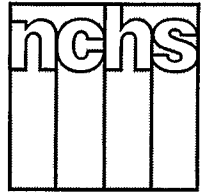


NATIONAL CENTER FOR  
HEALTH STATISTICS



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**The National  
Committee on  
Vital and Health  
Statistics, 1990**

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Public Health Service  
Centers for Disease Control

**CDC**

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**The National  
Committee on  
Vital and Health  
Statistics, 1990**

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DHHS Publication No. (PHS) 91-1205

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

Hyattsville, Maryland  
June 1991

# National Committee on Vital & Health Statistics

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RONALD G. BLANKENBAKER, M.D.  
CHAIRMAN

GAIL F. FISHER, PhD.  
EXECUTIVE SECRETARY

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

Dear Secretary Sullivan:

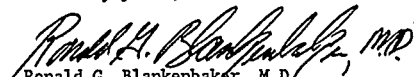
I am pleased to transmit to you the 1990 Annual Report of the National Committee on Vital and Health Statistics, as required by the Committee's Charter.

This year, in addition to describing the activities, accomplishments, and future plans of the Committee and subcommittees, the report includes a Committee commentary on the status of health data and statistics in the United States. It is our hope that this paper will foster dialogue on this important topic with interested groups in both the public and private sectors.

The appendixes of the report include approved Committee reports on the International Classification of Diseases, the Nursing Home Resident Assessment System, and the 1989 Workshop on Improving Cause-of-Death Statistics.

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

Sincerely yours,

  
Ronald G. Blankenbaker, M.D.  
Chairman

## Foreword

When an organization works in an advisory capacity, such as the National Committee on Vital and Health Statistics (NCVHS) does to the Department of Health and Human Services (DHHS), the question often arises, Do our efforts make a difference?

I first addressed this issue, along with Dr. William Felts and former Chairman Dr. Robert Barnes, at a special session of the 1985 Public Health Conference on Records and Statistics. At that time, we described NCVHS as having evolved from a purely technical orientation with many expert consultants to a Committee concerned with "statistical issues closely linked to both national and international policy." The Committee's role was explained as an interface between the public and private sectors that was necessary "to insure full input from the relevant policymakers and data users" and "to help assure a health statistics system that is geared to producing a healthier America."

I think our characterization of the Committee as it was evolving in 1985 is still apt; I also believe that, in the intervening years, the Committee has strengthened its infrastructure and expanded its horizons in ways that have enhanced its ability to fulfill its chosen role and to make a difference.

At the end of 1985, NCVHS had three active subcommittees and three newly proposed subcommittees. The membership was composed of 15 individuals who each served 3-year terms; during 1985, approximately nine separate subcommittee or work group meetings had been held, in addition to three meetings of the full Committee. Much of the Committee's activity was at the request of the departmental Health Information Policy Council or various DHHS agencies.

The Committee's 1985 report, which actually covered 1983-85, describes how the Committee contributed during that period to departmental review and development of the International Classification of Diseases (ICD), several uniform minimum data sets, the Vital Statistics Cooperative Program of the Federal and State Governments, and the statistical aspects of physician payment systems. Work was beginning on disease prevention and health promotion statistics and minority health statistics.

As we surveyed the Committee's agenda and accomplishments in the mid-1980's, we suggested that NCVHS was making a difference and that its influence was growing. The Department was seeking and responding to the Committee's advice on many occasions, and the private sector was finding NCVHS to be an important interface with the statistical activities of the Department.

Five years later, in 1990, NCVHS had six active subcommittees, including an Executive Subcommittee; a newly formed work group; and several individual members serving as monitors. Composed of 16 members with 4-year terms, the Committee has a dynamic 2-year work plan that is updated every 3 months and covers approximately 20 health statistics topics. Although still responsive to departmental requests, NCVHS has expanded into a number of areas on its own initiative, such as mental health statistics, indigent health care statistics, and community health statistics. The Committee has developed a systematic approach for assessing each new issue and for finding the most appropriate means for addressing it. Efforts have been oriented toward 1-year and 2-year goals, with the view toward completion and a formal report within 2 years, at most.

During 1990, in addition to the 3 full Committee meetings, subcommittees held 14 separate meetings and several telephone conference calls. A number of the meetings included testimony from a wide range of interested parties responding to the Committee and the subcommittees' requests for information, and seeking to focus NCVHS attention on specific health data needs. The Subcommittee on Ambulatory and Hospital Care Statistics, for example, received letters this year from over 30 Federal, State, and professional organizations in response to its inquiry concerning external cause-of-injury coding. Individuals and groups requesting information on the activities of the full Committee and subcommittees number in the hundreds, and the mailing lists continue to grow.

Have all of these efforts made a difference? I think so. This annual report and reports from previous years describe in some detail the accomplishments of the Committee. Without trying to be all-inclusive, I would like to cite some examples that are particularly noteworthy to me.

In the past few years, NCVHS has worked cooperatively with the Department and the World Health Organization (WHO) to resolve the issues surrounding WHO's copyright of the 10th revision of the *International Classification of Diseases*; collaborated with the National Center for Health Statistics (NCHS) to bring representatives of the public and private sectors together to develop strategies for improving cause-of-death statistics; initiated and completed a full review and revision of the Uniform Ambulatory Care Data Set, working hand-in-hand with an Interagency Task Force; worked closely with the Department on tracking progress toward achieving the 1990 Objectives and on development of *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*; held public hearings on the unmet statistical data needs for research and policy formulation on minority populations and the medically indigent; stimulated development of an advisory mechanism for NCHS development of the National Health Care Survey; provided advice on several important long-term care statistical activities; established the first NCVHS Subcommittee on Mental Health Statistics, which has strong staff and policy support from the National Institute of Mental Health; and contributed to the national debate on the use of a unique personal identifier in health data collections.

This year, for the first time, the Committee has developed an overall assessment of the status of our system for collecting health data in this country. I consider this to be an important contribution that the Committee hopes will stimulate some dialogue

with the public and private sectors. In addition, it certainly will help to direct our activities in the future. A special note of thanks to Bruce Steinwald for a yeoman's effort in this endeavor.

All of the above indicates to me that the Committee not only does make a difference but will continue to do so far into the future. This is a credit to the current and past members of the Committee, as well as a challenge to those who follow. It also reflects the willingness of policymakers, program officials, and researchers within and outside the Department to engage in dialogue and to listen. We have enjoyed excellent communication with and support from the Assistant Secretary for Health, as well as the Director of NCHS and the Administrator of the Health Care Financing Administration (HCFA). We, further, would like to give special thanks to the NCHS and HCFA staff who have supported our activities, often under severe resource limitations. Finally, it would have been nearly impossible to accomplish our tasks without the involvement of the many health-related organizations, agencies, and individuals who provided meaningful testimony and input; these interactions have been invaluable.

As always, it is our hope that this report will encourage others to act in ways that will support the collection, dissemination, and analysis of meaningful, high-quality health statistics. It is our firm conviction that this is the best way to assure that effective health programs and policies will be developed in the future.

Ronald G. Blankenbaker, M.D.  
Chairman, National Committee  
on Vital and Health Statistics

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# Executive Summary

During 1990, 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, six subcommittees, and several work groups and monitors:

- Developed a commentary on the status of health data and statistics in the United States, which is included in this annual report.
- Completed a report on the history, implementation, and ongoing maintenance of the *International Classification of Diseases (ICD)* that was the culmination of 4 years of work on the complex issues relating to the coding and classification systems. The report, which was transmitted to the Assistant Secretary for Health and can be found in appendix VI, identifies several major areas where gaps need to be filled and makes recommendations to improve current systems. The report further suggests that an ongoing study and evaluation of the feasibility of a uniform procedure code is necessary.
- Submitted an interim report to the Assistant Secretary for Health on the nursing home resident assessment system that was mandated by the Omnibus Budget Reconciliation Act of 1987. The report, contained in appendix VII, commends the Health Care Financing Administration (HCFA) and its subcontractors for their responsiveness to concerns raised by the Subcommittee and other interested parties and identifies additional issues for continued discussion.
- Endorsed and submitted to the Assistant Secretary for Health the Report of the Workshop on Improving Cause-of-Death Statistics. The report includes recommendations for a widespread educational effort involving physicians, the public, and policymakers, and for development of a model quality assessment program. The workshop was held in October 1989 and was cosponsored by NCVHS and the National Center for Health Statistics (NCHS). The workshop report is included in appendix V.
- Cosponsored with NCHS, the Health Care Financing Administration (HCFA), and the Association for Vital Records and Health Statistics (AVRHS) an exhibit on Improving Quality of Mortality and Morbidity Data at the 1990 meeting of the American Public Health Association.
- Recommended to the Department that a thorough and systematic review of the Uniform Hospital Discharge Data Set (UHDDS) should be undertaken, working in close cooperation with the National Uniform Billing Committee, which maintains the Medicare Uniform Bill (UB-82). Further recommended that a process be established in the Department to review the UHDDS in tandem with



NCVHS, along the lines of the previous Uniform Ambulatory Care Data Set review. In response, the Department developed an Interagency Task Force on the UHDDS, chaired by HCFA.

- Initiated the NCVHS formal review of the UHDDS with a meeting focusing on the collection and use of external cause-of-injury (E-coded) data.
- Recommended that the Department designate responsibility for an ongoing research program to ascertain the reliability and validity of major data sets established for administrative purposes and increasingly used in the formulation of public policy.
- Established a new Subcommittee on Mental Health Statistics to identify important mental health statistical issues for the full Committee and to facilitate the integration and coordination of general health and mental health statistical systems.
- Wrote to the Assistant Secretary for Health requesting that a departmental agency be designated to examine alternatives and to develop a proposal for standardizing age-adjusted tabulations in the Department.
- Held a second hearing on data needs for the medically indigent, with a focus on developing a workable definition of medical indigency, identifying gaps in data availability to address the problem, and recommending changes or additions to existing data systems.
- Continued to focus on the uniformity and adequacy of data on race and ethnicity in national health surveys to produce data on minority populations.
- Continued its role in following the statistical aspects of physician payment systems and other data systems and research concerned with encounters between patients and providers and the outcome of care.
- Monitored the responses within the Department to the final report on the Uniform Ambulatory Care Data Set and participated in a process to review agency comments and to reach agreement on the contents of the data set and on a recommended approach to foster implementation.
- Received regular updates on the development of the Objectives for the Year 2000 and participated in the national meeting on the release of *Healthy People 2000*.
- Assumed a role in examining community health status statistics and formed a work group to explore issues and concerns about the availability of statistics to monitor the health of communities.
- Held a special session on child health data needs. The session focused on new legislative requirements for maternal and child health data collection at the local level and for linkage of Medicaid data with the linked birth and infant death file, and on the adequacy of national data systems to monitor child and family health status and to produce information needed for policy development.
- Reviewed and provided comments on the 1990 publication of *Health, United States*, including the Chartbook on Minority Health.

In 1991, the Committee will continue and expand efforts related to many of the above activities.

# The Status of Health Data and Statistics in the United States: A Commentary

The National Committee on Vital and Health Statistics (NCVHS) is comprised of individuals of diverse backgrounds who share a common interest in health statistics and a common need for health data in the performance of their daily work. Every so often, the Committee steps back from its specific advisory responsibilities to examine the landscape of health data and statistics in the United States. We see both advances and shortcomings. At the Federal level, examples of advances include improvements in the thoroughness and timeliness of Medicare program data for policy analysis and the addition of longitudinal components to several population-based health surveys. We are also encouraged by the plans of the new Agency for Health Care Policy and Research to compile data on the effectiveness of health services. We are discouraged, however, by inadequate funding for many population and health care provider surveys, and by delays in much needed improvements to our national health statistics systems.

Health spending projections for the Year 2000 exceed \$1.5 trillion, more than twice the current level. It is imperative that we receive value for our dollars. Data and statistics provide the information necessary for decisionmakers at all levels to determine the effectiveness of medical care, and to decide which health services should be provided and to whom. Such data must be sufficiently detailed to identify the needs of minority and special populations, so that we can assure more equity in the provision of health care and close the gaps in health status between different groups in our population.

Reasonable people may disagree as to whether advances in health data development over the past decade have outweighed declines. More important is that data development clearly has not kept pace with the growth in our health system's size and complexity. Health care in the United States is an enormous enterprise whose expenditure and technological expansions are equally astonishing. Health data and statistics are the tools we use to evaluate the effects of this enterprise on the health status of the Nation. Our tools are becoming increasingly inadequate to perform the necessary evaluations.

Concerns of this nature prompted the Committee to prepare this paper.<sup>1</sup> In keeping with our advisory mission, we have identified three areas where attention is needed. These areas by no means represent the full extent of the Committee's concerns for the status of health data and statistics. If they were positively addressed, however,

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<sup>1</sup>This paper was developed by a work group consisting of the following NCVHS members: Nancy Cannon, Ph.D.; Judith Miller Jones; Risa Lavizzo-Mourey, M.D.; David Mechanic, Ph.D.; and Bruce Steinwald, work group chairman and principal author. Other NCVHS members also contributed. The full Committee approved the paper and recommended that it be disseminated widely.

and appropriate actions taken, this would be a valuable contribution to creating the tools needed to evaluate our health system's performance.

The three areas, discussed below, are: the need to develop baseline health data for future decisions, the growing reliance on administrative data sets for setting health policy, and the use of the social security number for linking health and related data.

## **Baseline Data for Future Decisions**

At the end of each of the past two decades, the Department of Health and Human Services has developed objectives for the Nation's health for the following decade. In September 1990, *Healthy People 2000: National Health Promotion and Disease Prevention Objectives* was released. One of the criteria for selecting objectives has been the existence of adequate baseline data to determine in the future whether an objective is met. In other words, our Nation's health objectives, presumably devised in part to shape health policy over the next decade, are dependent on the availability of baseline data. Some important health priorities receive little attention because baseline data are lacking.

*Healthy People 2000*, for example, includes a commendable objective of improving the quality of life of the United States population in conjunction with extending life expectancy. It is disappointing, however, that only one study in one metropolitan area could be identified as a source of baseline information for evaluating quality of life changes over time. Methodologies for measuring the health status and quality of life of the population have improved over the past several years. Numerous instruments have been developed that accurately depict the physical, mental, and social functioning and well being of both healthy and impaired populations. Most of this development has taken place in conjunction with focused studies of individual technologies and services. Consequently, comprehensive national data for application of these new measurement technologies do not yet exist.

An example of the high cost of inadequate baseline data is the Medicare catastrophic coverage program, enacted by Congress in 1988 and repealed in 1989. An enormous amount of time and energy was consumed in this legislative process, which was emotionally, as well as financially, costly. An important part of the Act was a new outpatient prescription drug benefit for Medicare beneficiaries. Unfortunately, available data were inadequate for evaluating alternative benefit structures before the program was enacted. Consequently, there was considerable disagreement about the costs of the benefit, and policymakers were uncertain about the spending consequences of the Act. Medicare program data were not useful because the Act sought to expand benefits, not alter those already in place. Program data cannot be used to evaluate either new benefits or expansion of existing benefits to noncovered populations. Yet, our health policy debates invariably include discussion of potential expansions of different types. If we do not have data to evaluate such potential changes, we will not be able to make informed policy decisions.

Currently, data are inadequate to track patients across health care settings, to assess the health consequences of increasing violence and other societal trends, to evaluate

the outcomes of health care, and to address the health care needs of the poor and those without adequate insurance. Some of these gaps in health data may be traced to inadequate Federal funding arising from the budget deficit crisis. The creation of national health data bases is a public good activity that could not be accomplished efficiently in the private sector. However, these data sets have enormous value to private organizations who could pay far more for them than is currently charged. In addition, substantial data are collected by private organizations, such as insurance companies, and by State and local jurisdictions, including health departments, but never assembled into national data bases from which health statistics may be generated. Improving health data and statistics should not be viewed simply as a worthy activity that may be sacrificed in order to balance the budget. In addition to Federal funding, we need creative thinking about ways to involve the private sector and local and State public agencies in this activity, as important contributors of both data and financing.

In sum, our need for baseline data to measure the outcomes of an increasingly sophisticated and expensive health system is growing. Our methodologies for measuring the impact of health services on health status have been improved, but the data for applying these measures to assess progress in meeting health objectives have not kept pace. Greater public investment in data development at all levels is important; and the private sector could readily contribute more if the appropriate mechanisms were developed. We cannot rely on traditional data collection efforts in the face of a rapidly changing health care system. In the long run, our inability to assess our health system's performance inevitably will undermine efforts to improve our Nation's health.

## **Administrative Data Sets**

A major portion of the U.S. budget is consumed by expenditures authorized by the entitlement programs established under the Social Security Act. The three principal benefits are: income support for retired and disabled persons, health care for the aged and disabled, and health care for the poor. These programs require administrative data to function. For the health care programs, extensive data are created as a byproduct of the transactions between providers of health services and the fiscal intermediaries and insurance carriers that administer these programs under contract to the Health Care Financing Administration.

The United States develops health data, which is not possessed by most other countries, as a byproduct of billing for health services. Most other countries' health care systems, for example, do not require bills to be submitted by hospitals. Bill data are extremely useful for measuring the frequency and relative costliness of performing different procedures and caring for different illnesses. By far, the most extensive data files pertain to services provided to elderly and disabled Medicare beneficiaries.

Medicare billing data represent a rich source of information on health care use and expenditure. This is a mixed blessing, however, because the data are collected primarily for administrative purposes, not for policy analysis. Moreover, the

thoroughness and accuracy of the data are partially dependent on the quality of medical records. We need a mechanism for assuring that these data are both valid and reliable for public policy analysis.

Among other things, hospital billing forms are used to compile data about patient diagnoses. Diagnosis information is used to construct hospital case-mix indexes, which measure the relative resource requirements for treating different hospital patient caseloads. It is virtually impossible to determine to what extent increases in these indexes over time indicate increased patient need or changes in the data. Nevertheless, case-mix measures are a critical determinant of hospital revenues under Medicare and many other hospital payment systems.

Some would say that the uses of these data should be confined to administrative purposes—paying bills and monitoring performance of health care providers. This is a painfully short sighted view. First, the Government's internal need for data goes far beyond administrative purposes. Data of poor quality will inevitably undermine the Government's efforts to analyze public policy alternatives regarding its health care programs.

In addition, these data are unique in several respects. They provide an annual record of hundreds of millions of health care encounters—hospital stays, surgeries, doctor visits, and other forms of utilization of health services. To use these data only for administrative purposes would be wasteful in the extreme. Yet making the data useful for policy analysis requires advance planning of data base design and quality control that exceeds the effort required for soley administrative purposes. Thus, when forms are evaluated as instruments for billing and payment, they must also be evaluated for the analytical uses of the data bases that will be constructed. When control mechanisms are established to monitor data quality and correct errors, analysis must be on an equal footing with payment. To do any less is to deny that these data will be, and should be, used for policy analysis, and undermines both the quality and capabilities of such analysis.

Although we seek to improve Medicare program data for policy, we cannot ignore its limitations. Program data pertain only to services that are covered and populations who are eligible for benefits. Medicare program data pertain to approximately 33 million elderly and disabled persons; however, the majority of the population is not represented. Moreover, data on noncovered services, such as prescription drugs, long-term care services, and many preventive services, are also not represented.

Comprehensive analyses pertaining to the entire population cannot be conducted with administrative data. We must also have access to data bases that pertain to broad populations and services. For example, the National Hospital Discharge Survey (NHDS), one of several health care surveys conducted periodically by the National Center for Health Statistics, can be used to examine hospital care for diverse populations. Compared with Medicare program data, however, the NHDS is very limited. The NHDS does not collect data on hospital charges, for example, because they are costly to obtain, even though such data are important for comparing resources devoted to the care of different types of patients or similar patients who receive different types of treatment.

Recognizing the need for data to guide health policy development, approximately half of the States now compile comprehensive data on all hospital stays. The States are building a capability to analyze data on hospital care and other services that exceeds the Federal Government's. The usefulness of these data for interstate comparisons and for national policy analysis will depend, in part, on national coordination to ensure data base uniformity.

We need, simultaneously, to make maximum use of administrative data for policy analysis and to recognize that such data will not serve all purposes. A coordinated effort is therefore necessary to ensure that comprehensive data from different sources will be available for national policy development.

## **Linking Data Sets with the Social Security Number**

A hopeful sign in the current health policy scene in the United States and elsewhere is the growing emphasis on developing data to associate health services with health outcomes. Congress, for example, created the Agency for Health Care Policy and Research in 1989, to strengthen our knowledge base on the relationship between services and outcomes and to use this information in the development of guidelines for health services. This type of research imposes severe data requirements, especially for conducting longitudinal studies.

Most health care data bases are confined to single types of events, such as the inpatient hospital data sets described above. Even population surveys that elicit information on different types of services seldom obtain information that permits linking these services to outcomes. Such linkages require data over time, perhaps even several decades, for analysis of chronic or recurring illness. Moreover, extensive information is needed on the characteristics of individuals to identify the factors that influence the receipt of services and the probability of different outcomes.

In the United States, only one unique personal identifier currently exists that could be used to link health and demographic data sets — the social security number. If the social security number were routinely appended to all personal data records in health care and related data bases, this would be an important tool for public policy. Discussions of the use of the social security number, however, frequently encounter issues related to confidentiality and the right to privacy. Opponents of the use of the social security number for linking data believe that these concerns outweigh the value of linked data for analysis.

What are the risks of using the social security number to link data sets? They are related to the ability to associate sensitive information, as health care data often are, with identifiable individuals. Sensitive data must be safeguarded to ensure that they

are not improperly used or divulged, and existing protections need to be assessed to ensure their effectiveness. No system of safeguards is foolproof, but our need for the ability to link health data is compelling. The social security number is essential for this purpose.

The social security number is routinely used by financial organizations in the private sector to link data for credit ratings and other purposes, and many health insurers use it to monitor billing and payment. To permit private enterprise access to this tool while denying it to organizations working in the public interest for the linking of health data is illogical and detrimental to all citizens.

## **Conclusion**

Recent advances in health data and statistics are not sufficient to meet the challenges that lie ahead. We believe that the current policy emphasis on health outcomes is appropriate, but even this creates new requirements for health data. Such an emphasis also increases our need to link patient and population data bases using the social security number. We must improve our ability to use administrative data for policy, but also recognize that limitations on administrative data make it important to enhance survey data for new policy development. These enhancements will require reordering spending priorities and devising innovative ways to involve the private sector in health data base development.

Subsequent sections of this report contain several specific recommendations for improving health data and statistics. However, the Committee also seeks a heightened awareness of health data issues and a consensus that these issues deserve the highest priority. Each of the problems we have outlined above is also an opportunity for cooperative effort to improve our Nation's health. We urge others both inside and outside government to participate in the identification of health data needs, the collection of appropriate data, and the use of health statistics for more effective decisionmaking at all levels. This effort will require both resources and a cooperative commitment within and between the public and private sectors. Our Nation's health can afford no less.

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

The National Committee on Vital and Health Statistics (NCVHS) took a broad look at the status of health data and statistics in the United States during 1990, as reflected in the commentary that introduces this annual report. At the same time, the Committee continued to work with agencies within the Department of Health and Human Services (DHHS) and with other groups in the public and private sectors to enhance the availability and comparability of high-quality health statistics.

During the year, the Committee carried out substantive activities in the following selected areas through its active subcommittee structure:

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

The activities, accomplishments, and future plans of the subcommittees 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 meeting dates of the full Committee can be found in appendixes I, II, and III, respectively.

The NCVHS benefited throughout the year from a number of opportunities to review its current and anticipated agenda with policymakers within the Department and to discuss how the Committee's work could be most responsive to their goals and concerns. The Assistant Secretary for Health met with the Committee for an informal exchange of views on emerging health data issues during the February NCVHS meeting and encouraged the Committee to continue its active advisory role.

The Director of the National Center for Health Statistics (NCHS) regularly attends the full Committee meetings to present an update on major NCHS programs and to provide feedback on issues and concerns. This year, as in the past, the Committee provided comments to NCHS on the development of *Health, United States*, the Secretary's annual report on the health of the Nation. In addition, an NCVHS member is monitoring the National Academy of Sciences contract to provide advice to NCHS on development of the Center's National Health Care Survey.



The full Committee receives regular reports from the Health Care Financing Administration (HCFA), which has a principal liaison working with the Committee and Executive Subcommittee. Further, the NCVHS Chairman met with the HCFA Administrator and members of her staff, following the June NCVHS meeting, to discuss Committee activities and their relevance to HCFA programs. Finally, at the request of the Executive Subcommittee, the Acting Administrator of the Agency for Health Care Policy and Research (AHCPR) has named a regular liaison to the Committee. This will facilitate the Committee's efforts to stay abreast of the wide range of AHCPR data responsibilities related to practice guidelines and outcome analysis.

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

During late 1989, the Committee had cosponsored, with NCHS, a Workshop on Improving Cause-of-Death Statistics. The full Committee received and endorsed the workshop report at its February 1990 meeting and transmitted the report, which can be found in appendix V, to the Assistant Secretary for Health. The Association for Vital Records and Health Statistics (AVRHS) subsequently informed the Committee that it had passed a resolution supporting the workshop recommendations and offering its assistance to NCVHS and NCHS in meeting the goals set out in the report. The workshop was one of four areas highlighted in an exhibit on "Improving Quality of Mortality and Morbidity Data" that was cosponsored by NCVHS, NCHS, AVRHS, and HCFA at the 1990 meeting of the American Public Health Association. Additional exhibits and a followup workshop are being planned.

The only area in which there was clear lack of agreement at the workshop was whether causes of death reported on death certificates should be open to or restricted from public inspection and whether the quality of cause-of-death statistics is improved by restricting public access. Because of the complexity of the issues involved, the participants had agreed that additional deliberations were necessary, and suggested that the Working Group to revise the Model State Vital Statistics Act and Regulations might be an appropriate vehicle for the broader discussions. The Chairperson of the Working Group was invited to the June NCVHS meeting to brief the Committee on the Group's plans to address the various issues related to access to vital records. Following this presentation, NCVHS accepted the invitation of the Working Group to report briefly on the Workshop recommendations and to participate in the exchange of ideas with the other invitees at the Working Group's meeting in late September. Dialogue among the two groups will continue.

The Committee has retained a strong interest in the development of the Year 2000 Objectives for the Nation and reviews progress in this important area at every full Committee meeting. The NCVHS Chairman and another member participated in the release of *Healthy People 2000: National Health Promotion and Disease Prevention Objectives* in September. At the February NCVHS meeting, the same member had

agreed to monitor issues related to the adequacy and accessibility of health status data, particularly at the State and local levels. The Administrator of an urban hospital and a rural State Health Officer addressed this topic from their perspectives at the November NCVHS meeting. Following these presentations, the Committee agreed to establish a new work group to explore issues and concerns about the availability of data to monitor the health of communities. The Work Group will be meeting early in 1991 to consider possible NCVHS roles in this area.

In 1989, an NCVHS member began monitoring reproductive, child, and family health data issues for the Committee. Subsequently, he organized a special session on child health data needs for the November 1990 NCVHS meeting. Departmental officials reported on the new legislative requirements under the Omnibus Budget Reconciliation Act of 1989 for collection of maternal and child health data at the local level and for linkage of Medicaid data with the linked birth and infant death file. Representatives from the Children's Defense Fund and Child Trends discussed the adequacy of national data systems to monitor child and family health status and to inform policy development. The Work Group noted in the preceding paragraph plans to address some of the issues raised in these presentations.

The Committee has a continuing concern about the quality and comparability of health data collected and analyzed in the public and private sectors, and offered several recommendations to the Department in this regard. At the February NCVHS meeting, a resolution was passed proposing that the Secretary designate responsibility for an ongoing research program to ascertain the reliability and validity of major data sets established for administrative purposes and increasingly used in the formulation of public policy. An example cited was the data based on the Medicare Uniform Hospital Bill. The Committee later clarified that its concern was not with the quality of the data to support reimbursement for medical and health services rendered to Medicare beneficiaries, but with the growing reliance on these data sets for purposes well beyond reimbursement. These concerns are articulated further in the Committee's commentary prepared for this annual report.

Another recommendation transmitted to the Assistant Secretary for Health following the June NCVHS meeting expressed the Committee's concern about the need to standardize the process of adjusting death rates prepared for publication by agencies within the Department. The Committee noted that recent DHHS publications had used four different standard populations to present age-adjusted mortality rates; it therefore recommended that some agency be designated to examine the alternatives and develop a proposal for a standard population to be used in all DHHS publications, as well as for monitoring progress on the Year 2000 Objectives. The Assistant Secretary responded that whenever age adjustment is appropriate for the latter activity, the Department has agreed to adjust the target rates to the U.S. population in 1940. This standard has been used by the Public Health Service for mortality statistics since 1945. The Assistant Secretary further noted that he had asked the Centers for Disease Control, through NCHS, to take the lead in developing a forum for further discussion and examination of these issues

and for making recommendations related to age-adjustment procedures in other applications. The NCVHS has offered to work with NCHS in this process.

During several of its meetings, the NCVHS Executive Subcommittee noted the lack of a clearly identified process within the Department for systematically finalizing, disseminating, evaluating, implementing, and developing educational materials for the uniform data sets periodically developed and revised by NCVHS and inter-agency committees. After learning about the plans of the Office of the Assistant Secretary for Health to come to closure both on the content of the recommended Uniform Ambulatory Care Data Set (UACDS) and on a process for advancing its use, the Subcommittee expressed the hope that a process would emerge from the UACDS experience that would be applicable to the other uniform data sets.

The activities of the full Committee, individual members, and the Executive Subcommittee have supported and complemented the work of the other NCVHS subcommittees, and have enabled the Committee to address an increasing number of health data issues.

# Medical Classification Systems

During 1990, 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 plans for *ICD-10*, including the copyright for *ICD-10*; issues for implementation and maintenance of the current classification; and the feasibility of a single procedure coding system. The Subcommittee completed its report on issues relating to the coding and classification systems. The report was approved by the National Committee on Vital and Health Statistics at its November 1990 meeting.

## Recommendations

The Subcommittee's report on issues relating to the coding and classification systems can be found in appendix VI. The following recommendations were made:

- The Coordination and Maintenance Committee composition should be expanded to include representation from the private sector.
- Development and approval of coding guidelines should be conducted in a public forum such as the Coordination and Maintenance Committee and be representative of a widely participative process.
- Guidelines should be transferable to all sites of services.
- The integrity of the classification should be maintained through administrative procedures consisting of the identification of source(s) authorized to meet defined responsibilities that include, but are not limited to:
  - control of code assignments beyond the fourth and fifth digits;
  - development and interpretation of national coding guidelines, including those in the ambulatory setting;
  - dissemination of these guidelines for all uses of the classification, including automated uses, to ensure safe harbor for those who voluntarily comply with approved guidelines;
  - the conduct of evaluation programs to monitor accuracy of coding (data quality issues);
  - receiving and disseminating coding information; coding problems; requests for changes, modifications, interpretations, and revisions of guidelines; and adjudicating disagreements.

- Identification of a process to determine the definition of government or nongovernment uses of *ICD-10* must be articulated as well as the procedure to apply for consideration of these uses.
- Continuous education programs for all user groups, including physicians, should be made a priority.
- An evaluation program to assess the accuracy of medical coding and the interface of data set definitions and *ICD-10* in nonacute settings should be established.
- There needs to be an ongoing study and evaluation to determine the efficacy of a single procedure coding system.

## **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. The NCVHS has been concerned with classification insofar as current health care data form the basis for future health data policy. The utility of the classification for describing health care in the United States is central to that function.

## **Current Year's Activities**

The Subcommittee held three meetings during 1990—March 12–13, August 27–28, and November 8. These meetings combined public testimony and discussion with working sessions in an effort to provide necessary interface between the public and private sectors. The Subcommittee's report, to be published as a Working Paper Series, summarizes the activities of the last 5 years and recommends necessary future directions for the issues that follow.

## **Progress Report on *ICD-10***

The final drafts of *ICD-10* were approved by the World Health Assembly in May 1990. Although some of the production deadlines have not been met, the World Health Organization target implementation date for mortality data remains January 1993.

There are no current plans for a U.S. modification of *ICD-10*. It is yet to be established whether the needs for additional corrections or changes will be met through an updating process patterned after the U.S. Coordination and Maintenance Committee activities. As an international document, however, updates will need to take advantage of input from the public and private sectors, both domestically and abroad.

Although actual implementation of the mortality classification is being planned for 1995, current plans call for the capability to code mortality data retroactively to

1993. Implementation of the morbidity classification is tentatively planned for October 1995 (fiscal year 1996). The disparity in implementation dates has drawn the attention of the Association for Vital Records and Health Statistics (AVRHS), prompting a resolution recommending that the National Center for Health Statistics (NCHS) coordinate the timing of *ICD-10* implementation to be within 6 months of the date of the Health Care Financing Administration's implementation of *ICD-10* for morbidity. The concerns of AVRHS focus on the issues of availability of resources and data quality.

### **Copyright of *ICD-10***

The copyright agreement between the Department of Health and Human Services and the World Health Organization (WHO) appears to be far less restrictive than earlier versions. It provides for copyright exemption of any *ICD-10* products deemed as "government use." However, some operational issues remain. These include the identification of the governmental agency empowered to produce or authorize a modification, as well as timeliness issues, because modifications at the three- and four-character level will require considerable consultation with WHO. In the United States, "government use" is not a single definition, given the shared jurisdiction over Medicare reimbursement and mortality and morbidity statistical data.

### **Implementation and Maintenance of the *ICD* Classification**

In late 1989, the Subcommittee again sought assistance from the community of interest to delineate a list of functions that would be required for successful implementation of the *ICD* classification. The responses formed important background information for the Subcommittee's report. The topics covered were: the need for a single source for approval of codes; the need for good communication with the vendor community; and a mechanism for review and approval of private sector products related to the classification.

Testimony from the private sector spoke to the need for a coordinated national implementation effort centered on mechanisms currently in place. Key implementation strategies will be needed for information systems development, training and education, and policy and transition activities.

The formation of the Morbidity Classification Branch within NCHS facilitates necessary interaction with HCFA and other NCHS divisions involved with the classification. It provides an improved, more formalized structure for interface with clinical specialists.

NCHS has awarded a contract to a private consultant to develop the scope of work that will be required to implement *ICD-10* in the United States. The opportunity for a comprehensive implementation plan, with suggested interactions between public and private sectors for input and cooperative efforts, is greater with the existence of the Morbidity Classification Branch.

The movement away from the purely hospital-based coding effort reflects the shift in patient care to the ambulatory setting. There must be concomitant recognition that the ambulatory encounter is shorter and more focused, using different descriptors and yielding different data. The classification must meet these ambulatory needs as well as those of hospitalized inpatients. A multidisciplinary approval process and proficiency in coding and data handling are even more critical.

### **Uniform Procedure Code**

The Subcommittee also addressed the issue of whether two procedure coding systems, *ICD-9-CM Volume 3* and *Physicians Current Procedural Terminology, 4th Edition (CPT-4)*, should be replaced by a single system, as recommended by the predecessor Subcommittee. Earlier review efforts uncovered structural problems in both *ICD-9-CM* and *CPT-4*. Concern for data quality issues and the cost of submitting data in more than one classification is significant. To further complicate the process, the two systems use different dates to implement changes (*CPT-4* updates are available in January, whereas *ICD-9-CM* updates are available in October).

The feasibility of creating a single procedure coding system that will satisfy all users is as yet unknown. The American Medical Association (AMA) sponsored a study to investigate the cost and benefit of a single system for physician payment. The study, conducted by Coopers and Lybrand, compared two alternatives: 1) a major restructuring of the current *CPT-4* to serve uses beyond physician offices; and 2) a replacement system for both *CPT-4* and *ICD-9-CM Volume 3*. The results of the study showed that the costs of a replacement system were significant and that the identification of benefits was difficult; thus, the consultants concluded that a replacement system for measuring physician services was not justified. The utility of a single code for uses beyond physician reimbursement has not yet been addressed; monitoring this issue will remain a part of the Subcommittee's ongoing work plan.

### **Continuing Work Plan**

The continuing work plan for 1991 has the following focus:

- Continue to provide an open forum for information on the progress of *ICD-10* and its implementation.
- Monitor the activities of NCHS and its Morbidity Classification Branch.
- Review and determine the structure and process needed to create a U.S. clinical modification of *ICD-10*, if necessary.
- Monitor the activities addressing the benefits and cost of a single procedure code in the United States.
- Monitor the effect of annual changes in diagnosis codes on data quality and research initiatives.
- Continue to monitor efforts of the Coordination and Maintenance Committee.

- Address other systems on medical classification as needed.

The Subcommittee appreciates its unique role as the time frame for *ICD-10* implementation strategies is increasingly constrained. The provision of a public forum for dialogue, resulting from the competitive diversity of data needs, will be a significant contribution of the Subcommittee.



# Long-Term Care Statistics

During 1990, the Subcommittee on Long-Term Care Statistics monitored the development of the resident assessment instrument for nursing homes, commonly referred to as the minimum data set (MDS). Development of the MDS, mandated by the Omnibus Budget Reconciliation Act of 1987, was delegated to the Health Care Financing Administration (HCFA). Review of the MDS entailed a study of the Resident Assessment System, which consisted of the utilization guidelines, the MDS instrument and common definitions, and the resident assessment protocols (RAP's) that are triggered by the MDS. The Subcommittee has been supportive of the development process and of the resultant resident assessment instrument as a clinical instrument for a unique assessment leading to enhanced individual care planning. The Subcommittee presented an interim report on its findings to the National Committee on Vital and Health Statistics (NCVHS), which approved the report at its November 1990 meeting.

## Findings

The Subcommittee's interim report on the nursing home resident assessment system can be found in appendix VII. The following points were emphasized:

- If used as intended, the resident assessment instrument (RAI) not only has the capability of improving the quality of care for nursing home residents, but also has the potential to produce a national data base of these residents.
- HCFA and its subcontractors have been responsive to concerns expressed by the Subcommittee, representatives from the nursing home industry, and advocates of nursing home residents about the impact on the facilities and staffs of these facilities of administering the MDS.
- Implementation of the MDS will be phased in so that, initially, the RAI will be used only for new admissions; quarterly updates or reassessments will be conducted when significant changes have occurred.
- The length of time to conduct the initial assessment for residents has been reduced so that it currently adds only 30 minutes to the usual routine assessments that the RAI will replace.
- More attention has been paid to the need for training staff to use the MDS.
- The potential uses of the clinical minimum data set have raised concerns about the reliability and quality of the data over time and the mechanism, if any, that

will be used to determine what data system will be made available to people who want to access the data.

## **Background**

Since 1989, the Subcommittee on Long-Term Care Statistics has been monitoring the development of the HCFA resident assessment instrument for nursing homes. In this regard, the Subcommittee has provided opportunities for public testimony on the MDS from both the provider and consumer communities. The current Subcommittee was formed in 1987 as a successor to the Subcommittee on Uniform Minimum Health Data Sets.

## **Current Year's Activities**

The Subcommittee held two meetings and a conference call during 1990 with a primary focus on review of the Resident Assessment System for Nursing Homes. Its interim report on the Resident Assessment System was endorsed by the full Committee in November 1990. At the end of 1990, the Secretary of Health and Human Services had distributed the MDS to the States for their adoption and supplementation.

Initially, the Subcommittee raised several issues about the impact of administering the MDS on the facilities and the staffs of these facilities. These concerns included:

- The length of time it would take to administer the MDS for each resident.
- The quality of data recorded in the assessment and their utility in care planning.
- The relationship of the RAP's to the MDS.
- The lack of training provisions for nursing home staff to administer the MDS.
- The low reliability, and therefore questionable validity, of some of the data items.

The resulting resident assessment instrument and its components are a reflection of many iterations that addressed the difficulties of implementation.

Several issues about the potential uses of the clinical minimum data set remain open for continued discussion. One is the issue of reliability and the quality of the data over time. A second concerns the presumed implementation of the MDS's into a national registry of nursing home residents. A third concerns the mechanism, if any, that will be used to determine what data systems will be made available to qualified researchers and policy analysts who want to access the data in a reasonable and effective way, and how the necessary confidentiality assurances will be provided.

Given the magnitude and range of the MDS, the data inevitably will be used for multiple purposes, including serving as a data set for both administrative and research purposes. Thus, the Subcommittee shares the ongoing concern of NCVHS

for the adequacy of the data set and urges HCFA to continue to monitor the reliability of data items and their validity over time. Further, the Subcommittee plans to continue to monitor the potential development of a national data system that could serve as a national registry of nursing home residents, because no such system currently exists.

The Subcommittee is monitoring data on the aging population. The Chairman attended meetings of the U.S. Government-sponsored Forum on Aging-Related Statistics in February and September 1990.

## **Continuing Work Plan**

The Subcommittee intends to carry out the following work plan in 1991:

- Review the Interagency Task Force report on the Long-Term Care Client Uniform Data Set, for applicability and relevance across care settings.
- Participate in the Interagency Forum on Aging-Related Statistics and monitor plans for possible longitudinal health and retirement studies and other aging issues.
- Monitor the implementation of resident assessment in nursing homes, data reliability, and the opportunity for the formation of a national data base to improve patient care.
- Undertake a collaborative effort with the Subcommittee on Mental Health Statistics on issues of common focus, such as functional status assessments, long-term care delivered through board-and-care homes, and quality of life assessment strategies in both long-term care facilities and alternative community settings.
- Review the classification and definitions used to identify a variety of residential settings, including alternative community settings, and their use with the decennial census and national health surveys.
- Make a final report to NCVHS on age-adjusted nursing home bed supply.

# Ambulatory and Hospital Care Statistics

During the first half of 1990, the Subcommittee on Ambulatory and Hospital Care Statistics actively pursued its charge to assess the need to reexamine the data elements and definitions contained in the Uniform Hospital Discharge Data Set (UHDDS) and the adequacy of the Medicare Uniform Bill (UB-82) as a principal vehicle for collecting the UHDDS. After consultation with collectors and users of hospital discharge data in the public and private sectors, the Subcommittee, at the June meeting of the National Committee on Vital and Health Statistics (NCVHS), recommended that a thorough and systematic review of the UHDDS should be undertaken, working in close cooperation with the National Uniform Billing Committee. The Subcommittee also proposed that a process be established in the Department of Health and Human Services (DHHS) to review the UHDDS in tandem with the Subcommittee. These recommendations were approved by NCVHS and transmitted to the Department. The Department concurred and informed NCVHS of its intent to establish an Interagency Task Force on the UHDDS, chaired by the Health Care Financing Administration (HCFA).

The Subcommittee initiated its review of the UHDDS and also continued its role in following the statistical aspects of physician payment systems, and other data systems and research concerned with patient-provider encounters. Further, the Subcommittee participated in a process within the Department to review the various agency comments on the Uniform Ambulatory Care Data Set, which was recommended by NCVHS and an Interagency Task Force in June 1989, and to come to closure on the data set and approaches for advancing its use. All of these activities will continue in the coming year.

## Recommendations

The following recommendations of the Subcommittee on Ambulatory and Hospital Care Statistics were endorsed at the June 1990 NCVHS meeting:

A thorough and systematic review of the UHDDS should be undertaken, working in close cooperation with the National Uniform Billing Committee, which maintains the UB-82.

The Subcommittee and full Committee believe that the outcome achieved in the review of the Uniform Ambulatory Care Data Set (UACDS) should serve as a

model for review of the UHDDS. The UACDS review involved departmental representatives working in tandem with the NCVHS Subcommittee on Ambulatory Care Statistics, and resulted in a single report recommending a common revision of the data set. The Subcommittee's new charge, as approved at the June NCVHS meeting, assumes responsibility for the NCVHS review.

The NCVHS recommends that a process be established in the Department to review the UHDDS in tandem with the NCVHS Subcommittee on Ambulatory and Hospital Care Statistics, with the objective of a final report by the June 1992 NCVHS meeting. This report should recommend any specific revisions needed in the UHDDS and address dissemination and implementation issues.

## **Background**

The Subcommittee on Ambulatory Care Statistics revised its charge and changed its name to the Subcommittee on Ambulatory and Hospital Care Statistics at the November 1989 NCVHS meeting. The Subcommittee on Ambulatory Care Statistics had been 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. The current Subcommittee has retained its interest in ambulatory care data and statistics related to physician payment systems, while expanding its focus to address hospital care data.

## **Current Year's Activities**

The Subcommittee held three meetings during 1990 to develop and pursue recommendations on the need to reexamine the data elements and definitions contained in the UHDDS, and to follow the numerous other health statistical activities covered in its charge.

The Subcommittee began its UHDDS inquiry by comparing the 1985 version of the UHDDS, the newly recommended UACDS, and the current UB-82, which called attention to differences among the three data sets. Several collectors and users of hospital discharge data in the public and private sectors were contacted and asked to comment on "the adequacy of the UHDDS as a common core of data elements and definitions to meet multiple needs for data on individual hospital discharges" and "the adequacy of the UB-82 as a principal vehicle for collecting the UHDDS." The majority of comments suggested that it was timely to take a fresh look at the UHDDS and the major vehicles used to collect the information in the data set.

Before making a recommendation to NCVHS, the Subcommittee met with a variety of departmental staff on April 18 to determine the urgency and optimal approach for undertaking a review and any revision of the UHDDS. The meeting identified a

substantial number of issues related to the adequacy, completeness, and comparability of current hospital discharge data. The discussion also emphasized the importance and increasingly wide uses of these data and the key role that the UHDDS can play in encouraging greater uniformity of data collection. In addition, the Subcommittee learned from HCFA and the American Hospital Association that a process had been initiated through the National Uniform Billing Committee (NUBC) to review the UB-82 format and data set, with the goal of developing a possible revision of the Uniform Bill by 1992.

In light of the above findings, the Subcommittee recommended, and the full Committee approved, that the Subcommittee and Department should undertake a review of the UHDDS, in close cooperation with NUBC. The Department subsequently concurred and informed NCVHS of its intent to establish an Interagency Task Force on the UHDDS, chaired by HCFA.

The Subcommittee initiated its formal review at a meeting on September 12 that focused on the collection and use of external cause-of-injury (E-coded) data. 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. A panel of experts reported on the impact of injuries on health in the United States and the need for causal data on nonfatal injuries to identify high-risk groups and to develop strategies for prevention and control. The panel also reviewed the most common reasons why E-codes are not being recorded voluntarily and suggested possible solutions. In addition, the Subcommittee received letters and written testimony from a number of other interested parties supporting the inclusion of E-codes in hospital discharge data. Before developing a recommendation to the full Committee, the Subcommittee decided to seek additional testimony from providers and third party payers on their concerns about the cost, ease, and utility of collecting E-codes as either part of diagnosis codes or as a separate data element for hospitalized patients.

Throughout the year, the Subcommittee monitored the responses within the Department to the final report on the Uniform Ambulatory Care Data Set, which had been submitted to the Department in June 1989. Following the September Subcommittee meeting, the Chairman participated in a meeting convened by the Office of the Assistant Secretary for Health to review agency comments and to reach agreement on the contents of the data set and on a recommended approach to foster implementation. The Subcommittee supports this process, as well as designation of a focal point to receive feedback from departmental agencies and other users on their experiences in using the data set.

At each of its three meetings, the Subcommittee received reports on the variety of HCFA data activities covered in its charge. These include the requirement for physician coding of diagnoses on the HCFA 1500, the implementation of a Unique Physician Identification Number, the development of the Common Working File, and the preparation of a Medicare model fee schedule, as required by the physician

payment reform provisions included in the Omnibus Budget Reconciliation Act of 1989. The Subcommittee commended HCFA staff for their excellent work in preparing the model fee schedule on a timely basis and in a way that lays out the unresolved issues and allows simulation of future payments. Subcommittee members and HCFA staff emphasized the importance of achieving conformity of data and data definitions from carrier to carrier, as a national system cannot permit the kind of variability that presently exists.

The Subcommittee also received presentations from the Health Resources and Services Administration, on the implementation of the National Practitioner Data Bank on September 1, and from the Agency for Health Care Policy and Research on its Medical Treatment Effectiveness Program and other Agency responsibilities for developing guidelines and standards for data uniformity. The Subcommittee will maintain liaison with these two agencies.

## **Continuing Work Plan**

The Subcommittee will pursue the following work plan in 1991:

- Continue a thorough and systematic review of the UHDDS in cooperation with the departmental Interagency Task Force on the UHDDS and the National Uniform Billing Committee.
- 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, the National Center for Health Statistics, the Health Resources and Services Administration, and the 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, 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 1990, the Subcommittee on Health Statistics for Minority and Other Special Populations continued its efforts to address the availability of data concerning access and financing of medical care for the medically indigent population in the United States. Testimony received and working sessions held focused on the types of data that exist, the gaps in data, and sources of data besides federal surveys. The Subcommittee also continued to review the uniformity and adequacy of the coding of race and ethnicity in national health surveys to produce data on minority populations.**

## **Background**

The Subcommittee on Minority Health Statistics was established by the National Committee on Vital and Health Statistics in 1986 after the Secretary's Task Force on Black and Minority Health noted that there was a need for data on minority populations as well as a need to improve and fully utilize available sources of data.

Subsequently, the Subcommittee recognized the need to expand its focus on populations defined by race and/or ethnicity to include groups whose health status and health care utilization needs and 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**

The Subcommittee held three meetings including a public hearing and one conference call during 1990. A fourth meeting scheduled for September 31–October 1 was canceled due to the government budget constraints.

The public hearing was held in June to receive comments from researchers working in areas related to medical indigency and to get their perspective and guidance on the following issues:

- The adequacy of current data sets in understanding medical indigency.



- The need to develop a universal working definition of “medical indigence” that is not tied to reimbursement programs, and therefore limited by program and locality.
- The need for standardization of definitions to facilitate comparisons across studies, which will increase understanding of the problem.
- The adequacy for use in policy development of data collected for research purposes.

A final report is being formulated and will be forwarded to the National Committee.

The Subcommittee reviewed the Objectives for the Year 2000 as they related to minority and special target populations. A letter was sent to Dr. Michael McGinnis, Deputy Assistant Secretary for Health (Disease Prevention and Health Promotion) expressing the Subcommittee’s concerns. First, it was felt that a chapter should be added in the preface to *Healthy People 2000* explaining the health disparity between the races, which would help to clarify the intent of many of the objectives targeting minority populations. (At face value, the objectives could be misinterpreted as perpetuating or widening the gap in health status between racial groups rather than narrowing it.) Secondly, it was suggested that another goal might be added that would set forth equal access to health care as a national goal, lessening concerns about double standards. Lastly, it was suggested that moving the cross-indexing of objectives related to minority populations to the beginning of the document would allow these objectives to be identified more easily.

A presentation was made to the Subcommittee on the 1990 *Health, U.S.* Chartbook on Minority Health that was being prepared by NCHS. The Subcommittee was given the opportunity to review and comment on the materials.

Contacts were made with several States to review the racial identifiers that are used in their reporting. It was found that all States are collecting data but not all are reporting information on all racial and ethnic groups. This information was validated through contact with George Gay, Chief of the Registration Methods Branch, Division of Vital Statistics, NCHS.

## **Continuing Work Plan**

The Subcommittee intends to carry out the following work plan in 1991:

- Continue to review the uniformity and adequacy of the coding of race and ethnicity on national health surveys for the purpose of determining the adequacy of the data systems to produce data on minority populations.
- Meet periodically with the Office of Minority Health and collaborating offices.
- Continue to pursue various avenues to encourage the Health Care Financing Administration and the Social Security Administration to improve the racial and ethnic identifiers in the Medicare and Medicaid data systems.

- Review the 1990 NCHS reauthorization provisions with regard to the mandate to improve minority health statistics and the program to give grants to public and nonprofit entities for the conduct and/or analysis of special surveys on the health of racial and ethnic populations.
- Make final recommendations to the full Committee regarding medical indigency and work with the full Committee to implement the recommendations.

## **Mental Health Statistics**

The Subcommittee on Mental Health Statistics seeks to improve the comprehensiveness and quality of mental health data, to stimulate integration between general health and mental health statistical efforts, and to encourage coordination among agencies within the Public Health Service and with other government agencies to achieve effective monitoring of the Nation's health. The Subcommittee also believes that effort must be given to encouraging integration of uniform mental health data collection into national and other large-scale, person-based health surveys, such as the National Health Interview Survey and the Medicare Current Beneficiary Survey. The Subcommittee would also like to see enhancements of mental health information on provider surveys, such as the National Ambulatory Medical Care Survey and the National Hospital Discharge Survey.

In 1990, the Subcommittee met twice. Major recommendations from these meetings include the need for the National Institute of Mental Health to form a work group that will help to formulate mental health content for major national surveys; the need to include a short depression measure on national general health surveys; and the need for reliability and validity work on Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) measures.

### **Recommendations**

The following recommendations were made by the Subcommittee on Mental Health Statistics:

The National Institute of Mental Health (NIMH) should form a technical work group, in cooperation with the Subcommittee, to develop appropriate mental health content for statistical surveys of other Federal agencies. This group also needs to develop a flexible battery of uniform questions for disability measures. We are persuaded that such a work group could be an important mechanism for providing the necessary link between mental health and general health data concerns.

A short measure of depressive symptoms should be included in most general health surveys.

The ADL and IADL measures are a central area for validity and reliability studies. The Subcommittee anticipates working with other subcommittees of the National Committee to encourage an appropriate program of studies.

## **Background**

The Subcommittee on Mental Health Statistics was formed during FY 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 has held two meetings since its formation, and is impressed that its concerns are shared by many colleagues in the health community and in many of the relevant government agencies. It has become clear that persons currently responsible for designing major government surveys are receptive to the inclusion of more mental health content on these surveys, but need direction on mental health data priorities for the use of limited survey time. The Subcommittee also believes that much more data are needed on the prevalence of major mental disorders, co-occurrence of mental and physical disorders, access to mental health services, use of services in relation to need, and expenditures for mental health services.

The Subcommittee has also identified a number of additional issues that need work during the next year. The members are impressed by the importance of depression in health status assessment. With the assistance of NIMH, the Subcommittee is reviewing existing measures and expects to make specific recommendations in this area during the coming year. The Subcommittee is further impressed by the increasing reliance on ADL and IADL measures. These are commonly used in monitoring the elderly and disabled populations, but there are growing indications of interest in adopting these measures for broader administrative purposes.

The Subcommittee has had discussions with the National Institute on Drug Abuse (NIDA), which has expressed interest in having the Subcommittee work with them to review data needs in the drug abuse area. This issue will be examined in the near future. Several members of the National Committee have expressed an interest in child mental health statistics, and the Subcommittee plans to explore this issue as well.

## **Continuing Work Plan**

In FY 1991, the Subcommittee will focus on the following major topics:

- The development of common definitions and measures for functional status.

- The development of a short measure of depression for national health surveys.
- An assessment of mental health statistics for children.
- Improved coordination of mental health statistics across Federal agencies.

# **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 Statistics 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, 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, M.D.  
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*

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

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

### *Ex Officio*

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

Nancy L. Cannon, Ph.D. (1993)  
Vice President  
Care Management Operations  
LifePlans, Inc.  
Two University Office Park  
Waltham, Massachusetts 02154

### *Executive Secretary*

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

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

### *Current Membership*

#### *(Date Appointment Expires)*

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

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

Laurence G. Branch, Ph.D. (1992)  
Professor of Socio-Medical Sciences  
and Community Medicine  
Boston University School of Medicine  
80 East Concord Street, M-936  
Boston, Massachusetts 02218

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

Judith Miller Jones (1992)  
Director  
The National Health Policy Forum  
2011 I Street NW, Suite 200  
Washington, D.C. 20006

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

Risa J. Lavizzo-Mourey, M.D. (1993)  
Acting Director  
Program in Geriatric Medicine  
University of Pennsylvania  
Ralston-Penn Center  
3615 Chestnut Street  
Philadelphia, Pennsylvania 19104-2683

David Mechanic, Ph.D. (1992)  
Institute for Health, Health Care  
Policy, and Aging Research  
Rutgers University  
30 College Avenue  
New Brunswick, New Jersey 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, Texas 78284

Bruce Steinwald (1991)  
Vice President  
Health Technology Associates  
Columbia Square  
555 13th Street NW  
Washington, D.C. 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, Michigan 48909

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

#### *Members Retired During 1990*

Jane L. Delgado, Ph.D.  
President and Chief Executive Officer  
National Coalition of Hispanic Health  
and Human Services Organizations  
1030 15th Street NW, Suite 1053  
Washington, D.C. 20005

Stephen F. Gibbens  
730 Arcady Road  
Montecito, California 93108

Joseph R. Martin  
General Manager  
Center for Hospital and Health Care  
Information  
American Hospital Association  
840 North Lake Shore Drive  
Chicago, Illinois 60611

Robert L. Mullin, M.D.  
Director of Continuing Care  
Hospital of Saint Raphael  
1450 Chapel Street  
New Haven, Connecticut 06511

#### **Meeting Dates**

*All meetings held in Washington, D.C.*

February 7-9, 1990  
June 6-8, 1990  
November 7-9, 1990

# Appendix IV.

## Subcommittees of the National Committee on Vital and Health Statistics

### Executive Subcommittee

#### Current Roster

##### *Chairman*

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

Judith Miller Jones (1992)  
Director  
The National Health Policy Forum  
2011 I Street, NW, Suite 200  
Washington, D.C. 20006

Bruce Steinwald (1991)  
Vice President  
Health Technology Associates  
Columbia Square  
555 13th Street, NW  
Washington, D.C. 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, Michigan 48909

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

#### *Background*

At the November 8, 1985, meeting of the National Committee on Vital and Health Statistics (NCVHS), based on the recommendations of the Ad-hoc Subcommittee

#### *Ex Officio*

Gail F. Fisher, Ph.D.  
Executive Secretary  
National Committee on Vital and  
Health Statistics  
6525 Belcrest Road  
Hyattsville, Maryland 20782

#### **Staff**

Jack Anderson, NCHS  
Marjorie S. Greenberg, NCHS  
Thomas S. Vissman, NCHS

John R. Cotter, HCFA

Stephen King, M.D., AHCPH

#### **Meeting Dates**

*Meetings held in Washington, D.C.*

February 7, 1989 (working session)

April 24, 1990

June 6, 1990 (working session)

November 7, 1989 (working session)

*Meeting held in Shepardstown, West Virginia*

August 22-24, 1990

on Policy and Directions, there was established an Executive Subcommittee of NCVHS.

### *Purpose*

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

### *Composition*

The Chairman of 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, respectively, remaining in their terms of appointment to 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 agency 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:*

1. In interim periods between the full Committee meetings of NCVHS, the Executive Subcommittee will monitor, through telephone calls, mail, 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 will be identified and resolved to accomplish the planned program.

2. The Executive Subcommittee will review work plans developed by the subcommittees and make recommendations to the full Committee.
3. The Subcommittee may confer with Chairmen of other subcommittees or with 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.
4. 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.
5. The Chairman of 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.
6. In unusual events where some actions, previously not approved by the Committee, may be required by 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.
7. In the absence of the Chairman at an Executive Subcommittee or full Committee meeting, the Executive Subcommittee member with the most seniority on NCVHS would act as Chairman.

## Subcommittee on Medical Classification Systems

### Current Roster

#### *Chairman*

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

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

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

Bruce Steinwald (1991)  
Vice President  
Health Technology Associates  
Columbia Square  
555 13th Street NW  
Washington, D.C. 20004-1109

### Staff

Lynnette Araki, NCHS  
Sue Meads, NCHS  
Perrienne Lurie, M.D., NCHS  
Patricia Brooks, HCFA

### Meeting Dates

*Meetings held in Washington, D.C.*

March 12-13, 1990  
August 27, 1990

## Charge to the Subcommittee on Medical Classification Systems

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

1. The progress toward the development of *ICD-10* ; to review and evaluate areas where conflicting proposals emerge and to participate in the development of recommendations that are most compatible with priority concerns in the United States.
2. The progress of international decisions regarding *ICD-10* as related to needs in the United States that would require the development of an *ICD-10-CM*; to consider alternative mechanisms and suggested time tables if an *ICD-10-CM* were perceived as necessary.
3. The progress of activities moving toward the development of a single classification system for procedures in the United States to be used for physician fee-for-services, diagnostic reporting, and hospital inpatient care reimbursement that will respond to data user needs.
4. The ongoing refinement of diagnosis-related groups (DRG's), case mix indexes, and severity indexes.
5. The progress in a number of related areas: systems for automated coding of medical diagnoses and improved medical terminology and nomenclature, quality of diagnostic data, and other related areas.

6. The Subcommittee will continue to work with existing *ICD-9-CM* Coordination and Maintenance Committee, chaired by the Health Care Financing Administration and the National Center for Health Statistics, to ensure the utility and integrity of *ICD-9-CM* in its broadly based multiuse applications throughout the United States.

## Subcommittee on Long-Term Care Statistics

### Current Roster

#### *Chairman*

Laurence G. Branch, Ph.D. (1992)  
Professor of Socio-Medical Sciences  
and Community Service  
Boston University School of Medicine  
80 East Concord Street, M-936  
Boston, Massachusetts 02215

Nancy L. Cannon, Ph.D. (1993)  
Vice President  
Care Management Operations  
LifePlans, Inc.  
Two University Office Park  
Waltham, Massachusetts 02154

Judith Miller Jones (1992)  
Director  
The National Health Policy Forum  
2011 I Street, NW, Suite 200  
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David Mechanic, Ph.D. (1992)  
Institute for Health, Health Care

Policy, and Aging Research  
Rutgers University  
30 College Avenue  
New Brunswick, New Jersey 08903

### Staff

Lynnette Araki, NCHS  
Joan Van Nostrand, NCHS  
Evelyn Mathis, NCHS

Aurora Argueta, OHPE, OASH

Martin Feuerberg, HCFA  
Mary Waid, HCFA

### Meeting Dates

*Meetings held in Washington, D.C.*

January 17, 1990 (conference call)

May 23, 1990

October 18, 1990

## Charge to Subcommittee on Long-Term Care Statistics

The care of the chronically ill and dependent is of increasing public policy importance. Demographic trends and reduced mortality are resulting in substantial increases in the number of older persons, especially the very old, and their share of the total population. The increasing prevalence of chronic conditions and dependency that accompanies aging implies substantial increases in the population needing long-term health care and personal services, and raises serious concerns about the availability and affordability of such services. The absence of comprehensive financing concentrated in a single program has created difficulties in assembling information required for analysis of policy choices. Similar concerns about information adequacy exist regarding care of the chronically mentally ill and the mentally retarded and developmentally disabled. Efforts to "deinstitutionalize" and "mainstream" have increased substantially the potential sources of care and, unfortunately, the potential for inadequate care. Increased fragmentation of the service system has also made collection of adequate data on these persons and their services more problematic.

Therefore, the National Committee established a Subcommittee on Long-Term Care Statistics to describe and assess the adequacy of information available pertaining to long-term care policy issues and to recommend steps to reduce any deficiencies. Specifically, the 1990 Charge for the Subcommittee on Long-Term Care Statistics is to:

1. Review the Interagency Task Force report on the Long-Term Care Client Uniform Data Set for applicability and relevance across care settings.
2. Participate in the Interagency Forum on Aging-Related Statistics; monitor plans for possible longitudinal health and retirement studies; and monitor other aging issues.
3. Monitor the implementation of resident assessment in nursing homes, data reliability, and the opportunity for the formation of a national data base to improve patient care.
4. Undertake a collaborative effort with the Mental Health Statistics Subcommittee on issues of common focus, such as functional status assessments, long-term care delivered through board-and-care homes, and quality of life assessment strategies in both long-term care facilities and alternative community settings.
5. Review the classification and definitions used to identify a variety of residential settings, including alternative community settings, and their use with the decennial census and national health surveys.
6. Make a final report to NCVHS on age-adjusted nursing home bed supply.

## Subcommittee on Ambulatory and Hospital Care Statistics

### Current Roster

#### Chairman

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

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

Nancy L. Cannon, Ph.D. (1993)  
Vice President  
Care Management Operations  
LifePlans, Inc.  
Two University Office Park  
Waltham, Massachusetts 02154

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

Judith Miller Jones (1992)  
Director  
The National Health Policy Forum  
2011 I Street, NW, Suite 200  
Washington, D.C. 20006

Bruce Steinwald (1991)  
Vice President  
Health Technology Associates  
Columbia Square  
555 13th Street NW  
Washington, D.C. 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, Michigan 48909

### Staff

Marjorie S. Greenberg, NCHS  
James Delozier, NCHS  
Beth Lowe, NCHS  
Linda Lawrence, NCHS  
Sahira Rafiullah, NCHS  
William Sobaski, HCFA

### Meeting Dates

*All meetings held in Washington, D.C.*

January 18-19, 1990  
April 18, 1990  
September 12, 1990

## Charge to 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. 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.

2. 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 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 HCFA 1500 to seek greater standardization of the definitions in use for place or site of health care services.
4. Provide a continuing liaison with the Health Care Financing Administration, the National Center for Health Statistics, and other relevant agencies concerning the statistical aspects of physician payment systems and other data systems and research and development projects that deal with encounters between patients and providers.
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: a) progress toward implementing the Medicare Common Working File, b) status of the revision of the HCFA 1500, c) progress toward 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.
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 a 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

### Current Roster

#### *Chairman*

Risa J. Lavizzo-Mourey, M.D. (1993)  
Acting Director  
Program in Geriatric Medicine  
University of Pennsylvania  
Ralston-Penn Center  
3615 Chestnut Street  
Philadelphia, Pennsylvania  
19104-2683

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

Sister Irene V. Kraus (1993)  
President  
Daughters of Charity National  
Health System  
11775 Borman Drive  
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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, Texas 78284

### Staff

Jacqueline P. Davis, NCHS  
Diane Makuc, Ph.D., NCHS  
Patricia Golden, NCHS  
Gregory Pappas, M.D., NCHS  
Margaret Cooke, NCHS

Frank Emerson, HCFA  
Mary Waid, HCFA

Harvey Schwartz, Ph.D., AHCPR

### Meeting Dates

#### *Meetings held in Washington, D.C.*

February 7, 1990 (working session)  
June 5, 1990  
July 26, 1990 (conference call)

#### *Meetings held in New York*

September 30–October 1, 1990  
(canceled)

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

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

1. Review and make recommendations on the uniformity and adequacy of the collection, analysis, and dissemination of minority health data.



2. Work with and support the Office of Minority Health and collaborating offices in their data-related minority health activities.
3. 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

### Current Roster

#### *Chairman*

David Mechanic, Ph.D. (1992)  
Institute for Health, Health Care  
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### Staff

Ronald Manderscheid, Ph.D., NIMH  
Edward Bacon, Ph.D., NCHS  
Dale K. Hall, NCHS  
Thomas Hoyer, HCFA

### Meeting Dates

*Meetings held in Washington, D.C.*

May 24, 1990  
October 11, 1990

## 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:

1. Identify major gaps in mental health statistics.
2. Explore the feasibility of filling existing gaps with ongoing data collection efforts, in order to explore how ongoing efforts might be supplemented.
3. Examine areas of measurement development necessary to meet national goals or priorities.
4. Work with Public Health Service (PHS) and other DHHS agencies to identify areas of needed initiatives, to identify opportunities for coordination of efforts, and to bring in other relevant Federal agencies.
5. Examine how major data sources (e.g., Medicare and Medicaid data) can be used to help meet mental health data needs.
6. Explore opportunities for data linkage relevant to data bases collected by NCHS, HCFA, and other Federal agencies.

7. Increase the availability, quality, and utility of data that deal with mental illness, including the provision of public-use data tapes.
8. Coordinate NCVHS review of the biennial publication, *Mental Health, United States*.

# Appendix V.

## Report of the Workshop on Improving Cause-of-Death Statistics

### Executive Summary

Much of the information on mortality patterns in the United States is based on the causes of death reported on death certificates. An important step in improving this information took place when 46 representatives from Federal, State, and professional organizations attended a 3-day Workshop on Improving Cause-of-Death Statistics, October 15–17, 1989. The workshop, which was held in Virginia Beach, Virginia, was sponsored by the National Center for Health Statistics (NCHS) in cooperation with the National Committee on Vital and Health Statistics (NCVHS).

After identifying and discussing the key issues, workshop participants developed an extensive set of recommendations for future action. The overwhelming need recognized by all participants was for a broad-based educational effort, which would involve the collaboration of Federal, State, local, and private organizations. The only area in which there was a clear lack of agreement was whether causes of death reported on death certificates should be open to or restricted from public inspection, and whether the quality of cause-of-death statistics is improved by restricting public access. However, there was general agreement that access to cause-of-death information should be maintained for bona fide research purposes.

Specific workshop recommendations include the following:

#### *Education of the Physician*

- A widespread educational effort should be undertaken to improve the quality of cause-of-death information, with primary focus on the physician. This effort should be pluralistic, with multiple approaches at various times in the physician's training and practice to provide continuous reinforcement.
- The educational program should encompass medical schools, internship and residency programs, and continuing education for practicing physicians. The licensure and board certification processes provide additional opportunities to communicate with physicians.
- Internship and residency are considered the appropriate and key times for first educating physicians on the procedures for reporting causes of death on a death certificate.
- States should be encouraged to analyze cause-of-death information by institution and individual certifier in order to target educational efforts.

- Medical records personnel also should receive education about the proper recording of cause-of-death information and could serve as resources to physicians.
- Although educational efforts will be varied, and tailored to particular locations, it will be important to document the types of activities undertaken and to encourage coordination of efforts and materials.
- Finally, it is essential to receive necessary institutional commitments to carry out these educational recommendations.

#### *Education of the Public and Policymakers*

- The educational effort should extend to the public and policymakers, and awareness of the importance of mortality data should be increased at all levels.

#### *Quality Control*

- The NCHS and State vital statistics offices should develop and disseminate a model quality assessment program.
- The quality control program should include primary on-site review, querying or secondary review, audit through periodic review of source documents, and a systematic amendment process for making changes or additions to the death certificate.

#### *Format*

- A study should be conducted to evaluate the potential effect of reversing the order of sequence of diagnoses as reported by physicians on the death certificate, as originally recommended by the Panel to Evaluate the U.S. Standard Certificates.

#### *Definitions*

- Standard operational definitions should be developed for homicide and “injury at work” and should be included in the *Medical Examiners’ and Coroners’ Handbook on Death Registration and Fetal Death Reporting*.

#### *Timeliness*

- To encourage wider use of autopsy data and to increase the value of these data, the deadline for completion of hospital medical autopsies should be shortened. A more expeditious closure of medical examiner and coroner investigations also should be encouraged.

#### *Confidentiality and Access to Records*

Several recommendations were proposed to increase confidentiality and maintain legitimate research access:

- The medical certification portion of the death certificate should be considered part of the medical record and should not be open to public inspection.
- The Model State Vital Statistics Act and Regulations Revision Committee should consider making the entire death certificate, or at least the cause-of-death portion, confidential, except when needed for legitimate research.
- The feasibility should be explored of developing a "short form" of the death certificate to be used at the family's option and to include the minimum information needed for legal and administrative purposes.

Because of the complexity of the issues involved, it was agreed that a broadly based group should be convened to identify and discuss the relevant ethical and legal questions related to access to cause-of-death information reported on the death certificate.

#### *Followup Activities*

- In addition to convening a group on legal and ethical issues, consideration should be given to followup workshops on other appropriate topics, such as evaluation of querying programs and training of physicians.
- A followup report should be prepared in 2-3 years to determine the progress and impact of the recommendations from this initial workshop; a followup workshop of the participating organizations also should be considered.

#### *Resources*

- The cost of specific data improvements must be weighed against the benefits achieved for specific uses.
- Adequate resources should be made available to support and strengthen efforts by NCHS to improve the quality of cause-of-death information.

Representatives of the private organizations participating in the workshop strongly concurred with the need for extensive education, and discussed specific ways in which their particular organizations could contribute to both educational and dissemination efforts. The State vital registration and statistics programs and the Federal agencies involved in data collection and analysis also were well represented and will be actively involved in carrying out many of the recommendations.

The Chairman of NCVHS promised to push forward the process for full consideration of the workshop recommendations. The NCVHS will monitor progress on all the recommendations from the workshop and assist the public and private organizations in any way it can.

The Director of NCHS committed the Center to a leadership role in developing more effective approaches for analyzing and disseminating mortality data, and looked forward to the United States entering the 21st century with a first-rate mortality data system that can be a model for other countries.

## **Workshop on Improving Cause-of-Death Statistics**

October 15–17, 1989  
Virginia Beach, Virginia

Improving statistics on causes of death was the focus of a 3-day workshop held in Virginia Beach, Virginia, October 15–17, 1989. The workshop, which was sponsored by the National Center for Health Statistics (NCHS) in cooperation with the National Committee on Vital and Health Statistics (NCVHS), included participation by 46 representatives of Federal, State, and professional organizations. The agenda and a list of participants by organization are presented at the end of this report.

The workshop was the outgrowth of a long standing interest by NCHS and NCVHS in improving the quality of health data available for decisionmaking and research. Both organizations recognized that achieving improvements in the vital statistics system required active collaboration with the States and with the many professional associations representing physicians, hospitals, medical schools, and related groups. This recognition was buttressed by a recommendation in the 1986 Report of the Panel to Evaluate the U.S. Standard Certificates and Reports. This report had suggested that NCHS explore the possibility of bringing together representatives of organizations who would be interested in physician training and who could be helpful in developing the materials and promoting their use.

### **Presentation of Issues**

In preparation for the workshop, the Association for Vital Records and Health Statistics (AVRHS) conducted a survey of State activities related to improving the quality of cause-of-death data. A summary of the survey results and three other background papers on the nature and accuracy of cause-of-death data, the impact of cause-of-death querying, and the mechanisms by which cause-of-death data get to the policymaker were prepared by NCHS staff for the meeting participants. These papers provided an empirical basis for the workshop deliberations, as well as some idea of the magnitude of the problem. Copies of the four papers, which are listed at the end of this report, are available upon request.

Dr. Manning Feinleib, Director of NCHS, began the workshop with a brief discussion of the key issues regarding the problems with cause-of-death reporting. These include the following:

- Cause of death of a sensitive nature may be underreported on the death certificate for a variety of reasons.
- There are problems with the confidentiality of death certificates in a number of States that place the physician in a position of having to deal with social pressures not to report sensitive causes of death.

- Physicians often do not understand how to complete the death certificate appropriately, especially in relation to the concepts of underlying and contributing causes; further, the concept of one underlying cause of death often is problematic with elderly decedents.
- There is a fundamental need to educate the public, physicians, and health decisionmakers about the importance of accurate reporting on the death certificate and about the impact of erroneous reporting on aggregate mortality statistics.
- Training of physicians on proper completion of the medical certification of cause of death on death certificates has been seriously inadequate and must be significantly improved.
- A systematic quality control program that includes querying by State vital statistics offices and amending of death certificates when more information becomes available can contribute to improved cause-of-death information.

Dr. Ronald Blankenbaker, Chairman of NCVHS, echoed many of the issues raised by Dr. Feinleib and expressed the hope that the workshop would serve as a catalyst for future action. He challenged the workshop participants to develop some significant recommendations that could be submitted to the Secretary of the Department of Health and Human Services by NCVHS.

The keynote speaker and panel of experts expanded on many of the themes outlined by Dr. Feinleib and Dr. Blankenbaker, as did the three small group sessions. Additional key issues identified were as follows:

- Death certificates and cause-of-death information are widely used for a number of different purposes, including legal registration and notification, medical research, and the development of health policy. These different uses make it difficult to target educational and improvement activities.
- Important medical information is not always available at the time of certification. This may create a special problem for reporting nursing home deaths and deaths of the elderly who have multiple conditions.
- Concerns about liability may result in omissions from the cause-of-death certification and underutilization of autopsy information.
- The order for sequencing diagnoses in the medical certification, which begins with the immediate cause and ends with the underlying cause, is considered "backward" by many physicians.
- Definitions for certain causes and manners of death, for example, homicides and "injury at work," are not standardized.
- State and local laws differ on the time allowed for completing the death certificate, on the methods for investigating certain deaths, and on the extent of access to death records. Applicable laws also are always subject to change by the State legislatures.



- The approach for financing any recommendations to improve the quality of cause-of-death statistics must be considered.

## Recommendations

Discussion of the many issues identified by workshop participants led to a significant number of specific recommendations. Although the recommendations were developed first in small group sessions, there were remarkable parallels in the priorities stressed by each group and general agreement on the majority of recommendations. The overwhelming need recognized by all participants was for a broad-based educational effort that involves the collaboration of Federal, State, local, and private organizations.

The only area in which there was a clear lack of agreement was whether causes of death reported on death certificates should be open to or restricted from public inspection and whether the quality of cause-of-death statistics is improved by restricting public access. However, there was general agreement that access to cause-of-death information should be maintained for bonafide research purposes.

The specific workshop recommendations were:

### *Education of Physicians*

A widespread educational effort should be undertaken to improve the quality of cause-of-death information, with primary focus on the physician. This effort should be pluralistic, with multiple approaches at various times in the physician's training and practice to provide continuous reinforcement. All training and feedback should cover the importance of cause-of-death statistics and their value in improving the practice of medicine, as well as the mechanics of completing the death certificate. The educational program should encompass:

- Medical School

The educational effort in medical school should focus on problem-solving techniques, the need for objectivity and data in the decisionmaking process, the importance of statistics and epidemiologic research, and the contribution that the individual doctor makes to aggregate morbidity and mortality statistics. The actual procedures for completing the death certificate probably should be reserved for later in the physician's training.

Through the auspices of the Association of American Medical Colleges (AAMC), State vital statistics offices should obtain the names of the instructors who teach biostatistics and epidemiology at the respective State medical schools and initiate a dialogue with these individuals. State personnel could develop packets of educational materials on mortality data for use by the instructors and also could offer to present or contribute to a lecture on the subject. It is anticipated that these instructors will have a greater interest in improving cause-of-death information than the medical school faculty at large.

- Internship and Residency

Internship and residency are considered the appropriate and key times for first educating physicians on the mechanics of filling out the medical certification on a death certificate. There are many possible approaches for this educational effort. These include training the senior residents to act as resources, developing an information packet for use on each floor with instructions tailored to the death certificate in the respective State, and making tapes and video cassettes available. It was learned, for example, that George Washington University Medical Center has an information packet on death certification that could be modified to include more instruction and examples on recording causes of death.

Certifier training should emphasize that multiple cause-of-death information has many uses, and should stress the need to enter all conditions leading or contributing to death in the cause-of-death section of the death certificate.

Formats for presentation of instructional materials should be improved. Workbooks to teach accurate completion of death records should be developed.

- Licensure and Board Certification

Licensure and Board certification provide additional opportunities to communicate with physicians about the importance of accuracy in certifying the cause of death. The respective mailing to the physician could include a copy of the *Physicians' Handbook on Medical Certification of Death*, prepared by the National Center for Health Statistics, or other State-specific instructional materials.

A question on cause-of-death certification should be added to Part 3 of the National Boards.

- Practicing Physicians

Education given during training must be reinforced for practicing physicians. State vital statistics offices should work with the State hospital associations and State medical societies to get continuing medical education (CME) credit for training in cause-of-death reporting. All groups that offer CME credit should incorporate training on the death certificate; this training should be coordinated by the Association of American Medical Colleges (AAMC). The NCHS, AAMC, AVRHS, and the American Hospital Association (AHA) should develop a model curriculum for CME training in the physicians' own idiom. The training should be conducted by the State vital statistics office and a State epidemiologist. CME credit on death certificate completion also could be obtained through the Medical Knowledge Self-Assessment Program.

States should be encouraged to analyze cause-of-death information by institution and individual certifier in order to target educational efforts. Providing feedback to physicians on how they compare with other certifiers and through analyses of State and local mortality data also can increase interest in

cause-of-death statistics. Articles in the newsletters of State medical societies and State health departments, as well as in specialty journals, all offer opportunities for communication. Technical papers and editorials on proper completion of the medical certification should be included in association, hospital, and medical journals.

The participation of Federal and State representatives in State medical society meetings, the 6-month meetings of the American Medical Association (AMA), and professional meetings to educate and disseminate information on cause-of-death certification also should be explored. State public health associations should give positive feedback to physicians on completion of death certificates.

A 30-second spot on death certificate completion should be included on the Medical Cable Television Network.

Training for medical examiners and coroners should be coordinated through the State and national medical examiner and coroner associations and should be conducted at annual meetings.

- Hospitals

Medical records personnel also should receive education about the proper recording of causes of death and could serve as resources to the physicians. For in-hospital deaths, a copy of the death certificate should be made a part of the medical record before the certificate leaves the hospital. The director of medical records should compare the cause-of-death certification to the medical record and call the certifier's attention to any discrepancies. Although it would be the certifier's responsibility to submit any amendments, providing information to the certifier on the process for amending death certificates would be useful.

Each hospital should identify one individual to work solely with death certificates and the certifiers to ensure that the certificates are completed properly. This individual also would educate physicians on proper completion of the cause-of-death certification.

Educational materials for other ancillary hospital personnel, such as admitting staff, also could be useful.

Although educational efforts will be varied and tailored to particular locations, it will be important to document the types of activities undertaken and to encourage coordination of efforts and materials. As indicated above, AAMC may be able to play a partial role in this regard. The AAMC collects information on medical school curricula and maintains a curriculum guide. The organization also is developing a new approach to postmortem analysis, which will have an impact on residency programs. A coordinating role also is suggested in the area of continuing medical education. Finally, it is essential to receive necessary institutional (for example, medical societies) commitments to carry out these educational recommendations.

## *Education of the Public and Policymakers*

Much of our public health knowledge and prevention practice is based on the availability of high quality cause-of-death information on death certificates. Awareness of the importance of mortality data should be increased at all levels—Federal, State, and the private sector. A specific source citation (for example, “Information from the death certificates filed in State vital statistics offices”) should be used whenever the data are published or compiled on NCHS public-use data tapes. Mortality data should be marketed to policymakers by highlighting compelling vital statistics in concise formats. Presentations should be made at the National Governors’ Conference.

The NCHS should lead a work group that would coordinate State registrar efforts to develop and disseminate a statement of purposes and uses of the death certificate. This would be coordinated with the medical societies and would be distributed to all users of the death certificate, including families, the public, medical researchers, medical ethicists, the media, and policymakers.

## *Quality Control*

The NCHS and State vital statistics offices should develop and disseminate a model quality assessment program, to include the following components:

- Primary on-site review, where applicable, should be carried out at point of origin of the death certificate by the institution (hospital, nursing home, medical examiner, and coroner). Possible mechanisms for this would include:
  - Review of death certificate as part of mortality review in hospitals. Death investigation by expert review committees at the hospital, local, and State level should be encouraged as a valid mechanism for improving the classification of cause of death. Such committees could be established to review, for example, maternal deaths, infant deaths, and deaths suspected to be caused by Sudden Infant Death Syndrome, suicide, and neglect or abuse. Legal protection should be in place for committee members and for the committee’s deliberations. Further, existing information available from the Centers for Disease Control (CDC) on the current legal status for committee protection in each State should be distributed to State health departments, State medical societies, and medical specialty groups.
  - Review by Chief of Service in hospital.
  - Linkages with autopsy data, claims data bases, and risk management systems. The CDC and State offices of vital statistics should encourage the investigation of linkages among the death certificate, autopsy, and other relevant data bases to maximize use of this information for epidemiologic purposes in the promotion of public health.

The purposes of all of these reviews should be educational rather than for peer review.

- Querying—a secondary review of death certificates by State registrars, as needed, to promote accurate cause-of-death reporting—should be encouraged in all States. There should be State and Federal monitoring of querying programs. States also should be encouraged to evaluate the impact of querying to increase the cost effectiveness and timeliness of the activity. There should be financial and technical support at the Federal level for evaluating the different State querying systems in a uniform manner. The evaluation should include a needs assessment to determine if a model automated query program is feasible.
- Audit—a periodic review of source documents, to check the accuracy of death certificates—should be carried out by the State registrar, a private contractor, or some other outside party.
- Amendment—making changes or additions to the death certificate—should be encouraged by educating physicians and developing easier methods for supplying supplemental information to be included on the death record.

Oversight groups for the above activities could involve groups such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), nursing home regulatory agencies, medical examiners and coroners, and the Health Care Financing Administration (HCFA).

#### *Format*

A study should be conducted to evaluate the potential effect of reversing the order of sequence of diagnoses reported by physicians on the death certificate, as originally recommended by the Panel to Evaluate the U.S. Standard Certificates.

The question should be clarified that concerns whether findings from an autopsy were available prior to completion of cause of death on the model U.S. Standard Certificate of Death. The certificate should ask explicitly whether the findings were used in determining cause of death. Check boxes could be possibly included to indicate what type of findings were used (for example, preliminary anatomic diagnosis, final anatomic diagnosis, or toxicological findings.)

Consideration should be given to fundamental long-term changes in the way vital statistics information is transmitted in order to take advantage of electronic data transmission and storage technologies. Development in this area should be coordinated with related work on a universal electronic record being conducted by the Institute of Medicine and the American Society of Testing Materials.

#### *Definitions*

Standard operational definitions should be developed for “homicide” and “injury at work” and included in the *Medical Examiners’ and Coroners’ Handbook on Death Registration and Fetal Death Reporting*. The work done by CDC on operational criteria for the classification of suicide should serve as a model for this effort. It is recommended that this be pursued expeditiously as a high priority activity.

## *Timeliness*

To encourage wider use of autopsy data and to increase the value of these data, the deadline for completion of hospital medical autopsies should be decreased from 90 days to 60 days, as recommended by JCAHO, and a 30-day limitation should be reconsidered. A more expeditious closure of medical examiner and coroner investigations also should be encouraged, and the input of the National Association of Medical Examiners and the International Association of Coroners and Medical Examiners is requested on this matter.

The NCHS and the State offices of vital statistics should be encouraged to continue to provide provisional mortality statistics in a timely manner and to review the possibility of expanding these statistics with information from additional data items.

## *Confidentiality and Access to Records*

As discussed above, opinions varied on the degree of confidentiality that should be afforded to cause-of-death information. Although some individuals believed that restricting access would improve the accuracy of the information, others contended that, in the long run, secrecy has never been in the public interest. The following recommendations to increase confidentiality but maintain legitimate research access came from two of the three small group sessions:

- To improve the accuracy of cause-of-death information, the medical certification portion of the death certificate should be considered part of the medical record and should not be open to public inspection. Access should be limited to family, medical researchers, and government agencies, as appropriate.
- Detailed cause-of-death information should be confidential and released only in aggregate form, unless needed for bonafide research purposes. The Model State Vital Statistics Act and Regulations Revision Committee should consider making the entire death certificate, or at least the cause-of-death portion, confidential except when needed for legitimate research.
- The feasibility should be explored of developing a “short form” of the death certificate to be used at the family’s option that would include the minimum information needed for legal and administrative purposes (for example, the manner of death but not the specific cause).

Because of the complexity of the issues involved, it was agreed that a broadly-based group should be convened to identify and discuss the relevant ethical and legal questions related to access to cause-of-death information reported on the death certificate. The group should include ethicists, lawyers, physicians, policymakers, government officials, lay persons, and members of the media. Although the current workshop had included representatives of several of these groups, it had not been possible to give the topic the full study that it deserved.

The results of the deliberations of the broader group should be disseminated and could serve to educate the public and providers about such issues as liability and risks, and could also be the impetus for new legislation, if considered necessary. The Revision Committee for the Model State Vital Statistics Act, which will begin meeting in 1990, intends to address these issues and may be an appropriate vehicle for the broader discussions.

### *Followup Activities*

In addition to convening a group on legal and ethical issues, consideration should be given to followup workshops on other appropriate topics, such as evaluation of querying programs and training of physicians.

A followup report should be prepared in 2-3 years to determine the progress and impact of the recommendations from this initial workshop, and a followup workshop of the participating organizations also should be considered.

### *Resources*

The cost of specific data improvements must be weighed against the benefits achieved for specific uses. A cost/benefit assessment should be done on all recommendations to determine whether or not they are feasible.

Adequate resources should be made available to support and strengthen efforts by NCHS to improve the quality of cause-of-death information.

## **Organizational Responses**

Following the presentation of recommendations by the chairmen of the three small group sessions, responses were made by the representatives of private organizations participating in the workshop. These representatives strongly concurred with the need for extensive education and discussed ways in which their particular organizations could contribute to both educational and dissemination efforts. In some cases, additional recommendations were made. The responses follow:

### *American College of Physicians*

The American College of Physicians (ACP) represents 63,000 doctors of internal medicine and subspecialties and consists of a number of divisions, departments, and committees. A variety of activities to support improvement of cause-of-death information should be possible through the Health and Public Policy, Publications, and Educational Divisions. These activities include the following:

- The Department of Scientific Policy can inform the relevant committees about the importance of the problem and recommend educational programs. Policy statements also can be issued after review by the committees and Board of the College.

- Continuing medical education offers the best opportunity for educational efforts. Approximately 5,000 physicians attend the annual meeting and participate in minicourses. In addition, it may be possible to include information on cause-of-death certification in the Medical Knowledge Self-Assessment Program, which is conducted through the mail for CME credit.
- If panels are convened to develop further recommendations, staff can obtain input from relevant committees such as the Ethics Committee. It was noted that many national professional organizations have a committee structure, which can be helpful in reviewing materials.
- A press release about the workshop or a human interest story about the importance of cause-of-death statistics could be included in the *ACP Observer*. Governors' newsletters in each region with an elected governor also could be a source of communication.
- A peer-reviewed article for publication in the *Annals of Internal Medicine* also should be considered.

#### *American Geriatrics Society*

- The American Geriatrics Society also has committees which can react to recommendations and provide participants for future workshops or expert panels.
- Efforts can be made to integrate improvement of cause-of-death statistics into research activities.
- The annual meeting of the Society offers an opportunity to discuss uses of cause-of-death statistics and to educate physicians about completing the medical certification.
- An editorial could be published in the *Journal of the American Geriatric Society* discussing the findings of the workshop.
- The Society can facilitate dissemination of educational materials to the medical directors of long-term care facilities.
- The Society will communicate with the Association of Nursing Home Medical Directors about the workshop recommendations and the importance of the problem.

#### *American Hospital Association*

The American Hospital Association (AHA) will pursue various avenues for disseminating information about the importance of cause-of-death statistics:

- A case study could be published in *Medical Staff Leader* magazine.
- The AHA newsletter, *AHA News*, and *Hospitals* magazine both could include a discussion of vital statistics on a yearly basis.
- The AHA, HCFA, and JCAHO are compiling a Mortality Guidebook to help physicians conduct mortality review. A section should be included in this guidebook on the death certificate and its contribution to aggregate statistics.



- Each State registrar and medical examiner should approach the State hospital association about the development and dissemination of materials on cause-of-death certification.
- The Association of Hospital Medical Educators also is a vehicle for education and dissemination.

#### *American Medical Association*

- The representative of the American Medical Association (AMA) will report the results of the workshop to the Education Committee and will point out the impact of cause-of-death statistics on resource allocation.
- An editorial emphasizing the importance of cause-of-death statistics might be appropriate in the *Journal of the American Medical Association*.
- Since the representative also is a member of the American College of Surgeons, similar suggestions will be offered to that organization.

#### *American Medical Record Association*

- The American Medical Record Association (AMRA) has 150 academic programs currently offering courses in vital statistics. More information can be included in these programs about cause-of-death certification and statistics.
- Information on the workshop recommendations and related issues can be publicized through the monthly *AMRA Journal*, and suggestions for action can be offered to hospital-based members.
- The hospital medical records staff often have the opportunity to orient new house staff and could include information on cause-of-death certification in these orientation sessions. Materials should be developed for this purpose.
- Including a copy of the death certificate in the medical record for all hospital deaths would permit the medical record practitioners to compare the certificate to the record.
- Further study is needed on the easiest method for submitting amendments to the death certificate. Appropriate and feasible communication channels among the medical record practitioner, the physician, and the State registrar need to be considered.

#### *Association of American Medical Colleges*

The Association of American Medical Colleges (AAMC) operates through various administrative divisions and councils and represents 400 teaching hospitals, 90 professional societies, and 126 medical school deans. Followup activities will include the following:

- A report on the workshop will be made to the staff of the Council of Teaching Hospitals.
- Input will be given to the working group that is developing a new methodology for postmortem analysis, the Integrated Postmortem Analysis Conference

(IPAC). This multidisciplinary approach aims to assemble all relevant information and findings on the deceased in a timely fashion to permit completion of reports and an IPAC within 1 month of the death. The plan is to make such conferences a regular event in teaching hospitals and medical schools and to designate a central staff person to coordinate and expedite the postmortem analysis and to provide feedback to the survivors. In conjunction with this effort, target rates will be developed for hospital autopsies.

- Articles and studies can be considered for publication in the AAMC journal *Academic Medicine*.

#### *Association of State and Territorial Health Officials*

- The representative of the Association of State and Territorial Health Officials (ASTHO) expressed his belief that ASTHO will agree with and support the workshop recommendations.
- Cause-of-death information should be analyzed by census tract of the decedent's most current personal residence to make the data more useful for public health decisionmaking. Economic indexes are considered extremely important in these analyses.

#### *College of American Pathologists*

The College of American Pathologists represents 14,000 pathologists in the United States and will be an active participant in efforts to improve cause-of-death information.

- The College will expect to receive materials from NCHS and CDC to disseminate to its membership and will look to these Federal agencies for guidance.
- The College will continue to promote autopsy data as a form of quality control for cause-of-death statistics and will encourage interaction and collaboration with the physician certifiers.

#### *International Association of Coroners and Medical Examiners*

There are approximately 300 active members of the International Association of Coroners and Medical Examiners, most of whom are physicians and pathologists.

- Efforts will be made to add a segment on cause-of-death certification to a course which is being developed for 50 coroners and medical examiners in conjunction with the Federal Bureau of Investigation's (FBI) Training Academy. This course, which is scheduled for 1990, is the second of its kind conducted with the Academy.
- The Association will support efforts to reverse the order of sequence of diagnoses on the medical certification.

## *Joint Commission on Accreditation of Healthcare Organizations*

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) accredits 80 percent of hospitals. The primary function of JCAHO is education, not regulation.

- The JCAHO Agenda for Change is promoting development of indicators for quality assurance and a data base monitoring system. This includes a natural interest in improving the quality of vital statistics.
- The *Quality Review Bulletin* is interested in publications related to quality issues, which could include cause-of-death statistics.
- Recommendations from the workshop could be published in the organization's official organ, *Perspectives*.
- The Joint Commission could consider developing standards on the use of vital statistics information in the hospital quality assurance process.
- The JCAHO recommends a standard on turnaround time for completion of autopsies.

## *National Medical Association*

The National Medical Association (NMA) represents 16,000 black physicians and has a major interest in health care for the poor and minority populations. At the most recent NMA national meeting, the membership expressed concern about the declining autopsy rate and the poor quality of death certificates and called for a national meeting on the subject.

- The NMA will continue to push for a national meeting to spread the message that autopsies are valuable and death certificates are important sources of information. This workshop was a significant first step but should be followed by a broad-based national effort with all interested parties.
- The NMA would like to be included in all educational activities resulting from this workshop.
- The representative will write an article about the workshop for the NMA newsletter and will encourage preparation of a scientific article for the *Journal of the National Medical Association*.
- The Quality Assurance Task Force of NMA is considering whether it would be useful to have a "second opinion" on the cause of death by an individual who is knowledgeable about medical certification of death.
- The death certification process should be examined as it relates to poor and minority people. The representative expressed disappointment that the workshop recommendations did not include his proposal to add a category on income to the death certificate. He stated that it was essential to distinguish income-related disease from minority-related disease.
- Autopsy results must be made available in a timely manner so they can be useful for education.

## *National Association of Medical Examiners*

- The representative of the National Association of Medical Examiners (NAME) will share the results of this workshop with the NAME Board and membership and seek opportunities to involve the organization in the recommended educational programs.
- The NAME will attempt to make other medical examiners aware of the querying process, and will encourage them to work with the State registrars to educate physicians about the importance of cause-of-death certification.

Dr. Blankenbaker responded to the statements of the organizational representatives by promising to push forward the process for full consideration of the workshop recommendations. He thanked the participants for their interest, enthusiasm, and hard work during the 3-day meeting and stated that the results of the workshop had far exceeded his expectations.

A draft of the recommendations would be shared with the full NCVHS membership at its upcoming November 1-3, 1989, meeting. Subsequently, a complete draft report would be sent to all workshop participants for review. Following the review process, a final report would be presented to the National Committee at its February 7-9, 1990, meeting. It is expected that NCVHS would then transmit the report, with comments, to the Assistant Secretary for Health.

The NCVHS will monitor progress on all the recommendations from the workshop and assist the public and private organizations in any way it can. Dr. Blankenbaker acknowledged that additional work was necessary to develop several recommendations and to examine outstanding issues, but noted that many of the suggestions could be acted upon promptly.

Dr. Blankenbaker reported that the American Academy of Family Physicians had not been able to attend the workshop but had agreed to publish an article or editorial on the results of the meeting in its journal. In light of the many similar commitments by participating organizations, preparation of a press release or article on the workshop would have high priority.

Dr. Feinleib concurred with Dr. Blankenbaker on the success of the workshop and expressed the hope that resources would be available to carry out the many excellent recommendations. Recognizing the tremendous need to educate physicians, policy-makers, and the public about the importance of cause-of-death statistics, Dr. Feinleib committed NCHS to a leadership role in developing more effective approaches for analyzing and disseminating mortality data.

In addition to the many other forms of communication recommended by the workshop participants, Dr. Feinleib said that he would include a discussion of the workshop results in his quarterly "Notes from the Director," which is sent to the directors of the 46 designated State centers for health statistics, the remaining States

and registration areas, and other interested organizations. Dr. Feinleib also noted the need for additional followup meetings.

Responding to the concern of the National Medical Association, Dr. Feinleib acknowledged the importance of linking mortality and other health status and outcome data with socioeconomic characteristics. He observed that some analyses have been performed using educational level but that additional opportunities for data collection and analysis should be explored in the periodic mortality followback surveys conducted by NCHS.

As an outgrowth of the workshop discussions, Dr. Feinleib intended to write to the editor of the *New England Journal of Medicine* to suggest that the Weekly Clinicopathological Exercise published in the *Journal* show a completed cause-of-death certification when the case described has died. He also suggested that this approach be used in the materials for the IPAC program described by the AAMC representative.

Dr. Feinleib concluded by expressing his personal aim that the United States will enter the 21st century with a first-rate mortality data system that can be a model for other countries.

# WORKSHOP ON IMPROVING CAUSE-OF-DEATH STATISTICS

## AGENDA

**SUNDAY, OCTOBER 15, 1989**

5:30 p.m.–7:30 p.m.

**REGISTRATION**

7:30 p.m.–8:00 p.m.

**WELCOME**

Dr. Manning Feinleib  
Director  
National Center for Health Statistics

Dr. Ronald G. Blankenbaker  
Chairman  
National Committee on Vital and  
Health Statistics

8:00 p.m.–9:00 p.m.

**KEYNOTE ADDRESS**

Dr. John Smialek  
Chief Medical Examiner  
State of Maryland

9:00 p.m.

**ADJOURN**

**MONDAY, OCTOBER 16, 1989**

8:30 a.m.–10:00 a.m.

**PLENARY SESSION:  
EXPERT PANEL ON THE ISSUES**  
(for example, Validity Training, Querying  
Confidentiality)

**Chairperson:**

Dr. Richard Havlik  
Office of Planning and Extramural Programs  
National Center for Health Statistics

**Panel Members:**

Mr. George H. Van Amburg  
Department of Public Health  
State of Michigan

Dr. Patricia Potrzebowski  
Department of Health  
State of Pennsylvania

Dr. Lewis Kuller  
Department of Epidemiology  
University of Pittsburgh

Dr. Susan Miller  
Division of Geriatrics  
George Washington University  
School of Medicine

Ms. Judith Randal  
Reporter

10:00 a.m.–10:30 a.m.

**COFFEE BREAK**

10:30 a.m.–12:00 noon

**BREAKOUT SESSIONS  
TO DISCUSS THE ISSUES**

Breakout Session A  
Breakout Session B  
Breakout Session C

12:00 noon–1:30 p.m.

**LUNCH**

1:30 p.m.–3:00 p.m.

**BREAKOUT SESSIONS  
TO IDENTIFY SOLUTIONS**

Breakout Session A  
Breakout Session B  
Breakout Session C

3:00 p.m.–3:30 p.m.

**COFFEE BREAK**

3:30 p.m.–5:00 p.m.

**PLENARY SESSION:  
CHAIRPERSON'S PROGRESS REPORT**

**Chairperson:**

Dr. James Weed  
Division of Vital Statistics  
National Center for Health Statistics

5:00 p.m.

**ADJOURN**

5:30 p.m.–7:00 p.m.

**SOCIAL**

**TUESDAY, OCTOBER 17, 1989**

8:30 a.m.–10:00 a.m.

**BREAKOUT SESSIONS TO PREPARE  
RECOMMENDATIONS**

Breakout Session A  
Breakout Session B  
Breakout Session C

10:00 a.m.–10:30 a.m.

**COFFEE BREAK**

10:30 a.m.–12:00 noon

**PLENARY SESSION:  
GENERAL DISCUSSION OF  
RECOMMENDATIONS AS PRESENTED  
BY CHAIRPERSONS**

**Chairperson:**

Mr. George Gay  
Division of Vital Statistics  
National Center for Health Statistics

12:00 noon–1:00 p.m.

**WORKING LUNCH**



1:00 p.m.–2:30 p.m.

**PRESENTATION OF RESPONSES BY  
ORGANIZATIONAL REPRESENTATIVES**

**Chairperson:**

Dr. Ronald G. Blankenbaker  
Chairman  
National Committee on Vital and Health  
Statistics

2:30 p.m.–3:00 p.m.

**CONCLUDING REMARKS**

Dr. Ronald G. Blankenbaker  
Chairman  
National Committee on Vital and Health  
Statistics

Dr. Manning Feinleib  
Director  
National Center for Health Statistics

3:00 p.m.

**ADJOURN**

# **WORKSHOP ON IMPROVING CAUSE-OF-DEATH STATISTICS**

## **PARTICIPANT LIST BY ORGANIZATION**

### **CENTERS FOR DISEASE CONTROL**

Ronald E. Aubert, Ph.D.

Susan Chu, Ph.D.

Roy T. Ing, Ph.D.

Deborah Landen, M.D.

Roy Gibson Parrish, M.D.

Joyce Salg, Ph.D.

Mr. Jack C. Smith

Steven L. Solomon, M.D.

### **NATIONAL CENTER FOR HEALTH STATISTICS**

Manning Feinleib, M.D., Dr.P.H.

Gail F. Fisher, Ph.D.

Mr. George A. Gay

Ms. Marjorie S. Greenberg

Ms. Nancy G. Hamilton

Richard Havlik, M.D.

Mr. Richard J. Klein

Ms. Julia Kowaleski

Mr. John Patterson

Harry Rosenberg, Ph.D.

Ms. Joyce Scott

James Weed, Ph.D.

### **HEALTH CARE FINANCING ADMINISTRATION**

Kathy Weis, Dr.P.H.

### **STATE REPRESENTATIVES**

State of Colorado

Joseph Carney

State of Connecticut

Ms. Kathryn Church

State of Pennsylvania

Patricia W. Potrzebowski, Ph.D.

State of South Carolina

Jacqueline Dickman, Esq.

State of Tennessee

Ms. Paula E. Taylor

State of Vermont

Ms. Mary Anne Freedman

State of Wisconsin

Raymond D. Nashold, Ph.D.

#### **ASSOCIATIONS REPRESENTATIVES**

American College of Physicians

David Borofsky, M.D.

American Geriatrics Society

Susan J. Miller, M.D.

American Hospital Association

Deborah Bohr, M.P.H.

American Hospital Association

Ms. Monica Dreuth

American Medical Association

Frederik C. Hansen, Jr., M.D.

American Medical Record Association

Rita Finnegan, R.R.A.

Association of American Medical  
Colleges

Douglas E. Kelly, Ph.D.

Association of State and Territorial Health  
Officials

C.M.B. Buttery, M.D., M.P.H.

College of American Pathologists

Tobias Kircher, M.D.

International Association of  
Coroners and Medical Examiners

Mr. Herbert H. Buzbee

Joint Commission on Accreditation  
of Health Care Organizations

Robert J. Marder, M.D.

National Association of Medical  
Examiners

John Smialek, M.D.

National Medical Association

Jesse B. Barber, M.D.

**NATIONAL COMMITTEE ON VITAL AND HEALTH  
STATISTICS**

Ronald G. Blankenbaker, M.D.

Mr. George H. Van Amburg

**REPORTERS**

Mr. William Hines

Ms. Judith Randal

**UNIVERSITY OF PITTSBURGH**

Lewis Kuller, M.D.

**LIST OF BACKGROUND PAPERS FOR  
WORKSHOP ON IMPROVING CAUSE-OF-DEATH STATISTICS**

*State Activities Related to Improving the Quality of Cause-of-Death Data*

*The Nature and Accuracy of Cause-of-Death Data*

*The Impact of Cause-of-Death Querying*

*Mechanisms By Which Cause-of-Death Data Get to the Policymaker*

Copies of these papers are available from:

Division of Vital Statistics  
National Center for Health Statistics  
6525 Belcrest Road  
Hyattsville, Maryland 20782

# Appendix VI.

## Report of the Subcommittee on Medical Classification Systems Concerning Issues Relating to the Coding and Classification Systems

### Executive Summary

The creation, review, and revision of health care policy relies on the availability of accurate and timely health care data generated by both providers and payers of health care and by statistical surveys and other research efforts. The key element of these information systems is the classification used to interpret and analyze patients' health care encounters. The *International Classification of Diseases (ICD)* (1) has traditionally served this role in the United States with adaptations of the international volume seeking to address interests of morbidity as well as mortality (2).

The *ICD* traces its heritage to mortality classification, that is, the internationally agreed upon set of rubrics used to report causes of death. Mortality classification was its original intent; however, in the United States, congressional and regulatory mandates have forced the largest and most consequential use of the data: provider reimbursement. Long-term stability so desirable in a research classification (the *ICD* has adhered to a traditional decennial revision schedule) is viewed as deficient and rigid when the classification system is considered for utility and equity of reimbursement.

Health care data, once synonymous with hospital inpatient statistics, have broadened in definition to encompass the complex requirements of multilevel health care programs. This increasing heterogeneity of data applications and the broad interchange of data among providers, payers, and so forth, coupled with current technology, has nourished the health care consulting industry and the vendor community which produces computer hardware and software to support it.

Given that the *ICD* is a nucleus of health information systems, the Subcommittee on Medical Classification Systems (henceforth referred to as the Subcommittee) of the National Committee on Vital and Health Statistics (NCVHS) reviewed chapter proposals from the World Health Organization (WHO) and preliminary international implementation plans for the 10th revision of the *ICD*. Particular attention was focused on whether or not the content and structure of the document itself could meet United States data needs. Special emphasis was placed on the appropriateness and adequacy of current structures to implement and maintain a classification in an environment rife with competitive diversity.

The Subcommittee sought to carry out its charge through public testimony, staff research and comment, and work group discussions. The following recommendations result from the last 4 years of the Subcommittee's efforts:

- The coordination and maintenance function should be expanded to include active participation of the private sector as members of the Coordination and Maintenance Committee.
- Development and approval of coding guidelines should be conducted in a public forum such as the Coordination and Maintenance Committee and be representative of a widely participative process.
- Guidelines should be transferable to all sites of services.
- The integrity of the classification should be maintained through administrative procedures consisting of the identification of a source(s) authorized to meet defined responsibilities that include, but are not limited to:
  - control of code assignments beyond the fourth and fifth digits;
  - development and interpretation of national coding guidelines, including those in the ambulatory setting;
  - dissemination of these guidelines for all uses of the classification, including automated uses, to ensure safe harbor for those who voluntarily comply with approved guidelines;
  - the conduct of evaluation programs to monitor accuracy of coding (data quality issues);
  - receiving and disseminating coding information; coding problems; requests for changes, modifications, interpretations, and revisions of guidelines; and adjudicating disagreements.
- Identification of a process to determine the definition of government or nongovernment uses of *ICD-10* must be articulated, as well as the procedure to apply for consideration of these uses.
- Continuous education programs for all user groups, including physicians, should be made a priority.
- An evaluation program to assess the accuracy of medical coding and the interface of data set definitions and *ICD-10* in non-acute settings should be established.
- There needs to be an ongoing study and evaluation to determine the efficacy of a single procedure coding system.

## Introduction

The *International Classification of Diseases (ICD)* began as the International List of Causes of Death. Published in 1893, it underwent minor modifications to accommodate its initial limited use. Over time, the creation and maintenance of the *ICD* became the responsibility of the World Health Organization (WHO).

Although succeeding revisions of the *ICD* have seen the incorporation of increasing clinical detail, its foundation as a mortality classification (with etiology of disease as the primary axis) supports its utility as a tool for vital statistics reporting. Until the 10th revision, which reflects a 15-year hiatus from its predecessors, the *ICD* has

maintained a decennial revision schedule. The content of the *ICD* is determined by a WHO voting structure representing participating member countries, and is influenced by the inherent politics of such an arrangement. Traditionally, member countries have been represented by statisticians and epidemiologists. Thus, the epidemiologic bias has continued to be favored over the more recent interest of the clinician. In the United States, for example, the National Center for Health Statistics (NCHS) has authority for the classification because of its use in morbidity and mortality statistics.

The 10th revision of the *ICD* is due to be implemented by WHO in 1993. In the meantime, the adequacy of *ICD-10* to meet both morbidity and mortality requirements must be evaluated. A thorough evaluation must address not only the structure, content, and format of the volume itself, but its implementation plan, maintenance schedule, and training programs.

### **History of the United States Modification of the *ICD***

The United States has taken the lead in modifying the *ICD* for morbidity use. Initially, independent modifications were developed by different groups for multiple purposes and, although these were similar (relying on the subdivision of existing *ICD* codes), they were not the same. The increasing use of the *ICD* for hospital indexing led to a federally funded study (3)<sup>1</sup> in 1956, the results of which supported the use of the *ICD*. Recognizing that multiple adaptations of the same classification compromised the collection of uniform data, NCVHS supported a single modification and appointed a small working party, composed primarily of medical record practitioners, to be responsible for its creation.

The efforts of the working party culminated in the first *International Classification of Diseases Adapted for Indexing Hospital Records by Diagnosis and Operation (ICDA)*. The *ICDA-7* (the "A" representing adapted for use in the United States) added greater levels of clinical detail and a procedure classification. The procedure classification is not an integral part of the WHO volume, but serves as an adjunct only to the United States' adaptations of the *ICD*. The unadapted, unmodified version of the *ICD* continued to be used to report mortality data in conformance with international treaty agreements governing the exchange of such information.

The 8th revision of the *ICD* brought about two separate, dissimilar adaptations in the United States. The U.S. Public Health Service issued an adaptation, *ICDA-8*, with expanded clinical detail, but designed for general use for both mortality and morbidity. The Commission on Professional and Hospital Activities (CPHA)

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<sup>1</sup>The report of the collaborative study between the American Hospital Association and the American Association of Medical Record Librarians (now AMRA) is entitled: "Efficiency in Hospital Indexing of the Coding Systems of the International Statistical Classification and Standard Nomenclature of Diseases and Operations." *Journal of the American Association of Medical Record Librarians* 30(95):110-111, 129. 1959.



created a second adaptation, adding more detail and removing rules peculiar to mortality coding. A subsequent second edition of the hospital adaptation of the *International Classification of Disease Adapted (HICDA)* was published in 1973 and further compounded the problem of disparate classification.

Although there was general recognition that the utility of data collected using different classifications was compromised, nowhere was this more keenly felt than in the public sector and the research community.

With the advent of the Medicare program and other publicly funded health care initiatives, such as Medicaid, Peer Review Organizations (PRO's), and such health planning programs as Regional Medical Programs and Health Systems Agencies, reliance on coded data as the basis for public policy became the standard. Unfortunately, the data gathered were often in different formats and not accurately translatable from one format to another. The expectation was that the publication of *ICD-9* would provide a single classification to replace *ICDA-8* and *HICDA-2*.

Although *ICD-9* provided greater levels of detail and clearly recognized the need to provide for classification of ambulatory care encounters, internal structural problems formed compelling arguments for an adaptation. The adaptation became known as a clinical modification or *ICD-9-CM*. The *ICD-9-CM* was created under the auspices of NCHS through a cooperative effort between the government and the private sector. The NCHS and HCFA have remained in charge of official adaptation or modification in the United States.

Recent years have seen an increasing interest in the *ICD-9-CM* classification by the clinical community, an interest that has expressed itself in the creation and publication of classifications for physician specialty use. These are as yet "unofficial" because no federal agency has exercised authority over them, nor has any federal agency approved them for legitimate inclusion in required data sets (for example, UB-82 (Uniform Bill) and Uniform Hospital Discharge Data Set (UH-DDS)).

## Uses of Coded Data

The original impetus for adaptation or modification was the support of hospital indexing. This, in turn, supported research and local (individual institution) planning efforts. However, by the mid-1960's the health data environment had changed. Computer technology made the collection, storage, and electronic transfer of information available on demand. Discharge abstract systems carried much of the responsibility for processing, formatting, and verifying the data; they literally became the data processors for many hospitals. Decisions were being made on coded data rather than on the narrative text of the diagnoses themselves. Expansion of health data policy, beginning with Medicare, accelerated the need for accurate and reliable data. For these purposes, the codes needed to reflect more clinical specificity than those needed only for statistical grouping and trend analyses.

Concern over the rising cost of health care, particularly the Medicare program, resulted in the creation of the prospective payment system (PPS) for Medicare, a system that was based on the diagnosis and procedure code used to describe a patient's hospital stay. Renewed attention was therefore focused on the code and the accuracy with which it was used. Incomplete or inaccurate data in a cost reimbursement environment lacked the financial consequences of the same omissions or inaccuracies in the PPS, wherein an inaccurate code could either eliminate or seriously decrease reimbursement for a hospital stay.

The PPS was based on a fixed fee for diagnosis or surgical procedure determined by diagnosis-related groups (DRG's). DRG's grouped over 1,400 *ICD-9-CM* diagnosis codes into 468 groups, each of which shared some similar characteristics. However, although each group shared similar features, many were heterogeneous; concern for the ability to discriminate a diagnosis or surgical procedure with a unique code joined the concern for coding accuracy. The HCFA, as the authoritative body for the Medicare program and for the DRG system, also had an interest in the use of codes and the need to modify and update the *ICD* classification system.

A mechanism to modify the classification was required if a mortality classification were to be used for reimbursement. Hospitals were well used to the coding conventions for DRG's and, in fact, the provider community—first hospitals and then physicians—had equal concern. The catastrophic health insurance program, which required physicians to code diagnosis, focused attention on the institutional bias surrounding the structure and maintenance of the codes. Although *ICD-9-CM* could classify any health care encounter, the guidelines for its use made it difficult to clearly differentiate a true diagnosis from a “rule out” diagnosis in the physicians' office.

With decisions being based on codes, issues of coding accuracy and specificity were often mixed with issues of access to care and financing of health care. In an attempt to address the often competing uses of statistical research and reimbursement, the authority for the classification became a shared responsibility between HCFA and NCHS. The lines of bifurcation are not always clear.

## Findings

### Maintenance of the Classification

*ICD-9-CM Coordination and Maintenance Committee*—The utility of the classification in today's environment is dependent upon its ability to be updated. Updates are needed to: (a) add new information; (b) correct errors; and, (c) reclassify or clarify diagnosis (for example, respiratory failure). The impetus for these updates may come from identified current needs or as a result of the changes in content of the new classification. Updating the existing code permits experience to be accumulated before the new code goes into effect.

The ICD-9-CM Coordination and Maintenance Committee was established in September 1985 to provide a mechanism for reviewing and updating the *ICD-9-CM* classification system. The charter (4) for the committee states that its functions are:

- To consider errata and/or addenda, as well as other modifications of *ICD-9-CM*, to reflect new procedures and technology, newly identified diseases, and coding problems.
- To promote the use of Federal and non-Federal educational programs and other communication techniques toward standardizing coding applications and upgrading the quality of coded medical data.

The charter established the structure of the committee which would be co-chaired by a representative from NCHS and one from HCFA. Other members include representatives from the Veterans Administration (now the Department of Veterans Affairs) and Department of Defense. Attendance by the private sector, including the American Hospital Association (AHA), the American Medical Record Association (AMRA), physician specialty groups, the American Medical Association (AMA), CPHA, and many others is encouraged.

The final authority is a decision-sharing process between the Director of NCHS and the Administrator of HCFA. Prior to the finalization of a revision, HCFA evaluates the need for modifications to the Grouper, Medicare Code Editor, and the Peer Review Organization (PRO) activities. Announcements of proposed changes to the *ICD-9-CM* classification system are printed in the *Federal Register* several months prior to implementation in order to inform the public of and receive comments from the public about planned changes to *ICD-9-CM*. A final rule is published in September with an implementation date for the changes. Revisions are also publicized through such channels as the Government Printing Office, government transmittals to hospitals and PRO's, and journal publications such as the *Journal of the American Medical Record Association and the Coding Clinic for ICD-9-CM*.

*The AHA Central Office on ICD-9-CM*—The 1962 agreement establishing the Central Office on *ICD-9-CM* stipulated that the Central Office was to be maintained and staffed by AHA in cooperation with AMRA. The relationship between NCHS and AHA was further defined to include:

- concurrence of NCHS in the selection of the director of the Central Office;
- representation of NCHS on an "advisory committee" along with AMRA and AHA;
- close working relationship between NCHS and AHA to "assure consistency of interpretation of the basic principles of the [ICD] and to prevent any wide divergence between ICDA and the basic *ICD* "; and
- ongoing communication link between NCHS and the AHA Central Office on "activities bearing directly on the use of the ICDA in hospitals." (5)

Originally, the central office answered coding questions submitted to member hospitals, and its director wrote a regularly published coding column for the *Journal*

of the American Medical Record Association. The column contained coding advice on specific questions related to diagnoses and procedures and on the creation or explanation of coding guidelines.

The recent PPS focus on accuracy and timeliness of codes resulted in a deluge of coding and diagnosis code sequencing questions directed to the central office. The AHA's publication of the *Coding Clinic for ICD-9-CM* was based on the accumulation of coding questions and coding guideline development. Although AHA's central office had achieved an informal "official" status, others—AMRA, data systems, PRO's, and so forth—published answers to coding questions and freely gave coding advice. These publications were often in conflict with one another and the need for a single authoritative source quickly became apparent.

*Cooperating parties*—In 1985, the principal players in the classification field representing the public and private sector interests formed a federally recognized informal partnership known as the "cooperating parties." The members—NCHS, HCFA, AMRA, and AHA—assume the following four responsibilities:

- To serve as a clearinghouse to answer questions on *ICD-9-CM*;
- To develop educational materials and programs on *ICD-9-CM*;
- To work cooperatively with AHA, NCHS, HCFA, and AMRA in maintaining the integrity of *ICD-9-CM*; and
- To recommend revisions and modifications to current and future revisions of *ICD*. (6)

The work of the cooperating parties was supplemented by the AHA Editorial Advisory Board for *Coding Clinic*, which was composed of representatives from hospitals, health data systems, and the Federal Government. It was an enlargement of AHA's long standing advisory board to the central office. Representation on the Editorial Advisory Board consisted largely of acute care hospitals reflecting both the source of the questions and the issues then at hand. Current trends, however, reflect a major shift in health care from the inpatient setting to outpatient ambulatory care or other alternate care settings. Acknowledging this shift and in recognition of the legislation requiring physician offices to submit codes on Medicare bills, the Editorial Advisory Board was expanded in 1989 to include physician representation.

*Vendor products*—Although systematic approval channels have been created for publication of official codes and guidelines, no such mechanism exists for vendor software materials. The widespread use of software (encoders, groupers, and so forth) introduces a new ingredient not present in earlier versions of the classification. Health care facilities and others rely on vendor support for system maintenance and updates, yet no mechanism for review and approval of those ancillary materials currently exists. The Subcommittee recognizes the need for such a review, but further study is required before a recommendation can be made.

*National Committee on Vital and Health Statistics*—The National Committee on Vital and Health Statistics (NCVHS) has a long history of involvement in coding and classification issues and was formally designated by AHA and NCHS, in the

agreement signed in December 1962, to serve as a mechanism through which the U.S. Public Health Service will "continue its responsibility for future revisions and official publication of such revisions." (5) This responsibility was delegated to one of the subcommittees of the Committee. Initially, this was in the purview of the Subcommittee on Disease Classification and Automated Coding of Medical Diagnoses, established in 1983.<sup>2</sup> In 1987, the Subcommittee's name was changed to the Subcommittee on Medical Classification Systems<sup>3</sup> to reflect the expansion of the Subcommittee's focus to medical classification systems, including, but not limited to, the scope of the *ICD*.

Subcommittee on Disease Classification and Automated Coding of Medical Diagnoses—The Subcommittee was charged primarily with reviewing developments in the disease classification systems and their effects on complex interrelationships in the private, public, and international sectors and with assessing where close coordination and independent development can proceed.

In carrying out its charge, the Subcommittee received public testimony from many organizations representing both private and public sectors. Presenters voiced their concerns about the medical, political, economic, and technical issues surrounding the classification and coding of diseases and procedures. Many expressed concern about the process for the Tenth Revision of the *ICD* (7).

The Subcommittee also received public testimony from various organizations involved in the development, maintenance, and use of procedure codes and learned that WHO had no plans for additional work on the taxonomy of procedures.

Two procedure codes were in common use: *Current Procedural Terminology-4* (*CPT-4*), which was created and maintained by the American Medical Association (AMA) for physician reimbursement, and *ICD-9-CM Volume 3*. The structure and intent of the two classifications differed and neither worked as well for purposes for which it was not intended. *ICD-9-CM* was often found wanting for reimbursement when technology, surgical skill, and/or time were not discriminated with specific rubrics. Conversely, *CPT-4* was problematic when describing specifics of a procedure for outcome analysis. For example, hysterectomy, as defined in *CPT-4*, includes that with or without removal of tubes and ovaries. Because *CPT-4* was required for Medicare outpatient claims (Part B) and *ICD-9-CM* for inpatient data (Part A), it meant that providers (hospitals) had to code the same data in two separate formats. The Subcommittee, in recognizing not only this cost burden but the difficulty of analyzing data in different formats, recommended the development of a common procedure coding system for the United States to be used for physician fee-for-services and hospital inpatient care reimbursement.

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<sup>2</sup>Subcommittee members were: Walter P. Bailey, Chairman (1985); Robert H. Barnes, M.D., Chairman (1983–85); Theodore Allison; Richard V. Bibbero; William R. Felts, Jr. M.D.; Carmault B. Jackson, Jr., M.D.; Grayson B. Miller, Jr., M.D.; and Nicole Urban, Sc.D.

<sup>3</sup>Subcommittee members are: Karel M. Weigel, R.R.A., Chairman; William R. Felts, Jr., M.D.; Joseph Martin; Robert Mullin, M.D., and Bruce Steinwald. Carmault B. Jackson, Jr., M.D., is a former member of the Subcommittee.

Further, the Subcommittee supported the need to update the *ICD-9-CM* procedure codes in view of the advances in medical technology occurring in the past decade and their importance to the Diagnosis Related Group (DRG) system, which is used to determine hospital reimbursement. To address this need, the Department of Health and Human Services (DHHS) established, in September 1985, the previously described ICD-9-CM Coordination and Maintenance Committee.

*Subcommittee on Medical Classification Systems*—The original Subcommittee underwent a name change and some modification of its charge. In addition to other responsibilities, the Subcommittee was charged to work with and to review the *ICD-9-CM* process “to ensure the utility and integrity of the [classification system] in its broadly based multi-use applications throughout the United States” (8). The Subcommittee’s initial charge was broadened to incorporate a liaison function with the ICD-9-CM Coordination and Maintenance Committee to identify major needs for modifications, additions, or deletions to the *ICD-9-CM* diagnosis and procedure codes (8, p.5).

In anticipation of the development and implementation of the *ICD-10*, the Subcommittee was further charged to review:

“[t]he progress of the development of the *ICD-10*; to review and evaluate areas where conflicting proposals emerge, and to participate in the development of recommendations that are most compatible with priority concerns in the U.S.”

“[t]he progress of international decisions regarding *ICD-10* as related to needs in the U.S. that would require the development of an *ICD-10-CM*. To consider alternative mechanisms and suggested time tables if an *ICD-10-CM* were perceived as necessary” (8, p.27).

Since its reorganization, the Subcommittee has held nine meetings in Washington, D.C.; two of these preceded the WHO Heads of Centers meetings to consolidate the United States input to the draft proposals for the Tenth Revision of the *ICD*, to ensure compatibility with the Nation’s priority concerns. The objectives of subsequent Subcommittee meetings progressed from the level of clinical technical input initiated earlier to the procedural issues surrounding implementation of a new classification.

To meet these goals, the Subcommittee received public testimony from representatives of private and public sector organizations who provided updates on *ICD-10* development and articulated their concerns over the implementation process. Testimony covered the following major issues related to *ICD-10*:

- Current status of *ICD-10*.
- Specialty-specific classifications.
- Implementation of *ICD-10* in the public and private sectors.
- Procedure classification.

## International Classification of Diseases (ICD-10)

According to current estimates, the Tenth Revision of the *ICD* is scheduled for mortality implementation in January 1993 and morbidity implementation in October 1995. The difference in implementation dates notwithstanding, *ICD-10* will be introduced into an environment vastly different from any of its predecessors:

- National requirements for the use of *ICD* codes have relied on adaptations or modifications. There are no current plans for a systematic adaptation of *ICD-10*; periodic updates will be used to satisfy that need.
- The code forms the basis of all reimbursement systems, hospital inpatient, ambulatory care, probably the physician office, and undoubtedly alternate care settings as well. The consequences of inaccurate data are greater than ever before.
- The WHO has exercised copyright restrictions on *ICD-10* to preserve its integrity and recover some of the cost. The operational mechanisms for dealing with copyright restrictions have not been spelled out. Testimony provided to the Subcommittee indicated concern over such issues as the copyright agreement (for example, who will determine the definition of a Government use); which agency in the Government would produce or authorize a modification; how commercial vendors will receive approval to produce material; what operational mechanisms will adjudicate differences; and how will physician specialty groups receive official approval from any U.S. authority or from WHO.
- Vendor software provides system maintenance for most users.
- Coding is no longer the sole province of hospitals; the "coder community" has expanded exponentially beyond initial *ICD-9-CM* estimates. Initial and ongoing education needs and efforts will be massive.
- In a related item, the format of *ICD-10* from WHO is not familiar to U.S. morbidity users. Therefore, increased educational efforts or a reprinting of the volume (copyright permitting) will be required.

Continued planning must be done in cooperation with WHO, but especially within the United States, to provide for morbidity applications. The issues delineated above are not trivial. The Subcommittee has attempted to address some of these issues as part of its recommendations.

*United States implementation of ICD-10*—In September 1989, a draft of *ICD-10* was approved by participants at the WHO Revision Conference and was subsequently approved by the World Health Assembly in May 1990. The WHO has made plans to fully implement *ICD-10* by 1993. The HCFA has stated that the earliest possible implementation of *ICD-10* for morbidity applications in the United States would be October 1995. Although the implementation date for mortality applications has not been finalized, the starting date will be later than 1993; NCHS has begun to make plans to produce *ICD-10* data retroactively to 1993, the official WHO starting date. Concern has been expressed about the different implementation dates and the impact on resources in the States. The Subcommittee has agreed to pursue this matter further.

In March 1990, the Heads of Centers' meeting convened to finalize implementation plans for *ICD-10* and set the following timetables for publication and release of the volumes (in either print or electronic form) (9):

Tabular List in English	end of June 1990
Instructions Volume	mid-November 1990
Alphabetical Index	end of February 1991

A decision as to whether there will be a clinical modification for *ICD-10* has not yet been made. However, recommendations for the development of such a modification have been suggested by some users from both the public and private sectors. Providing for morbidity application in *ICD-10* may not demand an extensive structural modification, but may likely be focused on several key issues:

- The need for and use of fifth characters in *ICD-10*.
- Modification of instructional notations designed for mortality coding for application to morbidity.
- Insertion of rubrics added to *ICD-9-CM* and not provided for in *ICD-10 (10)*.
- Efforts to create a systematic modification of *ICD-10* will match or exceed those undertaken for *ICD-9-CM* in 1978 (3 years with a core staff of about 30 and a cost approaching \$2 million). Delaying a decision for a full modification will result in increased consumption of staff and financial resources.

Modification may take the form of periodic updates. The North American Center for Classification of Disease introduced a proposal for establishing a system of updating *ICD-10* on an annual basis (11). Essentially based on the *ICD-9-CM* Coordination and Maintenance Committee system, the proposal suggests three basic guidelines to determine whether modification is necessary:

1. The modification should be made to preserve comparability with existing data; thus, most modifications will be made by adding a fifth character to an existing four character code.
2. All modification to the classification must be clinically correct, and extensive supporting documents will be required.
3. All modifications to the classification must follow the *ICD* principles and *ICD-9-CM* organization and format.

The impact of the changes will be monitored, and conversion tables will be prepared to ensure the maintenance of continuity of the data.

*Copyright restrictions*—During its negotiations with participating countries, WHO decided to copyright *ICD-10* to preserve its integrity as well as to recover some of the financial costs incurred by the organization in producing the *ICD*. The Subcommittee was concerned about the impact that a copyright on *ICD-10* would have on the cost and use of the *ICD* in the United States and on many of the considerations regarding acceptable format, updating, and correction of the volumes and dissemination of the *ICD* in other forms.

At the November 1988 meeting of the NCVHS, the Subcommittee on Medical Classifications Systems recommended, and NCVHS endorsed, the important



concept that there be no copyright by WHO that would impede the use of *ICD-10* in this country (12).

After receiving legal advice from the DHHS Office of the General Counsel concerning WHO's legitimate right to invoke copyright law on the work, a letter, requested by the Subcommittee and endorsed by NCVHS, was sent by the DHHS to the Director General of WHO requesting the need for clarification of the copyright and any restrictions it would impose on U.S. health policy administrators, professional societies, and health institutions to use or modify *ICD-10*.

After months of extensive negotiations between the United States and WHO, a decision was made to exempt the United States from copyright restrictions provided that *ICD-10* is used for U.S. government purposes. It further authorized the United States to adapt *ICD-10* "to meet specific requirements for the management of its health services ..." provided that any proposed changes or modifications be routed to WHO for "its comments and possible alternative proposals ..." (13).

Although the agreement appears to be far less restrictive than the earlier versions, some serious operational concerns still remain, notably:

- Which agency in the government would produce or authorize a republication or modification of *ICD-10*?
- Modification of existing *ICD-10* rubrics at the three and four character level will require considerable consultation with WHO. This has implications for the timeliness of modifications through the current coordination and maintenance process.
- How will commercial vendors (as agents of the U.S. Government) receive official approval to produce materials?
- Government use is not a single definition:
  - HCFA has jurisdiction over reimbursement issues for Medicare;
  - NCHS has jurisdiction over mortality and morbidity statistical data;
  - What role will the Agency for Health Care Policy and Research play?
- According to the agreement, DHHS will resolve issues that may arise over whether applications or modifications are consistent with classification standards. What are the operational mechanisms to provide this assurance?
- Under the terms of the agreement, physician specialty societies who expand descriptors of codes may need copyright relief.

Each of these issues pose questions for resolution as progress continues to be made toward implementation of *ICD-10*.

*Implementation in the public and private sectors*—The *ICD-10* revision schedule was lengthened from the usual 10-year cycle to 14 years to take maximum advantage of users' experience with *ICD-9*. This provides an exceptional opportunity to plan for the implementation of *ICD-10* in such a way as to take full benefit from the lessons

learned from *ICD-9* and *ICD-9-CM*. The decision for a modification to *ICD-9* was made so late that the work itself consumed several years and seriously contracted the lead time from publication to implementation. The intervening years, however, have seen a profound increase in the complexity of the classification issues. The reimbursement system, research programs, health planning initiatives, and quality assurance activities all rely on coded data for decisions. Both these and the changing dynamics of the health care delivery system have contributed to the growth and visibility of vendor software. Singularly or in combination, all of these demand early availability of a new code and computer compatible support materials. In consideration of those issues, the impact of a modification and the time required for its creation would be greater than was experienced with *ICD-9-CM*.

Although the work to implement the actual classification and its related materials (that is, conversion tables, data edit programs, and so forth) is substantial, equal effort must be directed to the following related areas:

1. *Education* : Testimony provided to the Subcommittee and a followup discussion focused on the need for a commitment to provide required programs for all user groups, including physicians and those concerned with data input and data analysis.

The issue of establishing a continuous coder education process was discussed, with concern focusing on the known differences in skill level of coders and the resulting data quality problems. Fundamental to the issue of data quality is the question of whether or not information on changes (modifications or revisions) reaches coders in all facilities in a timely manner (14).

2. *Clearinghouse function* : The need to identify a focal point to which requests for changes, modifications, and revisions can be made to the *ICD* and from which decisions on such changes and interpretations of guidelines can be disseminated to all users of the classification (both data producers and data users) is keenly felt in the user community. Formation of the Morbidity Classification Branch in the National Center for Health Statistics should provide much of this focus. Included in this recommendation is the need to clearly identify the process for making revisions, the criteria for proposals for change requests, and the procedures to follow in adjudicating disagreements in coding between data producers and data reviewers.

Further, the body responsible for overseeing the maintenance of the *ICD* will need to establish a mechanism for receiving and disseminating information to insure consistency and accuracy of coding from its broad base of users. The coding clearinghouse should clearly be identified as the source for providing official interpretation of coding principles and guidelines to resolve conflicting interpretations.

3. *Evaluation program* : For purposes of ongoing classification research, it is suggested that an on-site testing (in a statistically representative sample) of current terminology and documentation issues be conducted prior to the revision of a category to facilitate development of more comprehensive index entries.

*Coordination of updates*—The need to coordinate *ICD-10* updates with industry publications and the software vendor community is intuitively obvious. Similarly, the research community should be informed of all changes and modifications to the classification as these may affect trend data.

Annual updates create a corresponding need for translation tables or crosswalks between previous and revised categories. Interpretative guidelines for new categories should be incorporated into official addendum and sent to all users.

The Subcommittee should continue to serve as a forum for dialogue between the public and private sectors. As coding systems are more universally applied, this dialogue is critical to maintaining data integrity. The Subcommittee also serves as an information exchange that is important to clinicians, medical record practitioners in various settings, and software vendors.

### **Uniform Procedure Code**

The Subcommittee also addressed the issue of whether the two procedure coding systems, *ICD-9-CM Volume 3* and *Physicians' Current Procedural Terminology, Fourth Edition (CPT-4)*, should be replaced by a single system as recommended by the predecessor subcommittee. Earlier review efforts found structural problems in both *ICD-9-CM* and *CPT-4*. Concern for data quality issues and the cost of submitting data in more than one classification is significant. To further complicate the process, the two systems use different dates to implement changes (*CPT* updates are available in January whereas *ICD-9-CM* updates are available in October).

The feasibility of developing a single procedure coding system that will satisfy the interested physicians, other health care practitioners, hospitals, and payers, is as yet unknown. In an effort to provide some reliable data to respond to the question of feasibility and utility, the American Medical Association issued a request for proposal to investigate the cost and benefits of a single system. The study, conducted by Coopers and Lybrand, essentially compared two alternatives: a major restructuring of the current *CPT* to serve uses beyond those in physician offices; and a replacement system for both *CPT-4* and *ICD-9-CM Volume 3* (15).

The study methodology consisted of four parts: (a) an internal working group; (b) an advisory panel of experts; (c) interviews with key personnel at interested organizations; and (d) case studies. The internal working group developed a taxonomy of costs and benefits of both systems and identified measurements to compare costs and benefits; conducted, with the help of medical records professionals, an extensive

critique of *CPT-4* and evaluated a substantially new version of *CPT-4*; developed a broad architecture of an alternative procedural coding system; and made estimates of costs and benefits of both systems.

The advisory panel had two roles: to critique the study approach and to review the initial estimates made by the internal working group. Interviews conducted at various organizations ferreted out more information about problems with the current system, recommendations to include in an alternative system, and how to measure costs and benefits using the taxonomy of costs and benefits identified by the internal working group. Case studies were used to assess the impact of both systems by verifying the initial estimates of costs and benefits.

Costs were divided into three categories: (a) development, (b) implementation, and (c) maintenance and update. Benefits were divided into two categories: direct and indirect. Direct benefits included: more accurate coding, reduced accounts receivables for providers, elimination of multiple coding structures, and uniformity of code revision. Indirect benefits included: better payor control over claims, better control by provider business offices, and flexibility to accommodate new delivery sites.

The findings of the study showed that the costs of creating an alternative coding system for physician services were significant. Primarily, the contractors and expert panel of advisors experienced great difficulties in identifying and measuring the benefits of a replacement system. Thus, they concluded that an entirely new alternative procedural coding system for physician services would not justify the costs of establishing such a system (15).

## **Conclusions and Recommendations**

Considering the changes and updates which have led to the expansion of the system, the *ICD-9-CM* classification system has worked relatively well. By virtue of being able to respond to changes in the clinical environment, the system has increased its utility as both a statistical classification and an administrative tool. In part because of its use as a statistical classification, there is a general resistance to altering the existing classification system, except where changes are considered necessary to reflect current clinical trends.

Although the classification system has been responsive to the changing technologies and newly identified diseases that impact heavily on the community, there is concern that the *ICD* classification system may be stressed to a point where the quality of the system may soon be compromised. Both HCFA and NCHS recognize the pressures for timeliness and the need for flexibility of the system in order to be responsive to changes in technology or taxonomy. However, changes submitted only in response to reimbursement problems may have an insidious effect on future statistical data whose structure is defined by the content of the *ICD* revision. An example would be redefining the content of categories or adding very specific detail to the extent that most users are forced to use the unspecified categories.

Although the implementation of *ICD-10* in the United States will include the systems that support current classification, several major areas have been identified either to fill the existing gaps or to improve upon the current structures.

- The Coordination and Maintenance Committee composition should be expanded to include representation from the private sector. The purpose of this is to address such functions as joint planning of agendas and to assure professional input from the private sector on the final recommendations to the decisionmakers. The final decision on changes and modifications to the classification should be retained by the government as it is the organization responsible for implementing the *ICD* in the United States.
- Development and approval of coding guidelines should be conducted in a public forum such as the Coordination and Maintenance Committee and be representative of a widely participative process (14, p.7). The present process precludes interaction by the public in that deliberations are made by a select or limited group, that is, the cooperating parties or the Coding Clinic Editorial Advisory Board, neither of which is required to solicit public input.
- Guidelines should be transferable to all sites of services. Presently there are different guidelines for hospital outpatient, hospital updates, and physicians' offices.
- The integrity of the classification should be maintained through administrative procedures consisting of the identification of a source(s) authorized to meet defined responsibilities that include, but are not limited to:
  - control of code assignments beyond the fourth and fifth digits;
  - development and interpretation of national coding guidelines, including those in the ambulatory setting;
  - dissemination of these guidelines for all uses of the classification, including automated uses, to ensure safe harbor for those who voluntarily comply with approved guidelines;
  - the conduct of evaluation programs to monitor accuracy of coding (data quality issues);
  - receiving and disseminating coding information; coding problems; requests for changes, modifications, interpretations, and revisions of guidelines; and adjudicating disagreements.
- Identification of a process to determine the definition of government or nongovernment uses of *ICD-10* must be articulated, as well as the procedure to apply for consideration of these uses. The clarification of this issue must be widely disseminated to users and producers of the classification systems.
- Continuous education programs for all user groups, including physicians, should be made a priority. Presently, the onus of seeking information and education on the proper uses of the classification system falls upon individuals who request the information. Problems arise when users are not aware of the available resources from which to obtain such information or when different resources provide conflicting information.

- An evaluation program to assess the accuracy of medical coding and the interface of data set definitions and *ICD-10* in nonacute settings should be established. Data collected from the *ICD* codes are often used to develop health care and reimbursement policies. Thus, the accuracy and reliability of these data are crucial.
- An ongoing study and evaluation of the feasibility of a uniform procedure code is necessary. Such an evaluation should address HCFA's responsibility as a catalyst in determining the efficacy of a single procedure coding system.

# **Appendix VII.**

## **Interim Report of the Subcommittee on Long-Term Care Statistics on the Nursing Home Resident Assessment System**

### **Introduction**

As part of its overall charge, the Subcommittee on Long-Term Care Statistics has been monitoring the development of the resident assessment instrument for nursing homes that was mandated by the Omnibus Budget Reconciliation Act of 1987 (OBRA '87). The responsibility for developing the minimum data set (MDS) of nursing home residents, on which such an instrument would be based, was assigned to the Health Care Financing Administration (HCFA).

The Subcommittee has spent more than a year following the progress of the resident assessment instrument development and, at times, has provided opportunities for public testimony on the MDS from both the provider and consumer communities. At the present time, HCFA has completed its initial development of the MDS, and the Secretary of Health and Human Services (HHS) has distributed it to the States for their adoption and supplementation. At this juncture, it is appropriate for the Subcommittee on Long-Term Care Statistics to make a report to NCVHS on this charge. The following interim report describes the resident assessment instrument and some aspects of the development process that were of particular interest to the Subcommittee.

### **Background**

In May 1982, HCFA announced its intention to propose changes in certain regulations governing the conditions of participation for certifying the eligibility of nursing homes in the Medicare and Medicaid programs and for receiving payments. The response from consumer groups and many State regulatory agencies protesting the changes prompted Congress to order HCFA to defer implementation of the proposed changes. As a consequence, in October 1983, HCFA commissioned the Institute of Medicine (IOM) of the National Academy of Sciences to conduct a study which would provide an "appropriate and effective" (16) basis for adjusting Federal and State policies and regulations governing the certification of nursing homes.

One underlying factor prompting the IOM study was a pervasive perception among residents, resident advocacy organizations, and informed experts in the nursing home arena that Government regulation of nursing homes was inadequate because

the regulations allowed "too many marginal or substandard nursing homes" to continue to operate (16). Regulatory responsibilities of nursing homes are shared between the Federal and State Governments, with the States bearing a larger responsibility. Performance criteria are developed by the Federal Government, whereas the responsibility for inspections of nursing homes and certification for participation in Medicaid has been delegated to the States.

The Federal Government has the sole responsibility for developing and promulgating the conditions and standards for participation of certified Medicare facilities. State governments are authorized to inspect the facilities for the Federal Government and to make recommendations about certification. However, the Federal Government retains final authority for Medicare certification. The Federal Government's regulatory sanction option is limited to decertification of a facility to receive Medicare funds. Given the shortage of beds, this option, viewed as a drastic measure, is seldom invoked.

Recognizing the need to increase the range of enforcement sanction options, a new Federal regulation was promulgated in 1981 that allowed decertification of a facility to receive Medicare funds for new admissions. Mechanisms devoted to enforcing this sanction included Federal review (colloquially referred to as "look behind" actions) of States' surveys and certification activities. However, for many reasons, including labor shortages, only 3 percent of facilities were subjected to these annual reviews.

The role of State governments in regulatory activities is more pronounced. States may develop and promulgate Medicaid criteria for conditions of participation and standards governing all aspects of nursing homes. States may monitor the performance of nursing homes in compliance with the criteria through periodic surveys, inspections of care, and investigations of complaints of neglect. Where unsatisfactory performance is found, States may enforce compliance with performance standards. Because decertification is considered to be drastic, most States rely on intermediate sanctions such as fines, suspension of admissions, and receiverships. These authorities vary widely among States (16).

States are also responsible for licensing nursing homes, thus licensure standards vary from State to State. For example, the IOM report stated that:

- 1/4 of States' regulations for intermediate care facilities (ICF's) are identical to Federal certification standards;
- 1/4 of States' regulations for ICF's are less stringent than Federal certification standards; and,
- 1/2 of States' regulations for ICF's are more stringent than Federal standards. Similarly,

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<sup>4</sup>Figures are based on the number of responses to the IOM mail survey of 50 states and the District of Columbia health facility licensure and certification agencies, that is, 47 out of 50 possible responses.



- 1/3 of States' regulations for SNF's (skilled nursing facilities) are more stringent than the Federal requirements;
- 1/3 of States are equally stringent with Federal requirements for SNF's; and,
- 1/3 of States are less stringent than Federal requirements for SNF's (16, p. 319-320).<sup>4</sup>

The Omnibus Budget Reconciliation Act of 1987 (OBRA '87) mandated many of the IOM recommendations for nursing home reform, including: new requirements for aide training; increased minimum staffing patterns for registered nurses; assurance of quality of care, quality of life, and resident rights; and a national system for assessing nursing home residents (17).

## **Description of National Resident Assessment System**

The development of a national resident assessment system containing uniform data elements and definitions to assess all residents in nursing home facilities was mandated by OBRA '87. Essentially, the components of the resident assessment instrument include: individualized resident care planning consisting of the minimum data set (MDS) (that is, core items necessary for a comprehensive assessment of nursing home residents) and items identifying residents for whom specific Resident Assessment Protocols (RAP's) for care planning were "triggered." Eighteen areas (domains) have been identified for this purpose: delirium, cognitive loss/dementia, visual function, communication, ADL functional/rehabilitation potential, urinary incontinence and indwelling catheter, psychosocial well-being, mood state, behavior problems, activities, falls, nutritional status, feeding tubes, dehydration/fluid maintenance, dental care, pressure ulcers, psychotropic drug use, and physical restraints.

## **Process**

Development of the MDS involved two major steps: (a) development of the conceptual framework and draft instrument, and (b) development of a reliability test of the instrument and training materials. To accomplish the first step, HCFA contracted with the Research Triangle Institute, Hebrew Rehabilitation Center for the Aged, Brown University, and the University of Michigan.

Initially, an extensive review of more than 60 existing assessment instruments was made. These included instruments used for: preadmission screening and case management, State instruments for case-mix payment systems, individual homes and groups of homes, and research (18). An expert clinical consultant panel and an advisory committee (the latter representing consumers, resident advocates, providers, industry representatives, regulators, and measurement specialists) were established to advise and review the development of the MDS, RAP's, and training modules.

## **Minimum Data Set (MDS)**

Two multi-State pilot tests of the instruments were conducted in different types of facilities reflecting geographic diversity and variation in ownership. After each testing, revisions were made to the MDS. The criteria used to evaluate the draft MDS instruments and the resulting data focused heavily on the clinical usefulness of the items. The following primary factors were evaluated specifically: inter-rater reliability; relevance to care planning; and significance as an indicator of quality of care (18).

The MDS has undergone many iterations, in large part as a result of field testing for reliability and acceptability. The reliability of each item was ascertained by comparing dual assessments made by the nurse assessors, one of whom was employed by the facility. During the development phase, minimally acceptable reliability was 0.4, but most of the items scored higher (for example, ADL's were 0.9). Most items that showed poor reliability were dropped, such as medical conditions using *ICD-9* codes where it was difficult to obtain a level of specificity and agreement between the assessors. However, some items that scored a 0.4 reliability were retained because they were perceived as clinically important. An example is "dehydration"; it was difficult to assess reliably in the clinical setting but the condition was felt to be vital to the assessment process.

## **Triggers and Resident Assessment Protocols (RAP's)**

Each State must specify a Resident Assessment Instrument (RAI) for use by all Medicare or Medicaid participating facilities within the State. States have the flexibility either to use the instrument developed by HCFA or to develop their own assessment instrument that must include all of the items and common definitions of the MDS; States may expand (but not collapse) the response options in the MDS and they may add new items for their purposes, but they may not eliminate any MDS items. Another mandated aspect of HCFA's RAI is "triggers," which are one MDS item or combinations of MDS items that are used to screen for the need for further assessment. RAP's are 18 problem oriented guidelines for additional assessment, which are "triggered" if clinically warranted by the responses on the MDS. Once a RAP is triggered, a summary statement must be made regarding the findings of the additional assessment and a decision must be made regarding whether or not to "care plan" that problem. RAP's are intended to provide assistance and structure for the facility to perform the comprehensive assessment and to identify options for care planning. They are not meant to substitute for clinical evaluations of the total person in developing care plans, to be prescriptive, or to serve as survey standards; however, if used effectively, RAP's could improve quality of care and quality of life for nursing home residents.

All RAP's were tested in different types of facilities in several States. Final validity testing of the RAP's was completed in June 1990. The process initially involved the facility's selection of an expert clinician who would identify residents with and

without the problems addressed in the RAP's. RAP's were performed for these residents; extensive case-by-case discussions among project team members and the staff members involved with the care of these residents were conducted to evaluate whether residents were appropriately identified by the triggers.

In the field test, the assessors' responses to the RAP's were positive. The RAP's served as a guide for them as they assessed each resident and sometimes suggested options for care they may not have considered otherwise.

## **Computerization of MDS**

The HCFA is currently considering a proposal that would require nursing facilities to be capable of encoding the MDS in a machine readable format. The collection of electronic data from the MDS would enable the establishment of a national registry of nursing home residents. Potential uses of the data are numerous, but still need to be determined. Potentially, the data may be used to describe the expected course of treatment for various types of long-term care clients. This could be used by clinical staff to monitor the progress of individual residents, and at the facility level for quality assurance and program evaluation.

Although a tentative implementation date for computerization of October 1, 1992, is being considered, this date may be optimistic. If computerization of the MDS is mandated, nondata issues, such as the need to designate who will pay for the acquisition of computers in the nursing homes, need to be addressed. Options that the Government may allow include a one-time reimbursement (not to exceed a specified amount) for the first-time acquisition of a computer to support the transfer of electronic MDS data to HCFA, or the inclusion of acquisition costs in the negotiated reimbursement rates.

## **Training for Implementing the MDS**

The HCFA is in the process of developing a nursing home resident assessment training manual that focuses on the elements and common definitions of the MDS. Surveyors will be trained using an expanded version of the same manual. A videotape will also be developed to accompany the self-instructional manual.

## **Current Status**

Originally, full implementation of the Resident Assessment Instrument (RAI) was planned for October 1, 1990. However, the implementation date has been delayed. The transmittal of the manual to accompany the RAI was sent to the States in early

September 1990 instead of April 1990, as was initially scheduled. The RAI consists of: (a) utilization guidelines for the MDS; (b) the MDS instrument; and (c) the Resident Assessment Protocols (RAP's), which provide the framework for a comprehensive assessment of the 18 domains identified in the OBRA '87 legislation and the Requirements for Long-Term Care Facilities as published on February 2, 1989 in the *Federal Register*.

As mentioned above, the States will be able to develop their own instruments. However, the instruments must meet certain criteria to be approved by HCFA: (a) all MDS items must be included in the instrument although States can change the order of major sections of the MDS; (b) documentation must be provided for any additional elements; (c) although the minimum domains must be stipulated, RAP's will allow the greatest flexibility for the States because elements can be combined or alternative triggers may be used; however, supporting documents for any changes must be provided.

States were requested to inform HCFA by October 19, 1990 about which instrument they plan to designate as their RAI. As of October 25, 45 of the 53 entities (which include Guam, Puerto Rico, and the District of Columbia) have formally responded. Of these, 31 indicated that they plan to use the MDS; 7 plan to use the MDS Plus, which includes all MDS information plus more data and was developed by another office in HCFA for a demonstration project; and 7 plan to supplement the MDS with additional State-specific items.

## **Current Version of MDS**

The form presented at the end of this report is the version that was designated as the core of the Department of Health and Human Services RAI and sent by the Secretary to the States.

## **Summary**

The Subcommittee on Long-Term Care Statistics has reviewed the Resident Assessment System (utilization guidelines, MDS and common definitions, resident assessment protocols, and so on) from its earliest stage to its present stage. Accordingly, the Subcommittee has been impressed with both the development process and the result of the RAI as a clinical instrument for a unique assessment leading to individual care planning. If used as intended, the instrument not only has the capability of improving the quality of care for nursing home residents, but also has the potential to produce a national data base of these residents.

## Initial Concerns

The Subcommittee initially had raised several issues about the impact of administering the MDS on the facilities and staffs of these facilities, including but not limited to:

- the length of time it would take to administer the MDS for each resident;
- the quality of data recorded in the assessments and their utility in care planning;
- the relationship of the RAP's to the MDS;
- the lack of training provisions for nursing home staffs to administer the MDS; and,
- the low reliability and therefore questionable validity of some of the data items.

Representatives from the nursing home industry and advocates of nursing home residents have raised similar concerns throughout the development process.

## Accomplishments

The HCFA and its subcontractors are to be commended for their responsiveness to these concerns. The resulting RAI and its components are a reflection of having undergone many iterations to address the difficulties.

## Implementation of Assessment at Local Level

The immediate impact upon the facilities to implement the MDS has been phased in so that initially the RAI will be used only for new admissions with quarterly updates or reassessments where significant changes have occurred. States will have until October 1, 1991 to conduct the RAI on the rest of the nursing home population, but, during the interim, will have to complete assessments as defined in the February 2, 1989 Requirements for Long-Term Care Facilities published in the *Federal Register*. The length of time required to conduct the initial assessments for residents has been reduced so that it currently adds approximately 30 minutes to the average facility's previous assessment process, which the RAI will replace. The time required to administer the MDS may be further reduced as facilities' staff become familiar with the MDS. In the Subcommittee's estimation, the gains for purposes of care planning and quality management are sufficiently large to make that a good investment.

## Training

More attention has been paid to the need for training of staff to use the MDS. In large measure, the quality of data collection will improve when staff are able to understand the relevance of the MDS data elements to care planning. Training should include:

- a discussion of potential problematic areas in the MDS;
- a case study of materials and/or exercises, including residents with particular problems;
- an example of a completed Resident Assessment Instrument; and,
- a description of linkage to other assessments.

### **Data linkages**

The Subcommittee is mindful of NCVHS' oft-stated concern for the use of a common identifier to link data sets. The Subcommittee applauds HCFA and the contractors for using the social security number of residents as the unique identifier. The "MDS Plus" (used in the HCFA Multi-State Case Mix and Quality Demonstration Project) also includes all of the MDS elements, including the social security number, plus additional elements. The Subcommittee will endeavor to have the social security number included in any other instrument used in a similar fashion to facilitate linkage among data sets.

### **Continuing Concerns**

Several issues about the potential uses of the clinical minimum data set remain open for continued discussion. One of these is the issue of reliability and the quality of the data over time. Another concerns the mechanism, if any, to determine what data system will be made available to people who want to access the data in a reasonable and effective way, and that will provide the necessary confidentiality assurances.

### **Reliability of Data Items**

Given the magnitude and range of the MDS, the data will inevitably be used for multiple purposes, including serving as a data set for both administrative and research purposes. Thus, the Subcommittee shares the ongoing concern of NCVHS for the adequacy of the data set and urges HCFA to continue to monitor the reliability of data items and their validity over time. Issues of particular interest include: how common data elements can be applied across all care settings, such as home health care; the accessibility and availability of the data to researchers; and the flexibility of the RAI/MDS data set over time to allow for changes in clinical practices.

Further, recognizing the heterogeneity of the nursing home population, it is important not only to know the average reliability but also to understand how reliability differs in different kinds of nursing homes, so that more targeted efforts can be made to improve reliability. Thus, the Subcommittee encourages HCFA to obtain information not only to increase the reliability and quality of the data but also to assess how reliability varies in different types of institutions.

The Subcommittee plans to continue to monitor the usefulness and reliability of the data during major phases of the project, or at least once a year.

### **Computerization at Local Level**

Although there appears to be no statutory requirement to computerize the MDS, it is likely that these data will be used for administrative and research purposes. In this regard, the quality of the data becomes increasingly important.

The HCFA has begun internal discussions addressing the feasibility of computerization of the MDS. Many data issues still need to be addressed, including whether to collect all the MDS/RAP data or just a subset; where the data should be reported and stored; how accessibility to the data should be determined; and how confidentiality and privacy will be assured.

The Subcommittee plans to continue to monitor the potential development of a national data system that could serve as a national registry of nursing home residents because no such system currently exists.

**MINIMUM DATA SET FOR NURSING HOME RESIDENT ASSESSMENT AND CARE SCREENING (MDS)**  
(Status in last 7 days, unless other time frame indicated)

**SECTION A. IDENTIFICATION AND BACKGROUND INFORMATION**

1. ASSESSMENT DATE	<input type="text"/> <input type="text"/> <input type="text"/>	Month Day Year
2. RESIDENT NAME	<input type="text"/> <input type="text"/> <input type="text"/>	(First) (Middle Initial) (Last)
3. SOCIAL SECURITY NO.	<input type="text"/> <input type="text"/> <input type="text"/>	
4. MEDICAID NO. (if applicable)	<input type="text"/>	
5. MEDICAL RECORD NO.	<input type="text"/>	
6. REASON FOR ASSESSMENT	1. Initial admission assess.    5. Significant change in status 2. Hosp/Medicare reassess.    6. Other (e.g., UR) 3. Readmission assessment 4. Annual assessment	
7. CURRENT PAYMENT SOURCE(S) FOR N.H. STAY	(Billing Office to indicate; check all that apply) Medicaid <input type="checkbox"/> VA <input type="checkbox"/> Medicare <input type="checkbox"/> Self pay/Private insurance <input type="checkbox"/> CHAMPUS <input type="checkbox"/> Other <input type="checkbox"/>	d. e. f.
8. RESPONSIBILITY/LEGAL GUARDIAN	(Check all that apply) Legal guardian <input type="checkbox"/> Family member responsible <input type="checkbox"/> Other legal oversight <input type="checkbox"/> Resident responsible <input type="checkbox"/> Durable power attorney/health care proxy <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/>	d. e. f.
9. ADVANCED DIRECTIVES	(For those items with supporting documentation in the medical record, check all that apply) Living will <input type="checkbox"/> Feeding restrictions <input type="checkbox"/> Do not resuscitate <input type="checkbox"/> Medication restrictions <input type="checkbox"/> Do not hospitalize <input type="checkbox"/> Other treatment restrictions <input type="checkbox"/> Organ donation <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/> Autopsy request <input type="checkbox"/>	f. g. h. i.
10. DISCHARGE PLANNED WITHIN 3 MOS.	0. No    1. Yes    2. Unknown/uncertain	
11. PARTICIPATE IN ASSESSMENT	a. Resident    0. No 1. Yes            1. Yes b. Family    0. No 1. Yes            2. No family	
12. SIGNATURES	Signature of RN Assessment Coordinator  Signatures of Others Who Completed Part of the Assessment _____ _____ _____	

**SECTION B. COGNITIVE PATTERNS**

1. COMATOSE	(Persistent vegetative state/no discernible consciousness) 0. No    1. Yes (Skip to SECTION E)	
2. MEMORY	(Recall of what was learned or known) a. Short-term memory OK—seems/appears to recall after 5 minutes 0. Memory OK                    1. Memory problem b. Long-term memory OK—seems/appears to recall long past 0. Memory OK                    1. Memory problem	
3. MEMORY/RECALL ABILITY	(Check all that resident normally able to recall during last 7 days) Current season <input type="checkbox"/> That he/she is in a nursing home <input type="checkbox"/> Location of own room <input type="checkbox"/> NONE OF ABOVE are recalled <input type="checkbox"/> Staff names/faces <input type="checkbox"/>	d. e.

= Code the appropriate response     = Check all the responses that apply

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4. COGNITIVE SKILLS FOR DAILY DECISION-MAKING	(Made decisions regarding tasks of daily life) 0. Independent—decisions consistent/reasonable 1. Modified Independence—some difficulty in new situations only 2. Moderately impaired—decisions poor; cues/supervision required 3. Severely impaired—never/rarely made decisions	
5. INDICATORS OF DELIRIUM—PERIODIC DISORDERED THINKING/AWARENESS	(Check if condition over last 7 days appears different from usual functioning) Less alert, easily distracted <input type="checkbox"/> Changing awareness of environment <input type="checkbox"/> Episodes of incoherent speech <input type="checkbox"/> Periods of motor restlessness or lethargy <input type="checkbox"/> Cognitive ability varies over course of day <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/>	a. b. c. d. e. f.
6. CHANGE IN COGNITIVE STATUS	Change in resident's cognitive status, skills, or abilities in last 90 days 0. No change    1. Improved    2. Deteriorated	

**SECTION C. COMMUNICATION/HEARING PATTERNS**

1. HEARING	(With hearing appliance, if used) 0. Hears adequately—normal talk, TV, phone 1. Minimal difficulty when not in quiet setting 2. Hears in special situations only—speaker has to adjust tonal quality and speak distinctly 3. Highly impaired/absence of useful hearing	
2. COMMUNICATION DEVICES/TECHNIQUES	(Check all that apply during last 7 days) Hearing aid, present and used <input type="checkbox"/> Hearing aid, present and not used <input type="checkbox"/> Other receptive comm. techniques used (e.g., lip read) <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/>	a. b. c. d.
3. MODES OF EXPRESSION	(Check all used by resident to make needs known) Speech <input type="checkbox"/> Signs/gestures/sounds <input type="checkbox"/> Writing messages to express or clarify needs <input type="checkbox"/> Other <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/>	c. d. e. f.
4. MAKING SELF UNDERSTOOD	(Express information content—however able) 0. Understood 1. Usually Understood—difficulty finding words or finishing thoughts 2. Sometimes Understood—ability is limited to making concrete requests 3. Rarely/Never Understood	
5. ABILITY TO UNDERSTAND OTHERS	(Understanding verbal information content—however able) 0. Understands 1. Usually Understands—may miss some part/content of message 2. Sometimes Understands—responds adequately to simple, direct communication 3. Rarely/Never Understands	
6. CHANGE IN COMMUNICATION/HEARING	Resident's ability to express, understand or hear information has changed over last 90 days 0. No change    1. Improved    2. Deteriorated	

**SECTION D. VISION PATTERNS**

1. VISION	(Ability to see in adequate light and with glasses if used) 0. Adequate—sees fine detail, including regular print in newspapers/books 1. Impaired—sees large print, but not regular print in newspapers/books 2. Highly Impaired—limited vision; not able to see newspaper headlines; appears to follow objects with eyes 3. Severely impaired—no vision or appears to see only light, colors, or shapes	
2. VISUAL LIMITATIONS/DIFFICULTIES	Side vision problems—decreased peripheral vision (e.g., leaves food on one side of tray, difficulty traveling, bumps into people and objects, misjudges placement of chair when seating self) <input type="checkbox"/> Experiences any of the following: sees halos or rings around lights; sees flashes of light; sees "curtains" over eyes <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/>	a. b. c.
3. VISUAL APPLIANCES	Glasses: contact lenses; lens implant; magnifying glass 0. No    1. Yes	



**SECTION E. PHYSICAL FUNCTIONING AND STRUCTURAL PROBLEMS**

1. ADL SELF-PERFORMANCE—(Code for resident's PERFORMANCE OVER ALL SHIFTS during last 7 days—Not including setup)			
0. INDEPENDENT — No help or oversight — OR — Help/oversight provided only 1 or 2 times during last 7 days			
1. SUPERVISION — Oversight, encouragement or cueing provided 3+ times during last 7 days — OR — Supervision plus physical assistance provided only 1 or 2 times during last 7 days			
2. LIMITED ASSISTANCE — Resident highly involved in activity; received physical help in guided maneuvering of limbs or other nonweight bearing assistance 3+ times — OR — More help provided only 1 or 2 times during last 7 days			
3. EXTENSIVE ASSISTANCE — While resident performed part of activity, over last 7-day period, help of following type(s) provided 3 or more times: — Weight-bearing support — Full staff performance during part (but not all) of last 7 days			
4. TOTAL DEPENDENCE — Full staff performance of activity during entire 7 days			
2. ADL SUPPORT PROVIDED — (Code for MOST SUPPORT PROVIDED OVER ALL SHIFTS during last 7 days; code regardless of resident's self-performance classification)		(1)	(2)
0. No setup or physical help from staff			
1. Setup help only			
2. One-person physical assist			
3. Two+ persons physical assist			
a.	BED MOBILITY	How resident moves to and from lying position, turns side to side, and positions body while in bed	
b.	TRANSFER	How resident moves between surfaces—to/from: bed, chair, wheelchair, standing position (EXCLUDE to/from bath/toilet)	
c.	LOCOMOTION	How resident moves between locations in his/her room and adjacent corridor on same floor. If in wheelchair, self-sufficiency once in chair	
d.	DRESSING	How resident puts on, fastens, and takes off all items of street clothing, including donning/removing prosthesis	
e.	EATING	How resident eats and drinks (regardless of skill)	
f.	TOILET USE	How resident uses the toilet room (or commode, bedpan, urinal); transfer on/off toilet, cleanses, changes pad, manages ostomy or catheter, adjusts clothes	
g.	PERSONAL HYGIENE	How resident maintains personal hygiene, including combing hair, brushing teeth, shaving, applying makeup, washing/drying face, hands, and perineum (EXCLUDE baths and showers)	
3. BATHING		How resident takes full-body bath/shower, sponge bath, and transfers in/out of tub/shower (EXCLUDE washing of back and hair. Code for most dependent in self-performance and support. Bathing Self-Performance codes appear below)	
0. Independent—No help provided			
1. Supervision—Oversight help only			
2. Physical help limited to transfer only			
3. Physical help in part of bathing activity			
4. Total dependence			
4. BODY CONTROL PROBLEMS		(Check all that apply during last 7 days)	
	Balance—partial or total loss of ability to balance self while standing	a. Hand—lack of dexterity (e.g., problem using toothbrush or adjusting hearing aid)	g.
	Bedfast all or most of the time	b. Leg—partial or total loss of voluntary movement	h.
	Contracture to arms, legs, shoulders, or hands	c. Leg—unsteady gait	i.
	Hemiplegia/hemiparesis	d. Trunk—partial or total loss of ability to position, balance, or turn body	j.
	Quadriplegia	e. Amputation	k.
	Arm—partial or total loss of voluntary movement	f. NONE OF ABOVE	l.
5. MOBILITY APPLIANCES/ DEVICES		(Check all that apply during last 7 days)	
	Cane/walker	a. Other person wheeled	d.
	Brace/prosthesis	b. Lifted (manually/mechanically)	e.
	Wheeled self	c. NONE OF ABOVE	f.

6. TASK SEGMENTATION	Resident requires that some or all of ADL activities be broken into a series of subtasks so that resident can perform them 0. No 1. Yes	
7. ADL FUNCTIONAL REHABILITATION POTENTIAL	Resident believes he/she capable of increased independence in at least some ADLs Direct care staff believe resident capable of increased independence in at least some ADLs Resident able to perform tasks/activity but is very slow Major difference in ADL Self-Performance or ADL Support in mornings and evenings (at least a one category change in Self-Performance or Support in any ADL) NONE OF ABOVE	a. b. c. d. e.
8. CHANGE IN ADL FUNCTION	Change in ADL self-performance in last 90 days 0. No change 1. Improved 2. Deteriorated	

**SECTION F. CONTINENCE IN LAST 14 DAYS**

1. CONTINENCE SELF-CONTROL CATEGORIES (Code for resident performance over all shifts)		
0. CONTINENT — Complete control		
1. USUALLY CONTINENT — BLADDER, incontinent episodes once a week or less; BOWEL, less than weekly		
2. OCCASIONALLY INCONTINENT — BLADDER, 2+ times a week but not daily; BOWEL, once a week		
3. FREQUENTLY INCONTINENT — BLADDER, tended to be incontinent daily, but some control present (e.g., on day shift); BOWEL, 2-3 times a week		
4. INCONTINENT — Had inadequate control. BLADDER, multiple daily episodes; BOWEL, all (or almost all) of the time		
a.	BOWEL CONTINENCE	Control of bowel movement, with appliance or bowel continence programs, if employed
b.	BLADDER CONTINENCE	Control of urinary bladder function (if dribbles, volume insufficient to soak through underpants), with appliances (e.g., Foley) or continence programs, if employed
2. INCONTINENCE RELATED TESTING		
(Skip if resident's bladder continence code equals 0 or 1 AND no catheter is used)		
Resident has been tested for a urinary tract infection		a.
Resident has been checked for presence of a fecal impaction, or there is adequate bowel elimination		b. c.
NONE OF ABOVE		
3. APPLIANCES AND PROGRAMS		
	Any scheduled toileting plan	a. Pads/briefs used
	External (condom) catheter	b. Enemas/irrigation
	Indwelling catheter	c. Ostomy
	Intermittent catheter	d. NONE OF ABOVE
	Did not use toilet room/commode/urinal	e.
4. CHANGE IN URINARY CONTINENCE		
Change in urinary continence/appliances and programs in last 90 days 0. No change 1. Improved 2. Deteriorated		

**SECTION G. PSYCHOSOCIAL WELL-BEING**

1. SENSE OF INITIATIVE/ INVOLVEMENT		
At ease interacting with others		a.
At ease doing planned or structural activities		b.
At ease doing self-initiated activities		c.
Establishes own goals		d.
Pursues involvement in life of facility (e.g., makes/keeps friends; involved in group activities; responds positively to new activities; assists at religious services)		e.
Accepts invitations into most group activities		f.
NONE OF ABOVE		g.
2. UNSETTLED RELATIONSHIPS		
Cover/open conflict with and/or repeated criticism of staff		a.
Unhappy with roommate		b.
Unhappy with residents other than roommate		c.
Openly expresses conflict/anger with family or friends		d.
Absence of personal contact with family/friends		e.
Recent loss of close family member/friend		f.
NONE OF ABOVE		g.
3. PAST ROLES		
Strong identification with past roles and life status		a.
Expresses sadness/anger/empty feeling over lost roles/status		b.
NONE OF ABOVE		c.

### SECTION H. MOOD AND BEHAVIOR PATTERNS

1.	SAD OR ANXIOUS MOOD	(Check all that apply during last 30 days) VERBAL EXPRESSIONS OF DISTRESS by resident (sadness, sense that nothing matters, hopelessness, worthlessness, unrealistic fears, vocal expressions of anxiety or grief) DEMONSTRATED (OBSERVABLE) SIGNS of mental DISTRESS — Tearfulness, emotional groaning, sighing, breathlessness — Motor agitation such as pacing, handwringing or picking — Failure to eat or take medications, withdrawal from self-care or leisure activities — Pervasive concern with health — Recurrent thoughts of death—e.g., believes he/she about to die, have a heart attack — Suicidal thoughts/actions NONE OF ABOVE	a. b. c. d. e. f. g. h.
2.	MOOD PERSISTENCE	Sad or anxious mood intrudes on daily life over last 7 days — not easily altered, doesn't "cheer up" 0. No 1. Yes	
3.	PROBLEM BEHAVIOR	(Code for behavior in last 7 days) 0. Behavior not exhibited in last 7 days 1. Behavior of this type occurred less than daily 2. Behavior of this type occurred daily or more frequently WANDERING (moved with no rational purpose, seemingly oblivious to needs or safety) VERBALLY ABUSIVE (others were threatened, screamed at, cursed at) PHYSICALLY ABUSIVE (others were hit, shoved, scratched, sexually abused) SOCIALLY INAPPROPRIATE/DISRUPTIVE BEHAVIOR (made disrupting sounds, noisy, screams, self-abusive acts, sexual behavior or disrobing in public, smeared/threw food/teeces, hoarding, rummaged through others' belongings)	a. b. c.
4.	RESIDENT RESISTS CARE	(Check all types of resistance that occurred in the last 7 days) Resisted taking medications/injection Resisted ADL assistance NONE OF ABOVE	a. b. c.
5.	BEHAVIOR MANAGEMENT PROGRAM	Behavior problem has been addressed by clinically developed behavior management program. (Note: Do not include programs that involve only physical restraints or psychotropic medications in this category) 0. No behavior problem 1. Yes, addressed 2. No, not addressed	
6.	CHANGE IN MOOD	Change in mood in last 90 days 0. No change 1. Improved 2. Deteriorated	
7.	CHANGE IN PROBLEM BEHAVIOR	Change in problem behavioral signs in last 90 days 0. No change 1. Improved 2. Deteriorated	

### SECTION I. ACTIVITY PURSUIT PATTERNS

1.	TIME AWAKE	(Check appropriate time periods over last 7 days) Resident awake all or most of time (i.e., naps no more than one hour per time period) in the: Morning a. Evening c. Afternoon b. NONE OF ABOVE d.
2.	AVERAGE TIME INVOLVED IN ACTIVITIES	0. Most—more than 2/3 of time 2. Little—less than 1/3 of time 1. Some—1/3 to 2/3 of time 3. None
3.	PREFERRED ACTIVITY SETTINGS	(Check all settings in which activities are preferred) Own room a. Outside facility d. Day/activity room b. NONE OF ABOVE e. Inside NH/off unit c.

### SECTION J. DISEASE DIAGNOSES

(Check only those diseases present that have a relationship to current ADL status, cognitive status, behavior status, medical treatments, or risk of death. (Do not list old/ inactive diagnoses.)	
1. DISEASES	(If none apply, CHECK the NONE OF ABOVE box)
HEART/CIRCULATION	PSYCHIATRIC/MOOD
Atherosclerotic heart disease (ASHD) a.	Anxiety disorder p.
Cardiac dysrhythmias b.	Depression q.
Congestive heart failure c.	Manic depressive (bipolar disease) r.
Hypertension d.	SENSORY
Hypotension e.	Cataracts s.
Peripheral vascular disease f.	Glaucoma t.
Other cardiovascular disease g.	OTHER
NEUROLOGICAL	Anemia v.
Alzheimer's h.	Arthritis w.
Dementia other than Alzheimer's i.	Cancer x.
Aphasia j.	Diabetes mellitus y.
Cerebrovascular accident (stroke) k.	Explicit terminal prognosis z.
Multiple sclerosis l.	Hypothyroidism aa.
Parkinson's disease m.	Osteoporosis bb.
PULMONARY	Seizure disorder cc.
Emphysema/Asthma/ COPD n.	Septicemia dd.
Pneumonia o.	Urinary tract infection— In last 30 days ee.
	NONE OF ABOVE ff.
2. OTHER CURRENT DIAGNOSES AND ICD-9 CODES	a. b. c. d. e. f.

4. GENERAL ACTIVITY PREFERENCES (adapted to resident's current abilities)	(Check all PREFERENCES whether or not activity is currently available to resident)
Cards/other games a.	Spiritual/religious activities f.
Crafts/hobbies b.	Trips/shopping g.
Exercise/sports c.	Walking/wheeling outdoors h.
Music d.	Watch TV i.
Read/write e.	NONE OF ABOVE j.
5. PREFERS MORE OR DIFFERENT ACTIVITIES	Resident expresses/indicates preference for other activities/ choices 0. No 1. Yes

### SECTION K. HEALTH CONDITIONS

1. PROBLEM CONDITIONS	(Check all problems that are present in last 7 days unless other time frame indicated)
Constipation a.	Pain—resident complains or shows evidence of pain daily or almost daily j.
Diarrhea b.	Recurrent lung aspirations in last 90 days k.
Dizziness/vertigo c.	Shortness of breath l.
Edema d.	Syncope (fainting) m.
Fecal impaction e.	Vomiting n.
Fever f.	NONE OF ABOVE o.
Hallucinations/delusions g.	
Internal bleeding h.	
Joint pain i.	
2. ACCIDENTS	
Fell in past 30 days a.	Hip fracture in last 180 days c.
Fell in past 31-180 days b.	NONE OF ABOVE d.

3.	STABILITY OF CONDITIONS	Conditions/diseases make resident's cognitive, ADL, or behavior status unstable—fluctuating, precarious, or deteriorating  Resident experiencing an acute episode or a flare-up of a recurrent/chronic problem  NONE OF ABOVE	a.
			b.
			c.

4.	SKIN PROBLEMS/ CARE	Open lesions other than stasis or pressure ulcers (e.g., cuts)  Skin desensitized to pain, pressure, discomfort  Protective/preventive skin care  Turning/repositioning program  Pressure relieving beds, bed/chair pads (e.g., egg crate pads)  Wound care/treatment (e.g., pressure ulcer care, surgical wound)  Other skin care/treatment  NONE OF ABOVE	a.
			b.
			c.
			d.
			e.
			f.
			g.
			h.

### SECTION L. ORAL/NUTRITIONAL STATUS

1.	ORAL PROBLEMS	Chewing problem  Swallowing problem  Mouth pain  NONE OF ABOVE	a.
			b.
			c.
			d.
2.	HEIGHT AND WEIGHT	Record height (a.) in inches and weight (b.) in pounds. Weight based on most recent status in last 30 days; measure weight consistently in accord with standard facility practice—e.g., in a.m. after voiding, before meal, with shoes off, and in nightclothes.  HT (in.) <input type="text"/> WT (lb.) <input type="text"/>  c. Weight loss (i.e., 5%+ in last 30 days; or 10% in last 180 days) 0. No      1. Yes	
3.	NUTRITIONAL PROBLEMS	Complains about the taste of many foods  Insufficient fluid; dehydrated  Did NOT consume all/almost all liquids provided during last 3 days  NONE OF ABOVE	a.
			b.
			c.
			d.
4.	NUTRITIONAL APPROACHES	Parenteral/IV  Feeding tube  Mechanically altered diet  Syringe (oral feeding)  Therapeutic diet  Dietary supplement between meals  Plate guard, stabilized built-up utensil, etc.  NONE OF ABOVE	a.
			b.
			c.
			d.

### SECTION O. MEDICATION USE

1.	NUMBER OF MEDICATIONS	(Record the number of different medications used in the last 7 days; enter "0" if none used)	
2.	NEW MEDICATIONS	Resident has received new medications during the last 90 days 0. No      1. Yes	
3.	INJECTIONS	(Record the number of days injections of any type received during the last 7 days)	
4.	DAYS RECEIVED THE FOLLOWING MEDICATION	(Record the number of days during last 7 days; enter "0" if not used; enter "1" if long-acting meds. used less than weekly)	
			Antipsychotics
			Antianxiety/hypnotics  Antidepressants
5.	PREVIOUS MEDICATION RESULTS	(SKIP this question if resident currently receiving antipsychotics, antidepressants, or antianxiety/hypnotics—otherwise code correct response for last 90 days) Resident has previously received psychoactive medications for a mood or behavior problem, and these medications were effective (without undue adverse consequences) 0. No, drugs not used 1. Drugs were effective 2. Drugs were not effective 3. Drug effectiveness unknown	

### SECTION M. ORAL/DENTAL STATUS

1.	ORAL STATUS AND DISEASE PREVENTION	Debris (soft, easily movable substances) present in mouth prior to going to bed at night  Has dentures and/or removable bridge  Some/all natural teeth lost—does not have or does not use dentures (or partial plates)  Broken, loose, or carious teeth  Inflamed gums (gingiva); swollen or bleeding gums; oral abscesses, ulcers or rashes  Daily cleaning of teeth/dentures  NONE OF ABOVE	a.
			b.
			c.
			d.
			e.
			f.
			g.

### SECTION P. SPECIAL TREATMENT AND PROCEDURES

1.	SPECIAL TREATMENTS AND PROCEDURES	SPECIAL CARE—Check treatments received during the last 14 days  Chemotherapy  Radiation  Dialysis  Suctioning  Trach. care  THERAPIES—Record the number of days each of the following therapies was administered (for at least 10 minutes during a day) in the last 7 days:  Speech—language pathology and audiology services  Occupational therapy  Physical therapy  Psychological therapy (any licensed professional)  Respiratory therapy	a.
			b.
			c.
			d.
			e.
			f.
			g.
			h.
			i.
			j.
2.	ABNORMAL LAB VALUES	Has the resident had any abnormal lab values during the last 90-days? 0. No      1. Yes      2. No tests performed	
3.	DEVICES AND RESTRAINTS	Use the following codes for last 7 days: 0. Not used 1. Used less than daily 2. Used daily  Bed rails  Trunk restraint  Limb restraint  Chair prevents rising	

### SECTION N. SKIN CONDITION

1.	STASIS ULCER	(open lesion caused by poor venous circulation to lower extremities) 0. No      1. Yes	
2.	PRESSURE ULCERS	(Code for highest stage of pressure ulcer) 0. No pressure ulcers 1. Stage 1 A persistent area of skin redness (without a break in the skin) that does not disappear when pressure is relieved 2. Stage 2 A partial thickness loss of skin layers that presents clinically as an abrasion, blister, or shallow crater 3. Stage 3 A full thickness of skin is lost, exposing the subcutaneous tissues—presents as a deep crater with or without undermining adjacent tissue 4. Stage 4 A full thickness of skin and subcutaneous tissue is lost, exposing muscle and/or bone	
3.	HISTORY OF RESOLVED/ CURED PRESSURE ULCERS	Resident has had a pressure ulcer that was resolved/cured in last 90 days 0. No      1. Yes	

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