect reimbursement should not be a reason to disregard this particular coding requirement. The UHDDS is mandatory for all patients in hospitals that accept payment under Medicare and Medicaid. Because the hospital is already under global contract with HCFA for collecting and coding records, E-codes should be part of their standard work. Nonetheless, the Subcommittee would not oppose an incentive payment, such as that being considered in the State of Maryland, if it would promote more complete and accurate recording of E-codes.

In mandating recording of E-codes, the intent is not to expand data collection responsibilities, but to make clear that E-codes, as part of the disease classification system, are a high priority for inclusion in the coded data. It is important that a way be found to efficiently report injury information. Hospitals are an important part of our public health infrastructure and must respond to the health problems in their communities, of which intentional and unintentional injuries represent a significant share. By gathering information about the causes of injury in the populations they serve, hospitals will be in a better position to care for patients and reduce health care costs.

A final cost issue recognized by the Subcommittee is the concern that reporting of E-codes will expose the hospital to payment delays and rising accounts receivable from third-party payers, especially Medicare. However, as noted above, occurrence codes for possible liability insurance already are required by Medicare. Although the possibility of recovering hospitalization costs from a liability insurer is attractive, and in some cases essential, for public and private insurers, this should constitute secondary recovery whenever possible. There is no evidence that payment delays do not already exist with injury cases when there is inadequate coding of necessary information.

I. E-codes could increase the risk of liability to the physician and the hospital.

Concerns about hospital and physician liability also hinder support for E-coding. Physicians worry that when they attest to the diagnoses in a patient's chart, the coded information on the external cause of injury will leave them vulnerable to lawsuits. An example would be a code implying blame in a domestic dispute.

Health care facilities are also concerned about recording a number of codes they consider sensitive, in particular those between E870 and E876. These codes, commonly referred to as "misadventures," describe such things as "accidental cut of another organ during surgery," and other injuries medical staff are not anxious to report. The risk for hospital administrators is that these codes also may fuel lawsuits. In California the medical records association strongly objected to the inclusion of E-codes that deal with injuries occurring inside the hospital, or the so-called medical or surgical misadventures. They found that reporting of misadventures among area hospitals was inconsistent, usually geared toward making the hospital look better, and putting those who were conscientious about reporting at a disadvantage. It was felt that risk management programs within the hospital are a much superior way to tracking and remedying these problems.

Testimony received by the Subcommittee indicated that there should not be a problem with the physician attesting to the external causes, as his or her responsibility is to attest only to the patient's medical diagnoses. Nonetheless, a HCFA staff person has suggested in *Medical Records Briefing* that the Peer Review Organizations would have to check accuracy and omissions of E-codes if they were mandatory (37).

Concerning the issues of liability, the Subcommittee consulted with Walter J. Wadlington, J.D., Professor of Legal Medicine at the University of Virginia Law School. While not rendering a formal legal opinion on the matter, Dr. Wadlington reviewed the Subcommittee's deliberations and the E-code classification system and offered the following observations.

In summary, Dr. Wadlington did not anticipate major legal problems stemming from properly drafted E-codes that are entered on the basis of accurate information, but he was concerned about ambiguity or overbreadth in the current categories, about whether the information contained in hospital records will be accurate or sufficient in many instances, and about requiring a coder to make "judgment calls" that may be verging on legal opinions. His main concern centered on E-codes that call for rendering a judgment on what can be complex legal matters, such as existence of "criminal intent." An example is the code for "Abandonment of child, infant, or other helpless person with intent to injure or kill." He noted that this is an example of a determination that can be key to prosecution for certain offenses and that often involves disputed and difficult "calls" in the legal world. He added that if the injury prevention field is serious about enforcing the use of such codes, greater legal input into their drafting seems highly important or they will be meaningless or misleading (33).

Dr. Wadlington also expressed concern about the "misadventure" codes. He offered as an example the E-code for "Performance of inappropriate operation" and suggested that this could refer to "wrong member" surgery, unnecessary surgery, or even discredited surgical procedures. Because these codes may carry at least the innuendo of substandard care, he suggested liaison between coders and risk managers when they are used.

On the general issue of liability, Dr. Wadlington observed that if the information is part of the medical or hospital records (regardless of whether it is coded), it would probably be subject to discovery according to the rules of the jurisdiction involved. An alternative for highly sensitive information is to deal with it in a privileged setting, such as a mortality or infections committee.

Modifications in the E-coding classification system and the national guidelines developed for recording E-codes must remove the burden of responsibility for making legal judgments from physicians and coders. They also must ensure that recording the external causes of injury, either for misadventures or abuse, will not expose physicians to legal reprisal. There are ways currently to code external causes that indicate that the manner of the injury, unintentional or intentional, is unknown. Nonetheless, the efforts to improve the E-code classification system might benefit from legal consultation, as suggested by Dr. Wadlington.

At the same time, "misadventures" are not likely to be a principal cause of hospital admission, which is the focus for most E-coding and injury prevention programs. The States California and Washington, in mandating E-coding, excluded misadventures from the requirement for the reasons cited above. Furthermore, the 10th revision of the International Classification of Diseases (ICD-10) will separate iatrogenic occurrences from the spontaneous injury classifications. The former are not considered injuries.

VIII. Recommendations

There is consensus within the NCVHS Subcommittee on Ambulatory and Hospital Care Statistics that the NCVHS should make the following recommendation to the Secretary of DHHS: Whenever an injury is the principal diagnosis or directly related to the principal diagnosis for a hospitalized patient, there should be an external cause of injury recorded in the medical record. (Principal diagnosis is defined as the condition established after study to be chiefly responsible for occasioning the admission of the patient to the hospital for care.) When there is an external cause recorded in the record, applicable E-codes should be reported in the hospital discharge data set. A minimum of one E-code should be reported for cause; a second E-code or a fifth digit, as suggested above, is strongly encouraged for place of occurrence, where appropriate. A hospital record or bill should be regarded as incomplete if there is evidence of an injury and no E-code is recorded.

The Subcommittee advises that E-coding should be recommended for all hospitalized patients, in all DHHS programs that deliver care, regardless of the payment source. The Subcommittee concurrently recommends that the revised Uniform Bill (UB-82) for hospitals accommodate the collection of E-codes. The Subcommittee also strongly encourages all other jurisdictions and programs collecting UHDDS data to include E-coding as a requirement for injury hospitalizations. The Subcommittee is concerned that, without strong financial incentives or sanctions, the mandate to report E-codes may not succeed nationally and will continue to watch the experience in the States that have required E-coding and to monitor implementation.

A. Limitation to inpatient hospital setting

While recognizing the value of external cause-of-injury information from emergency rooms as well as other ambulatory care settings, the Subcommittee recommends that the mandate for E-coding begin with the hospital. First, patients with the most severe nonfatal injuries generally are hospitalized. Second, the Subcommittee notes that the history of the UHDDS is an evolutionary one and that development of core data sets in other settings followed implementation in the hospital sector. Other sites will gradually adopt E-coding on their own as greater experience in using the classification is gained and the value of the data is demonstrated. Trying to implement E-coding universally might receive support, but the value of the information from other settings would be questionable. The potential for greater success in getting E-codes reported accurately from everybody would be to start slowly with the inpatient hospital segment, letting the rest follow over time.

B. Location

As discussed above, the Subcommittee has considered the issue of whether there should be a separate field for E-codes within the UHDDS or whether E-codes should be recorded as one of the patient's diagnoses. In the interest of providing maximum flexibility to the National Uniform Billing Committee in its revision of the UB-82, the Subcommittee is deferring to the NUBC to decide which approach is preferable when E-codes are recorded on the billing form. Preliminary feedback from the NUBC favors a separate dedicated field, and the Subcommittee concludes that, in the long run, one or more separate fields are most desirable and should be the goal for all systems. Recognizing that only 17 of the 29 States with hospital discharge data systems use the UB-82 (38), the Subcommittee encourages the remaining States to give strong consideration to a separate field or fields but to select the approach that will maximize the recording of one, and preferably two, E-codes for injury patients.

The primary consideration seems to be timing. Expanding the diagnosis spaces has taken several years and is not yet final for 1991. To seek approval for an entirely new data element could be excessively time consuming when the data are needed. There is agreement that, on an interim basis, either approach is acceptable as long as E-codes are obtained.

C. Number of E-codes

A minimum of one E-code must be recorded whenever injury is the principal diagnosis or directly related to the principal diagnosis. Those systems that can accommodate a second E-code for "place of occurrence" are strongly encouraged to do so. When a separate field is designated for E-codes, addition of a fifth digit or, alternatively, designation of a second, one-digit field for place of occurrence could be considered. Recording additional E-codes beyond two should be optional. Although several States have allowed for more than two E-codes, most injury specialists believe two codes are sufficient. While the cause (for example, fall, motor vehicle crash, and others) is paramount, injury prevention and control programs are greatly enhanced by also knowing the place of occurrence. Place E-codes also can give rudimentary information on occupational injuries. The Oregon Department for Human Resources, for example, has determined that 50.5 percent of the injury cases in its surveillance data (excluding at-the-scene deaths) required a place code (39). Developing guidelines for sequencing and prioritizing multiple E-codes should be the responsibility of the group developing overall reporting guidelines.

D. "Misadventure" Codes

The Subcommittee recommends not including the misadventure codes as part of required reporting of E-codes for three reasons:

1. There are serious problems with the codes and the descriptors as documented by Professor Wadlington and others;
2. The findings and experience in California indicate that these codes will complicate implementation of external cause-of-injury codes without any meaningful gain in information for injury prevention and control; and
3. *ICD-10* will separate the misadventure codes from the other E-codes.

E. Development of guidelines

National guidelines for recording E-codes must be developed before a national mandate to include E-codes in the UHDDS is implemented. At its February 4–5, 1991, meeting, the Advisory Committee for Injury Prevention and Control passed a motion that "in the event that E-codes are mandated in the UHDDS, the Division of Injury Control (CEHIC) should participate with the National Center for Health Statistics in developing national guidelines for E-coding for those states that have adopted the UHDDS. These national guidelines should include quality assurance aspects for obtaining reliable and specific E-code data (40)."

The Subcommittee recommends that the development of guidelines should be undertaken by the Morbidity Classification Branch, NCHS, in cooperation with CEHIC, and the Editorial Advisory Board of the Coding Clinic, which includes input from the physician community. The Coding Clinic develops and publishes guidelines jointly with the American Hospital Association, the American Medical Records Association (AMRA), HCFA, and NCHS. The Coordination and Maintenance Committee traditionally has not promulgated guidelines, making the Coding Clinic the more appropriate body. In developing the guidelines, efforts should be made to build on State and IHS experience with collecting and using E-codes. Organized medicine also should be involved in the process.

The guidelines must be accompanied by training materials. Training sessions should be conducted by AMRA, physician organizations such as the AMA, specialty societies (for example, ACEP), and other interested parties.

F. Improvement of E-code classification system in ICD-9

The E-code classification system and alphabetic index need immediate attention. Work can begin in this area, even before final decisions are reached on a national mandate. The Subcommittee encourages the Morbidity Classification Branch, NCHS, to begin this work in collaboration with other interested parties. Review of proposed changes in the classification and alphabetical index should be the ultimate responsibility of the Coordination and Maintenance (C&M) Committee, which makes recommendations to the Administrator, HCFA, and the Director, NCHS.

Improvement of the supplement and the alphabetical index can take place concurrently with the development of guidelines and instructional materials for the present classification. The Coordination and Maintenance Committee can consider modifications to the current code book without national guidelines. The Editorial Advisory Board and related groups can review guidelines for existing codes and, when additional codes are added, modified, subdivided, or expanded, the guidelines can be revised. This approach is recommended in the interest of moving the process forward as quickly as possible.

Although the proposed mandate will not include misadventures, the Morbidity Classification Branch, NCHS, and C&M Committee should give attention to modifying and improving these codes. For example, the distinction should be made between what is an iatrogenic injury and what is a normal part of the operative process.

G. Timing

Reporting should be required with the implementation of the revised UB-82, tentatively scheduled for October 1992. Hospitals should be strongly encouraged immediately to improve recordkeeping on external causes of injury and to begin reporting E-codes voluntarily as one or more of the injured patient's diagnoses as soon as feasible. This will be facilitated when the diagnostic fields on the UB-82 are expanded to nine spaces, projected for October 1991. The reporting requirement for E-codes will have an appropriate phase-in period before implementation of *ICD-10*. Implementing the E-codes under ICD-9 rather than waiting for *ICD-10* also will eliminate the additional confusion of using an entirely new classification system. Moreover, this will ensure that E-codes will be collected as soon as possible, rather than waiting until 1996, currently the earliest date projected for implementing *ICD-10* for morbidity coding. Work on national guidelines for E-coding with *ICD-9-CM* should begin immediately. When *ICD-10* is implemented, E-codes will already have been well in place, and guidelines only will need to be modified.

H. Resources

A budget should be established for the following functions to assure successful implementation of high-quality external cause-of-injury coding:

1. Evaluation and improvement of the tabular list and alphabetical index for E-codes.
2. Development and promulgation of national guidelines.
3. Development of educational materials for coders and physicians.
4. Conduct of educational sessions.
5. Further research into automated systems for assigning codes and flagging injuries, as currently carried out by the Indian Health Service.

It is likely that the costs will be borne by both the public and private sectors; however, it is important that adequate attention is given to the resources needed to make national implementation a reality.

IX. Conclusion

Recognizing the national need for cause-of-injury data and the importance of obtaining this information at the earliest possible time, the NCVHS Subcommittee on Ambulatory and Hospital Care Statistics recommends the mandatory inclusion of E-codes in the Uniform Hospital Discharge Data Set. The Subcommittee further recommends that the revised Uniform Bill (UB-82) for hospitals accommodate the collection of E-codes. Implementation of this mandate should be in conjunction with the development of national guidelines and training materials for using E-codes. Work should begin on modifications to the *ICD-9-CM* classification system for recording external causes of injury, including the alphabetical index for E-codes, to facilitate the recording of data at the hospital level. Adequate resources should be made available to support each of these functions.

Appendix A

Charge to the Subcommittee on Ambulatory and Hospital Care Statistics

1. Conduct a thorough and systematic review of the Uniform Hospital Discharge Data Set (UHDDS) for the purpose of recommending any revisions needed to meet current and anticipated needs. Carry out this review in tandem with the Department of Health and Human Services (DHHS) and in close cooperation with the National Uniform Billing Committee (NUBC). As part of the review process, receive appropriate input from other governmental agencies, the research community, and the private sector. Report preliminary results of the UHDDS review by the February 1992 National Committee on Vital and Health Statistics (NCVHS) meeting and present a final report by the June 1992 NCVHS meeting.
2. Monitor the responses within DHHS to the final report on the Uniform Ambulatory Care Data Set (UACDS), which was submitted to the Assistant Secretary for Health by the NCVHS and the Interagency Task Force. Monitor any implementation plans that are developed by the agencies.
3. Follow the efforts of the Uniform Claim Form Task Force for the Health Care Financing Administration (HCFA) 1500 to seek greater standardization of the definitions in use for place or site of health care services.
4. Provide continuing liaison with the HCFA, the National Center for Health Statistics (NCHS), and other relevant agencies concerning the statistical aspects of physician payment systems and other data systems and research and development projects concerned with patient-provider encounters.
5. Follow these data systems and related activities by receiving periodic updates, having an opportunity to react to developments, and, where appropriate, framing recommendations concerning their future course. Among those activities for which data policy, data coordination, and data quality issues will be reviewed are:

    - progress towards implementing the Medicare Common Working File;
    - status of the revision of the HCFA 1500;
    - progress towards implementation by the Medicare program of the unique physician identification number (UPIN);
    - status of research and demonstration projects on prospective payment methodologies for ambulatory care;
    - Medicaid data development; and
    - development of the National Practitioner Data Bank.

6. Follow plans for implementing the requirement for physician coding of diagnoses on the HCFA 1500. Examine issues of data quality and coordination.
7. Follow the status of relative value scale research, development, and implementation through physician payment reform legislation and the associated data requirements.
8. Consider the importance of emerging and projected quality-of-care activities for relevance to existing data systems and implications for revisions to those

systems. Examine data quality issues related to measurement of the effectiveness and quality of care. Provide liaison with the Agency for Health Care Policy and Research for these types of activities.

Appendix B

Roster

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Appendix C

Organizations in Support of E-coding

Health Departments

CITY

Anchorage: Injury Prevention Program, Department of Health and Human Services

San Antonio: Metropolitan Health District

New York: Assistant Commissioner, Community and Occupational Health Promotion, Department of Health

STATE

Colorado: Health Statistics Section, Department of Health and Disability Prevention Project, Injury Prevention Project, Department of Health

Florida: Injury Control Administration, Emergency Medical Services, Department of Health and Rehabilitative Services

Maryland: Injury Prevention and Control Program, Department of Health and Mental Hygiene, Local and Family Health Administration

Utah: Bureau of Epidemiology, Epidemiological Studies Program, Division of Community Health Services, Department of Health

Vermont: Department of Health, Epidemiology and Disease Prevention, Agency of Human Services

California: Childhood Injury Prevention Program, Child Health Promotion Section, Maternal and Child Health Branch, Department of Health Services, Health and Welfare Agency

Massachusetts: Commissioner, Department of Public Health; Office of Disability Prevention, Bureau of Parent, Child and Adolescent Health, Department of Public Health; and Division of Health Resources Statistics, Bureau of Health Statistics, Research and Evaluation, Department of Public Health, Executive Office of Human Services

Missouri: Division of Health Resources, Department of Health

North Carolina: Injury Control Section, Division of Epidemiology, and Office of Prevention, Division of Maternal and Child Health, Department of Environment, Health and Natural Resources

Oregon: Health Division, Department of Human Resources and Environmental, Occupational and Injury Epidemiology Section, Office of Epidemiology and Health Statistics, Health Division

Pennsylvania: Department of Health

New York: Injury Control Program, Office of Public Health, Department of Health

Washington: Health Promotion and Chronic Disease Prevention Department of Health

University Affiliated

University of North Carolina: Highway Safety Research Center, Injury Prevention Research Center, Department of Biostatistics, Department of Emergency Medicine, and Center for Health Promotion and Disease Prevention,

University of Washington: Harborview Injury Prevention and Research Center

University of Wisconsin: Center for Health Systems Research and Analysis

Appendix C

Organizations in Support of E-coding—Con.

Health Departments		*University Affiliated*
Alaska: Injury Control Program, Section of Epidemiology, Division of Public Health, Department of Health and Social Services	Virginia: Division of Emergency Medical Services, Division of Emergency Medical Services, Department of Health	
	Iowa: Iowa Department of Public Health	
	Minnesota: Minnesota Department of Health	

Organizations in Support of E-coding—Con.

Federal Programs

- Injury Prevention Program, Indian Health Service, Public Health Service, Department of Health and Human Services
- U.S. Navy, Medical Service Corps, Armed Forces Epidemiological Board, Department of Defense
- Sentinel Injury Surveillance System, Massachusetts Health Research Institute

Health/Medicine: Academic and Professional

- North Carolina: Trauma Registry Data Collection Unit, State Center for Health and Environmental Statistics, State Medical Society, State Medical Database Commission
- Medical College of Wisconsin
- Johns Hopkins University: School of Hygiene and Public Health, Department of Maternal and Child Health and Department of Health Policy and Management, Injury Prevention Center
- University of Alabama at Birmingham, School of Medicine, Injury Prevention Research Center
- University of Oklahoma, Health Sciences Center, College of Medicine (Dr. Edward N. Brandt, Jr. Chair, Centers for Disease Control, Advisory Committee for Injury Prevention and Control)
- American College of Emergency Physicians, Physician Reimbursement Department
- Valley Children's Hospital, Trauma Department (CA)
- University of Iowa: Institute of Agricultural Medicine and Occupational Health, Department of Preventive Medicine and Environmental Health, College of Medicine

Associations and Not-for-Profits

- National Safe Kids Campaign (DC)
- Association for the Advancement of Automotive Medicine (IL)
- The Workplace Health Fund (DC)
- National Association of Health Data Organizations
- The Pittsburg Research Institute, Center for Health Services Research
- Educational Development Center, Inc., Childhood Injury Prevention Resource Center
- Seventh Principle Project, Unitarian, Universalist (MA)
- Marshfield Research Foundation (WI)
- Council of State and Territorial Epidemiologists
- Missouri Safety Council
- AFL–CIO, Building and Construction Trades Department
- Labor Research Advisory Committee on Occupational Safety and Health Statistics, Amalgamated Clothing and Textile Workers Union
- National Fire Protection Association International
- Neurotrauma Disability Resource Network, MPS Associates, Inc.

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Appendix VII.
Report on Medical Indigence

Subcommittee on Health Statistics for Minority and Other Special Populations 1991

I. *Background*

Medical indigence is recognized as a critical and growing problem in the United States, with the lack of health insurance being the major contributing factor. The number of persons without health insurance in the United States, the numbers of these persons in various geographic areas, the socioeconomic factors affecting them, what we know about their health status, and their problems with access to medical care, has emerged as one of the most compelling set of health policy issues of the last decade. These issues have adversely affected Federal, State, and local government as well as providers and consumers of health care services.

Unlike most other Western nations that sponsor health benefits through a single comprehensive public program, the United States has a number of different programs financing or providing health care.

- Private health insurance is usually job related and is partially financed by tax benefits for employer-provided health insurance. Rising health care costs among other factors have led to an increasing percent of workers required to contribute toward the cost of premiums for all health plans throughout the 1980's (1). About three-quarters of the population are covered by private health insurance (2).
- The Federal Medicare program, which is for the elderly, disabled, and certain people with end-stage renal disease, covers about 95 percent of those age 65 years and over (2).
- The joint State and Federal Medicaid program provides medical assistance to about 24 million eligible low-income persons in families with dependent children, pregnant women as well as those who are aged, blind, and disabled. Recent expansions have increased Medicaid coverage for poor pregnant women and infants (3).
- Federal programs providing health care for military personnel, veterans, and their dependents cover about 6 million persons (2).

There is some overlap between these programs, but there are also many gaps that leave about 31–37 million persons without health insurance (2,4,5). An estimated three-quarters of the total uninsured population are either working or are dependents of those who are working (6). The recent slowing of the economy has resulted in increases in unemployment and, therefore, potential loss of job-related health insurance.

II. *Issues*

In February 1989, the Subcommittee on Health Statistics for Minority and Other Special Populations was asked by Dr. Ronald Blankenbaker, Chairman of the National Committee on Vital and Health Statistics, to review the statistical issues related to medical indigence. The Subcommittee formulated this charge into the following questions:

- Who are the medically indigent and how should medical indigence be defined?
- Which of the currently existing data sets can be used to measure the magnitude and scope of the problem?
- Are these data sets adequate?
- What actions should the National Committee on Vital and Health Statistics take in addressing this problem?

III. *Process*

In order to gather the information necessary to answer these questions, the Subcommittee conducted two public hearings. The first, held May 3, 1989, specifically asked the presenters to address the scope and magnitude of the problem and the adequacy of current data. The second hearing, June 5, 1990, targeted researchers to provide a current definition of medical indigence and to discuss the data sets they used in their work on medical indigence. Presentations were made by spokespersons from the National Center for Health Services Research; New Jersey State Department of Health; Children's Defense Fund; American Hospital Association; Office of Representative Louis Stokes; The American Cancer Society; Migrant Clinicians Network; Lewin-ICF Associates; Agency for Health Care Policy and Research; and a health policy consultant from New York.

Written testimonies were submitted by Alan B. Cohen, Sc.D., The Robert Wood Johnson Foundation; Karl Yordy, The National Academy of Sciences; Paul W. Newacheck, M.P.P., University of California, San Francisco; Jerry Johnson, M.D., University of Pennsylvania; Janice Hays Chadha, Saint Louis University; Howard Watzkin, M.D., Ph.D., University of California, Irvine; Eli Ginsberg, Columbia University; and Jose J. Escarse, M.D., University of Pennsylvania. In addition, a number of researchers submitted copies of published articles that were germane to the issue.

The information presented at these hearings was supplemented by a selective review of the literature conducted by the Subcommittee staff. Subsequently, several meetings and conference calls were held to synthesize the information and finalize the recommendations.

IV. *Findings*

Who are the medically indigent and how should medical indigence be defined?

The testimonies received indicated that the majority of persons considered medically indigent fall into one or all of the following categories:

- Those who are uninsured.
- Those who are underinsured.
- Those who have difficulty obtaining necessary medical care due to the inability to pay.
- Those who receive substandard care due to the inability to pay.

Even though the term "medical indigence" has gained some popularity, its precise meaning and definition are ambiguous. The uninsured are the easiest to define and most research has focused on this group. The remaining three categories present many definitional and measurement problems.

There is no government wide uniform definition for uninsured, nor did any attempts to develop a definition come to light during the hearings. Although such a definition would not be impossible to establish, it would require the cooperation of the many agencies that are responsible for providing and monitoring health care. There are inconsistencies in the way that the uninsured are counted in different national surveys. In some surveys, a point prevalence is used (those uninsured at any given moment), whereas others use period prevalence (those uninsured during a defined period of time, usually a year). Similarly, some surveys solicit information only about health insurance coverage under policies held by household members. Other surveys include additional questions about coverage of household members by policies held by others (outside of the household), for example, a divorced or separated parent.

Simple lack of insurance may not imply indigence because some individuals have other resources with which to pay for care or are unlikely to incur medical expenses (7). Still other individuals choose limited policies or choose not to be insured at all. Although the risk is low, the high cost of care for a major accident, for example, would make essentially all persons without insurance medically indigent.

Limitations in insurance coverage may lead to indigence because gaps in coverage often inhibit a person from receiving needed care. Individual policies are often inadequate and may exclude preexisting medical conditions. There have been recent medical care cost containment efforts by Federal and State governments, hospitals, health insurance companies, and employers. These efforts have led to increases in premiums, deductibles, coinsurance and copayments, which have placed an increasing out-of-pocket burden onto many persons with private insurance as well as led to increases in the percent of workers required to contribute toward the cost of premiums. Ever rising medical care costs are eroding the value of health care policies and, as medical care cost continue to rise, coverage limits that once may have seemed unreachable, may now be reached during a single episode of a serious illness. These changes may cause persons to forgo or delay necessary medical care.

The number of persons without adequate coverage is difficult to estimate because of the great variety of policies. Since the Medicaid programs of many States have limited the extent and duration of services, even those persons who do qualify for Medicaid could be considered to be persons with inadequate coverage (8).

Difficulty obtaining health care is an important component of medical indigence. It has been estimated that 38.8 million Americans have difficulty obtaining health care when they need it, with the most common reason being inability to pay for care (4). The medically indigent, despite generally poor health status, are less likely to receive the care they need and preventive care. Low awareness of the need for preventive services may contribute to the failure to seek such care.

The inability to pay for medical care is reflected in the financial burden imposed on institutions. Uncompensated and charity care has had rapid growth in the last decade. It is well known that a small proportion of hospitals provide a large proportion of care to uninsured individuals. Most often, such hospitals are the principal source of care for people who, because of inability to pay, cannot obtain care elsewhere. Hospitals often increase their charges to paying patients in order to subsidize their bad debt and charity care. While the financial burden on institutions provides an indicator of the problems caused by medical indigence, it cannot directly be used to estimate the number of people affected.

Measurements of quality of care and substandard care are relatively new areas in health statistics. Work in this area is being conducted primarily by agencies concerned with patterns of reimbursement. Basic work has not yet been done on quality of care as it relates to access.

In order to fully define medical indigence, three additional factors, access, health status, and risk of illness, must be considered. Limited access to care among Medicaid recipients and the disproportionate burden this places on minority groups is well documented. Minority populations have been found to be in poorer health than nonminorities. Elevated morbidity and mortality rates among minorities have been well documented, with the highest disparity among low-income and groups, rural and the elderly.(9) In addition, the maldistribution of health care services may make some services so costly for individuals to obtain that they forgo or delay obtaining needed care. The case of a migrant worker who must travel a full day and lose a day's pay in order to see a physician is an example.

Access to care is complex and relates to factors other than a financial burden. The hearings illustrated the importance of including access to health care for the indigent as a component of the definition. This has been addressed as an immediate crisis in the report of the Institute of Medicine, *The Future of Public Health* (10). While other similar perspectives have been developed, previous reports have fallen short of providing a definition that can be easily operationalized (11,12). Thus, more easily attained proxy indicators, such as insurance status, have been the definition used by some groups working in this area.

There are also those persons who are not currently facing health-related financial burdens, but because of their circumstances, are at very high risk to do so. For example, women at child-bearing age without insurance coverage for obstetrical care are at high risk of becoming medically indigent, as are older adults with dementing illness who do not have long-term care insurance. Persons who are left impoverished as a result of major medical expenses are likely to be at high risk for further episodes of illness and subsequent indigence.

There was a general acknowledgment that having health insurance does not always measure financial burden or barriers to access because changes in the insurance industry are resulting in increased financial out-of-pocket burdens for policy holders; ever rising medical care costs are eroding the value of health care policies; and having certain types of medical insurance, particularly Medicaid, may not necessarily ensure access to care. The financial burdens of many health care policy holders have increased because of higher premiums and deductibles, more severe copayments or coinsurance, more restrictive benefits, more exclusions for preexisting conditions and noncoverage of family members. It was pointed out during the hearings (and in the literature) that these hardships are particularly but not exclusively felt by those employed by small businesses.

Which of the currently existing data sets can be used to measure the magnitude and scope of the problem?

The relevant information collected by various surveys was summarized for the Subcommittee by Lewin and Associates and is reproduced in Table 1. No single data set provides all of the information, and because the data systems are designed differently, it is difficult to combine information.

The most complete data set is the 1987 National Medical Expenditures Survey (NMES), but it does not have information on preexisting medical conditions that may limit health insurance benefits. Furthermore, the survey is administered every decade, most recently in 1987, and this information will soon be out of date. Also, the sample size does not allow for the analysis of the data for some categories such as minority populations.

The other three data sets do not provide detailed information on health insurance policies and costs. Thus, no information on the underinsured can be obtained. There is extremely limited, if any, information available on those persons who have difficulty obtaining medical care due to the inability to pay or those who receive substandard care due to the inability to pay. The available information is generally from occasional small scale surveys conducted outside of the government.

Are existing data sets adequate?

Clearly, some persons with medical insurance are not adequately covered because of limitations in their policies. Thus, the concept of underinsured is also important in defining medical indigence. However, the measurement of underinsured is not defined as well. There is no consensus concerning what is considered essential coverage. Dental and mental health services are given high priority by many, but are not included in most policies. Basic survey methodologies to establish and verify levels of coverage are not developed. Until a great deal more work is done in this area, and, until better data are available, measurements of the underinsured will be impressionistic.

Special surveys have been done to estimate the number of persons who have difficulties obtaining health care. Those who have difficulty obtaining health care because of inability to pay, certainly overlap with the uninsured and the underinsured, and they may need to be measured separately.

Testimonies indicated that the data should be able to drive analyses aimed at measuring the number of medically indigent, as well as analyses that would explain the reasons for and provide solutions to the problem. Existing data sets are inadequate for these tasks.

In addition, the following areas were thought to be inadequately analyzed because of limitations in the type of data or the frequency with which it is collected:

1. medical indigence among populations that are difficult to survey, such as the homeless or migrant workers
2. medical indigence at local levels (State, county, and city) as well as national level
3. the causes of medical indigence
4. the reasons for being uninsured, such as unemployment or employment by a small business
5. the role that ineligibility for Medicaid, and/or ineligibility for employer's insurance plays as an underlying cause
6. the extent to which the working uninsured have health conditions that would make them bad risks or uninsurable
7. the barriers the medically indigent face in receiving care
8. the links between health status and poverty
9. the relationship of medical indigence to use of prenatal care and pregnancy outcomes
10. monitoring of maternal and child health in indigent families for childhood lead poisoning, immunization, and nutritional status
11. the definition of emerging health problems and targeting scarce resources
12. the analysis of medical indigence among all racial and ethnic minority groups

These comments were based on consideration of the following data sets:

The National Medical Expenditure Survey conducted by the National Center for Health Services Research, The National Health Interview Survey, The National Health and Nutrition Examination Survey, The National Maternal and Infant Health Survey and the Vital Registration Systems (National Center for Health Statistics), National Cancer Institute studies (National Institutes of Health), The Current Population Survey (Bureau of the Census), Robert Wood Johnson National Access Survey, and the Medicare and Medicaid records (Health Care Financing Administration).

Most of the currently available data on the medically indigent are collected in infrequent cycles, lack consistency in definitions of conditions and reporting criteria, are not desegregated by race and ethnicity, and are not available for small geographic areas. There is no central accessible data base that systematically collects, analyzes, and stores the information in a timely and useful way. These deficiencies immensely hamper the formulation of sound health policies and programs to improve access to care for the medically indigent as well as all Americans. However, even with these limitations, current data could probably provide greater insights if there were sufficient funds and a rational plan for maximizing analysis.

V. *Conclusions*

The Subcommittee concludes that "medical indigence" is a major problem facing this Nation, and, that our current data collection and analysis efforts are inadequate to track, understand, and develop solutions to the problem. Because there is no precise or consistent definition, medical indigence has no value as a *statistical* term or concept at the current time. Since it is likely that the problem of medical indigence will continue, and even worsen in the United States, it is essential to develop, *through a comprehensive effort*, better tools to measure and monitor this problem.

VI. *Recommendations (What actions should the Committee take?)*

Medical indigence is an important problem that is extremely complex. Controversies exist regarding its definition and measurement, and, as a result, the figures are inconsistent. At the heart of the controversy is (1) whether existing data sets are adequate to accurately measure the medically indigent, and (2) which ones can provide the greatest insight into, not only the magnitude, but also the causes of the problem. Thus, medical indigence and its measurement pose a challenge for the Nation's ability to gather and analyze health statistics.

The data on medical indigence are currently collected by a variety of agencies including the National Center for Health Statistics, the Health Care Financing Administration, the Agency for Health Care Policy and Research, the Bureau of the Census, the Social Security Administration, and the Health Resources and Services Administration. In addition, there are other current efforts examining medical indigence within the Department; however, their major charge is not focused on data and statistical issues. Therefore, we recommend that:

1. The Secretary identify an appropriate group or develop some other mechanism, such as an interagency task force, to address the statistical and data issues related to medical indigence. The specific charges should include:

- To identify the groups and individuals currently involved with developing definitions of data or setting guidelines or standards for definitions of data to be used in measuring medical indigence;
- To identify the areas in which these groups are currently focusing their efforts;
- To consider fostering cooperative and collaborative efforts among these groups and individuals;
- To develop uniform definitions of data to be collected and used in measuring medical indigence, including consideration of a minimum data set;

- To develop a consensus on the assumptions to be used in measuring medical indigence (such as point compared with period prevalence);
- To develop common reporting formats and linkages for such data;
- To develop guidelines for the supplementation of existing data bases, including the collection of new information, to enhance data bases for the purpose of measuring medical indigence, and the design and development of new data bases that would be used in medical indigence-related analyses;
- To develop standards to assure the security, confidentiality, accuracy, and appropriate maintenance of such data; and
- To collaborate with other appropriate groups addressing the issue of medical indigence.

2. The National Committee on Vital and Health Statistics through the Subcommittee on Health Statistics for Minority and Other Special Populations, continues to be actively involved in the implementation of the recommendations.

Committee Members:	Risa J. Lavizzo-Mourey, M.D., M.B.A. - Chair Frederick A. Connell, M.D. Sister Irene V. Kraus Carlos A. Moreno, M.D.
Staff:	Jacqueline P. Davis Margaret A. Cooke Frank Emerson Patricia M. Golden Diane M. Makuc, Ph.D. Gregory Pappas, M.D. Harvey Schwartz, Ph.D. Mary Waid
Former Members:	Jane Delgado, Ph.D. James K. Hutchison Joseph Martin

Table I. Relevant data elements provided in alternative data files

Potential elements of indigent care definition	*Current Population Survey (CPS)*	*Survey of Income and Program Participation*	*National Medical Expenditures Survey (NMES)*	*National Health Interview Survey*
Income Thresholds	X	X	X	X
Insured Status	X	X	X	X[a]
Under Insured Status				
—Coverage			X	
—Cost Sharing			X	
—Pre-existing Condition				
Catastrophic Expenses			X	X[a]
Access Limitations		X[b]	X[b]	X[ab]
Annual Updates	X	X		
When Available	Now	Now	1991/1992	

[a] Information provided in some years only
[b] Information varies with survey

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Appendix VIII. Report on Mental Health Status Measures in National Surveys

Subcommittee on Mental Health Statistics

October 18, 1991

Executive Summary

Up-to-date statistical information on the numbers and characteristics of persons who suffer from different types of mental disorders is essential for mental health policy and planning, and for the management of mental health programs. Currently, such information is not available on a periodic basis. Because of this deficit, the Subcommittee on Mental Health Statistics heard testimony and considered relevant issues over the past year. The present document outlines the reflections and recommendations of the Subcommittee on this issue.

Because of very high incidence and prevalence, and the personal and service delivery consequences of depression and depressed mood disorders, it seems clear that a measure of depression is the highest priority for incorporation into a national health survey on an annual basis. The National Health Interview Survey (NHIS) is an appropriate vehicle for gathering this needed information.

One potential set of measures would be the Center for Epidemiological Studies Depression Scale (CES-D), which measures depressive symptoms, and the Brief Depressive Disorders Screen (BDDS), which measures probability of depressive disorders. The two scales overlap, except for two items. The strategy would permit simultaneous screening for depressive symptoms and disorders. The estimated interviewer time for both scales is 2–3 minutes.

The National Center for Health Statistics is planning a research meeting on the future of the NHIS, at which the question of mental health status measures will be addressed. The Subcommittee recommends that the NHIS adopt a measure of depression as an initial effort and consider a more encompassing strategy in the long-term future.

The Subcommittee on Mental Health Statistics recommends that the National Committee on Vital and Health Statistics commend the National Center for Health Statistics for incorporating mental health concerns in the proposed NHIS planning meeting.

Mental Health Status Measures in National Surveys

Background

For more than a year, the Subcommittee on Mental Health Statistics has been receiving testimony and discussing the merits of incorporating mental health status measures into national health surveys. The purpose of this document is to share background information and current recommendations with the National Committee on Vital and Health Statistics. Subcommittee members agree unanimously on the content of this document.

Are Mental Health Status Measures Needed?

A key issue in the mental health field is the lack of up-to-date statistical information on the numbers and characteristics of persons who suffer from different types of mental disorders. Although the National Institute of Mental Health Epidemiological Catchment Area (ECA) Project represents a landmark effort to provide such information, its high cost, complexity, and general unavailability of results in a strategic timeframe suggest that it cannot be used on a recurrent basis. Although the Institute's National Reporting Program for Mental Health Statistics collects extensive organizational data on mental health providers and service use data on clients in treatment, it does not have the capacity to collect data on community populations. Other ongoing mechanisms need to be identified to make such information available to planners, managers, and researchers. Such mechanisms to remedy this deficit are not available to the mental health field or to other medical care analysts who have a need for such information.

Which Disorders Need to Be Pursued First?

The mental health field is complex, and the number of mental disorders is large. Hence, strategic decisions need to be made regarding which disorders will be given priority for measurement in national health surveys.

Among the major mental disorders, results from the ECA show that disorders involving depression or depressed mood are diagnosed in the largest number of adults. The annual prevalence of major depression is estimated to be 7,950,000 persons; that of dysthymia or depressed mood, 8,586,000 persons; and that of manic-depressive disorder, 1,908,000 persons. This represents a total of more than 15 million adult Americans in a year.

Another characteristic of disorders involving depression or depressed mood is that the ratio of incidence to prevalence is quite high. For a year, the ratio of incidence to prevalence is about 83 to 100, for all disorders involving depression, suggesting that, for every current case, almost one new case occurs or reoccurs in a 1-year period.

Depression and depressed mood also have major consequences for the person, other family members, and for the health and mental health service delivery system. Depression is frequently associated with other disorders, such as alcohol abuse and a broad variety of somatic complaints. Also, approximately 4 in 10 persons with depression or depressed mood disorders seek professional care from a mental health service specialist or a general medical physician each year. This number is about 6,000,000 persons per year.

Because of overall prevalence, the high ratio of new cases each year, and the personal and service delivery consequences of depression and depressed mood disorders, it seems clear that a measure of depression is of the highest priority for initial incorporation into a national health survey.

Which National Health Surveys Would Be Appropriate for Incorporating a Measure of Depression on a Routine Basis?

The National Institute of Mental Health does not operate routine surveys that assess mental health status. Rather, the Institute has engaged in one-time developmental projects, such as the ECA. Hence, a survey mechanism is not available to the Institute for routine measurement of depression or depressed mood.

The National Center for Health Statistics National Health Interview Survey (NHIS) could serve as a mechanism for a routine measure of depression and depressed mood. This survey is conducted through a form completed by an interviewer for all residents of a household, based upon the responses of a single member. The NHIS has the advantages of covering a broad range of related health content, an annual cycle, and broad population coverage from a large sample. It has the disadvantages of not being able to cover a topic indepth and of being limited to the knowledge of the household respondent.

On balance, the NHIS has some clear advantages as a potential vehicle for a measure of depression and depressed mood. The annual survey cycle, the very large sample, and the potential to link measures with a broad range of other conditions and functional capacities are primary factors in this consideration.

What Items Can Be Used to Measure Depression and Depressed Mood?

Detailed items to measure depression and depressed mood disorder are available from the ECA within an interviewer-administered instrument, the Diagnostic Interview Schedule (DIS). The advantages of these measures are clinical acceptability, comparability across clinical and epidemiological studies, and treatment relevance. The disadvantages include the high cost of each assessment in dollars and in interviewer and respondent time, failure to detect subthreshold cases, and failure to rank cases by severity.

The affective disorders section of the DIS is part of the National Health and Nutrition Examination Survey (NHANES) III, which is in the field at the present time. Included are measures for manic-depression, major depression, and depressed mood disorder. Combined, these measures require from 15 to 25 minutes of interviewer time. For present purposes, they are clearly too burdensome to respondents, too labor intensive, and too costly to meet the objectives set above.

What is needed are measures of depressive symptoms that not only detect depressive syndromes associated with diagnosable disorders involving depression, but also are sensitive to subthreshold cases. The advantages of such measures include sensitivity to a broad range of depressive phenomena, economy, and the capacity to rank cases by severity. Because of brevity, such measures could be used repetitively on an annual basis. The disadvantages include lack of specificity to depression and unclear treatment relevance. It would be possible periodically to combine these measures with questions from the DIS, as in the RAND medical outcomes study, to examine treatment relevance and related issues more extensively. A number of scales are potentially available for this application.

The Subcommittee agrees that measures of depressive symptoms are preferred over a DIS-type approach for the reasons noted above. To implement this strategy, the Subcommittee has identified one approach that could be considered by the National Center for Health Statistics. This would involve joint use of the Center for Epidemiological Studies Depression Scale (CES-D), which measures depressive symptoms, and the Brief Depressive Disorders Screen (BDDS), which measures probability of depressive disorders. The former instrument contains 20 multiple response items; the latter, 8 items. However, six items overlap the two scales. The total items would be 22. Both instruments can be self-administered. This approach would permit simultaneous screening for depressive symptoms through the CES-D and screening for high probability of a depressive disorder through the BDDS. The estimated time to administer both scales is 2–3 minutes.

Since the CES-D and the BDDS are designed for self-responses by adults, it would be necessary to modify the NHIS convention of using a single respondent for an entire household. This could be accomplished through use of a supplemental survey form or interviewer questions directed toward each adult household member, either in person or by telephone. The Subcommittee feels that this issue could be solved through pretesting of various approaches.

What Strategy Needs to Be Employed to Implement a Measure of Depression?

Short- and long-term strategies need to be developed to incorporate the CES-D and the BDDS, or some other measures of depression, into the NHIS. In the short term, both scales could be included in the NHIS during the next survey cycle. Both have been subjected to psychometric studies, and both have already proven feasible in actual survey applications. In the long term, a broader approach would need to be developed. This broader approach would first screen all survey participants for any general problems of mental well being. This general screen would be followed by a set of measures that would only be used for participants reaching a predetermined threshold on the general screen. The set of measures would include the CES-D and the BDDS, or some other measures of depression, but other measures would be included as well to reflect other major types of psychiatric problems and disorders.

What Steps Are Currently Being Taken to Implement a Measure of Depression?

The National Center for Health Statistics has invited representatives of the Subcommittee, the National Institute of Mental Health, and the mental health statistical and measurement fields to participate in a research meeting on the future of the NHIS. It is anticipated that the meeting will be held during January 1992.

The participants will discuss the measurement of mental health status and the measurement of quality of life. The Subcommittee concurs that both topics will require discussion with key staff from the NHIS. The Chairperson of the Subcommittee has been invited to attend to present the point of view described in this document.

Recommendations for Action by the National Committee

The Subcommittee on Mental Health Statistics recommends unanimously that the National Committee on Vital and Health Statistics commend the National Center for Health Statistics for the steps being initiated to include appropriate mental health status measures in the NHIS.

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