

The United States National Committee on Vital and Health Statistics

Fiscal Year 1978

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NATIONAL CENTER FOR HEALTH STATISTICS

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service
Office of Health Research, Statistics, and Technology

ANNUAL REPORT OF

**The United States National Committee
on Vital and Health Statistics**

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**U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Office of Health Research, Statistics, and Technology
October 1979**

**ROSTER OF THE
UNITED STATES NATIONAL COMMITTEE ON
VITAL AND HEALTH STATISTICS**

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CHARTER

UNITED STATES NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Purpose

The Secretary and by delegation the Assistant Secretary for Health and the Director, National Center for Health Statistics, are charged under section 306 of the Public Health Service Act, as amended, 42 United States Code 242k, with the responsibility to collect, analyze and disseminate national health statistics on vital events and health activities, including the physical, mental, and physiological characteristics of the population, illness, injury, impairment, the supply and utilization of health facilities and manpower, the operation of the health services system, health economic expenditures, and changes in the health status of people; administer the Co-operative Health Statistics System; stimulate and conduct basic and applied research in health data systems and statistical methodology; coordinate the overall health statistical activities of the programs and agencies of the Health Resources Administration and provide technical assistance in the management of statistical information; maintain operational liaison with statistical gathering and processing services of other health agencies, public and private, and provide technical assistance within the limitations of staff resources; foster research consultation and training programs in international statistical activities; and participate in the development of national health statistics policy with Federal agencies.

Authority

42 United States Code 242k, section 306(i) of the Public Health Service Act, as amended. The Committee is governed by provisions of Public Law 92-463 which sets forth standards for the formation and use of advisory committees.

Function

The United States National Committee on Vital and Health Statistics shall assist and advise the Secretary and Assistant Secretary for Health to delineate statistical problems bearing on health and health services which are of national or international interest; to stimulate studies of such problems by other organizations and agencies whenever possible or to make investigations of such problems through subcommittees; 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, Education, and Welfare, (ii) by all programs administered or funded by the Secretary, including the Federal-State-Local cooperative health statistics system referred to in subsection (e) of section 306, 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; 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, Education, and Welfare, 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; 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 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.

Structure

The Committee shall consist of 15 members, including the Chairperson, selected by the Secretary, or his designee, who have distinguished themselves in the fields of health statistics, epidemiology, and the provision of health services.

Members shall be invited to serve for overlapping three-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 the expiration of the term for which his predecessor was appointed shall be appointed only for the remainder of such term. A member may serve after the expiration of his term until his successor has taken office.

Management and staff services shall be provided by the Office of Program Development and the Associate Director of Program Development, National Center for Health Statistics, who shall serve as Executive Secretary.

Meetings

Meetings shall be held biannually or at the call of the Chairperson, with the advance approval of a Government official who shall also approve the agenda. A Government official shall be present at all meetings.

Meetings shall be open to the public except as determined otherwise by the Secretary; notice of all meetings shall be given to the public.

Meetings shall be conducted, and records of the proceedings kept, as required by applicable laws and departmental regulations.

Compensation

Members who are not full-time Federal employees shall be paid at the rate of \$100 per day, plus per diem and travel expenses, in accordance with 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 \$20,758. Estimate of annual man-years of staff support required is 2.1, at an estimated annual cost of \$50,079.

Reports

An annual report shall be submitted to the Secretary through the Assistant Secretary not later than October 15 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 United States National Committee on Vital and Health Statistics is continuing, and a new charter shall be filed no later than July 23, 1978, 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: June 24, 1976

David Mathews
Secretary

ANNUAL REPORT OF THE UNITED STATES NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS FISCAL YEAR 1978

The United States National Committee on Vital and Health Statistics (USNCVHS) is the official external advisory body to the Secretary of Health, Education, and Welfare in the field of health statistics. Established by the Secretary in 1948 at the request of the World Health Organization (WHO), it received statutory authority in 1974 in Public Law 93-353. As part of the Public Health Service (PHS) reorganization that included transferring the National Center for Health Statistics (NCHS) to the Office of the Assistant Secretary for Health Statistics (OASH) in December 1977, the USNCVHS was also moved to OASH and is staffed by the Office of Statistical Policy, Office of Health Policy, Research, and Statistics (OHPRS).

Public Law 93-353 gives the USNCVHS a broad mandate to assist and advise the Secretary in all matters pertaining to the development of a responsive and efficient national health statistical system and to the promotion of international cooperation in health statistics. In previous annual reports the Committee has acknowledged the broad scope of health data systems sponsored by both public and private agencies in the United States and recognized the general high level of technical competence with which this Nation acquires, processes, and tabulates data. At the same time, the Committee has identified weaknesses in the way data systems of the Department of Health, Education, and Welfare (DHEW) are used, particularly for purposes of informing the public about health matters and illuminating political decisions. The op-

portunity to make fuller use of these data systems is diminished in part because of disparate coding conventions, terms, and definitions resulting in overlapping, sometimes duplicating, data sets organized under different jurisdictions and designed to meet different objectives. The opportunity is also diminished by the lack of resources devoted to analysis of data. Federal health statistical systems are a rich source of information concerning the nature of disease, medical care, and environmental exposure; data existing in the various statistical systems of constituent agencies of DHEW should be brought together through a problem solving approach that defines the issues for analysis, identifies and acquires the relevant data, and provides the resources needed to accomplish these activities.

In achieving a responsive and efficient national health statistical system, the USNCVHS is pleased to note substantial progress during the period covered by this report. The problem of divergent, duplicative coding conventions for classifying disease seems resolved by the agreement among major public and private sector parties to adopt compatible codes based on the Ninth Revision of the International Classification of Diseases beginning January 1, 1979. Evidence of growing awareness of the value of linking various governmental and private sector data sets on a problem solving basis is provided by the Health Services Research, Health Statistics, and Health Care Technology Act of 1978, which calls for mounting of a study of the feasibility of establishing a national data base and its use for actively assisting those exposed to hazardous substances. The USNCVHS is particularly pleased that this legislation identifies the coordinating role of NCHS in promulgating and implementing guidelines for the collection and analysis of data for environmental studies.

Further evidence of progress is found in the generally favorable response to the Statement of Principles on Information Needs for National Health Insurance. These principles, prepared by the USNCVHS Technical Consultant Panel on Statistical Systems for National Health Insurance, are intended as a foundation for the development of data and information systems under national health insurance; they stress the need for an epidemiologically sound (population-

based) data system coupled to an administrative structure that promotes efficiency and effectiveness in the collection, processing, analysis, and dissemination of information. The USNCVHS believes that many persistent problems involving the coordination of statistical systems can be resolved through the careful design of the reporting system that will inevitably accompany any version of national health insurance.

Finally, special note should be made of the progress within NCHS and the National Center for Health Services Research (NCHSR) toward the goal of using multiple sources of data from inside and outside the Government to develop an integrated analysis of health issues and problems relevant to policy. An excellent example of progress along this line is the annual report on the state of the Nation's health: *Health, United States, 1978*. The Committee believes this report stands as a model of the constructive use of health statistics by the Administration to inform Congress and the public about the Nation's health problems.

During the next fiscal year, the USNCVHS will continue its surveillance of the progress of health related statistical systems in the United States and elsewhere. The following sections detail committee activities during the period covered by this report. Adopting the convention of the previous year's report, the activities of the Committee are organized under four interrelated perspectives: conceptual, organizational, technical, and legislative.

CONCEPTUAL OR PLANNING ISSUES

If statistics are to serve as a dynamic instrument for planning and evaluating health policy, they must conform to certain conceptual principles. Chief among these principles is that the statistical system be population-based, i.e., have an epidemiological orientation. Additional principles include comprehensiveness and balance in statistical coverage; comparability in the conventions, terms, definitions, and classifications used; a cooperative approach to data collection, processing, analysis, and dissemination; adequate safeguards for privacy and the confidentiality of data on individuals; efficiency, timeliness, and effectiveness of dissemination; and professional review of the quality and utility of established data systems.

The USNCVHS recommends that these principles serve as guidelines for the construction of new data systems such as may emerge under national health insurance legislation. They should also serve to guide the coordination and reform of existing data sets including those produced by the major DHEW surveys, inventories, and program-specific data systems so that categorical as well as comprehensive statistical systems can contribute to an overall, coordinated, population-based health information system.

Committee Actions During 1978

1. *Health, United States, 1978*: One of the responsibilities of the USNCVHS is to assist and advise the Secretary in the preparation of this report for Congress, the President, and the public. The report provides the data base for information needed by policy decisionmakers. The 1978 report will contain two parts. Part A will have six

chapters: Cost Containment; Prevention; Children and Youth: Health Status and Use of Health Services; Mental Disorders; Long-Term Care: An Overview; and The Quality of Medical Care: Methods for Assessing and Monitoring the Quality of Care for Research and for Quality Assurance Programs. Part B, which includes almost 200 tables, will focus on trend data and will include four sections: Health Status and Determinants, Utilization of Health Resources, Health Care Resources, and Health Care Costs and Financing. Another focus of Part B will be on international comparisons with other developed countries.

2. *The Nation's Use of Health Resources*: The USNCVHS reviewed NCHS activities in developing a companion reference to the report *Health Resources Statistics*. *The Nation's Use of Health Resources* describes ambulatory medical care, inpatient care, home health care, and other health care. The basic data for the report come from NCHS surveys such as the National Ambulatory Medical Care Survey and the National Hospital Discharge Survey. Data are also received from the National Institute of Mental Health (NIMH) and other Federal statistical agencies.
3. *Activities of the Committee on National Statistics—National Research Council*: The USNCVHS heard a report about the Committee on National Statistics which was formed in 1972 by the National Research Council of the National Academy of Sciences. The purpose of the Committee is to encourage the appropriate use of statistical methods and to improve the statistical information on which important public decisions are based. The Committee has conducted studies and produced reports on: *Setting Statistical Priorities*, *Surveying Crimes*, and *Environmental Monitoring*. Ongoing studies are being conducted on Statistics of Skin Cancer, Privacy and Confidentiality Issues Related to Statistical Field Surveys, Productivity Statistics, and on preparation for the 1980 Census.

Other areas the Committee is actively engaged in are assisting the Commission on Federal Paperwork in reducing the reporting burden, working with the new Committee on Population and Demography of the Assembly of Behavioral and Social Sciences, and participating with the Institute of Medicine in planning a minisymposium on cancer incidence related to man-made chemical environmental carcinogens.

4. *Health Indicators:* The USNCVHS reviewed the work on Health Indicators of the Organization for Economic Cooperation and Development (OECD). OECD has been developing a set of internationally comparable health and social indicators. Eight countries and WHO working together under what are described as "Common Development Efforts" (CDE) areas are attempting to establish international comparability for measuring "Healthfulness of Life." Initial efforts have been aimed at developing a set of measures for the handicapped which could be used across countries. Although problems have been encountered regarding interpretation and translation of the measures, general agreement has been reached in the areas of mobility, self-care, and communications activities. Once the complete set of measures are firmly agreed on, they will be field tested and used by the eight countries in the CDE areas and possibly by other OECD countries as the "Health Indicators" in each of the countries. WHO has indicated an interest in the development of health and social indicators and a broader range of involvement than just that of the OECD countries. WHO is also developing domain specific indicators with the potential for international comparability that would be suitable for developing as well as developed countries.
5. *Terms and definitions:* The USNCVHS reviewed reports on the activities of the following national and international organizations: Council of International Organizations of Medical Sciences; North American Primary Care Research Group; World Organization of National Colleges, Academies, and Academic Associations of

General Practitioners/Family Physicians; Council on Clinical Classifications; Commission on Professional and Hospital Activities; Current Procedure Terminology; and specialty groups such as the pathologists who have developed the Standard Nomenclature of Medicine.

The review of these organizations and their activities directed at defining terms, constructing nomenclatures, and creating classifications schemes was undertaken to bring to the attention of the Committee and others the diversity of activities being carried out on a national and international basis. The review also demonstrated the need for leadership at the Federal level in fostering coordination and collaboration among the public and private sectors and national and international bodies.

6. *Implementation of TCP Report on Statistics Needed for Determining the Effects of the Environment on Health:* The Committee reviewed the progress of the implementation of the recommendations of the Technical Consultant Panel (TCP).

The recommendation to establish a National Death Index is being implemented by NCHS. The recommendation to strengthen the epidemiologic capabilities of NCHS has been accomplished through establishment of the Epidemiology Branch in the Office of Statistical Research. The recommendation to collect data on environmental exposures and morbidity through the ongoing surveys and activities of NCHS is being accomplished through the Health and Nutrition Examination Survey, which is measuring pesticide levels in blood samples and tap water samples.

ORGANIZATIONAL ISSUES

The USNCVHS in carrying out its mandate to advise the Secretary on statistical problems bearing on health and health services addressed the issues of coordination and cooperation emerging from the statistical responsibilities of the diverse health agencies within DHEW.

Particularly affected by these issues is the Cooperative Health Statistics System (CHSS) and its principle of decentralized voluntary cooperation among private and public users of health statistics. Because of limited Federal funding, CHSS has not begun to approach its full potential. This has resulted in widespread concern that CHSS would be unable to supply the data needed to carry out the specific responsibilities assigned to the Health Care Financing Administration (HCFA).

The USNCVHS was encouraged by the reorganization of PHS in December 1977. The creation of the Office of the Deputy Assistant Secretary for Health Policy, Research, and Statistics along with the subsequent realignment of its responsibility for the National Center for Health Statistics, National Center for Health Services Research, and USNCVHS was viewed as a constructive approach to alleviating organizational problems. The Committee also endorsed the proposed formation of a Health Data Advisory Committee in DHEW with a chairmanship rotating between the Deputy Assistant Secretary for Health Policy, Research, and Statistics and the Associate Administrator for Policy, Planning, and Research, in HCFA along with establishment of a PHS Health Statistics Coordinating Committee chaired by the Director of NCHS and staffed by the Office of Statistical Policy, OHPRS.

Committee Actions During 1978

1. *PHS reorganization*: During 1978 the USNCVHS received several briefings by the Deputy Assistant Secretary for Health Policy, Research, and Statistics on the reorganization of the Public Health Service.

The realignments of NCHS and NCHSR were discussed along with the relocation of the Executive Secretariat of the USNCVHS in the Office of Statistical Policy. The Committee learned that the former Health Data Policy Committee was reconstituted as the Health Data Advisory Committee (HDAC), which will serve as an internal advisory body to the Department and to participating components of other departments on major cross-cutting data issues. The HDAC relationship to the USNCVHS will be through an "informal dialogue" to provide each committee with an awareness of the other's activities. The proposed Charter for HDAC has been forwarded to the Secretary and is awaiting his approval.

As previously noted, a PHS Health Statistics Coordinating Committee was established to advise the Assistant Secretary on the technical and operational coordination issues relating to the statistical activities of the six agencies of PHS. The Committee is chaired by the Director of NCHS as delegated by the Deputy Assistant Secretary for Health Policy, Research, and Statistics and staffed by the Office of Statistical Policy.

The revised Charter of the USNCVHS under consideration by the Secretary is basically the same as the earlier version except that it explicitly states that the Committee reports to the Secretary on all health statistics matters of the Department, thus bringing it into conformance with the legislative mandate of the Committee.

The Committee expressed satisfaction with this progress and expressed the opinion that the work of the Com-

mittee in assisting and advising the Secretary on health statistics matters should be greatly facilitated by full participation of all major elements of the Department dealing with health statistical activities.

2. *USNCVHS review of statistical activities of HCFA:* During 1978 the USNCVHS spent considerable time reviewing and discussing the statistical activities of the newly created Health Care Financing Administration. The Committee heard reports from HCFA representatives regarding the impact of Public Law 95-142, which authorized the collection of uniform accounting and discharge data by HCFA.

The Administrator of HCFA is concerned with simplifying and unifying data requirements placed on providers by Professional Standards Review Organizations (PSRO's), Medicaid, and Medicare. The new data requirements have major impacts on hospitals, States, and physicians. It was pointed out that there are approximately 200 million medical bills transacted annually with substantial data requirements.

The Committee reviewed the requirements under Public Law 95-142 which authorize the Secretary to establish uniform reporting systems by type of provider, cost of services, rates, capital assets, and billing data. These data do not have to be reported on a daily basis but will instead be required only once a year; a standard system will have to be used. HCFA is in the process of developing regulations with respect to the collection of the data.

3. *President's Reorganization Project for the Federal Statistical System:* The USNCVHS received a report by Dr. James T. Bonnen, Project Director, of the President's review of the Federal statistical system conducted under the auspices of the Office of Management and Budget.

The issues that will be addressed by the project are

- Establishing priorities and allocating resources.
- Quality of data.
- Integration activities.
- Response burdens.
- Integrity.
- Policy relevance.
- Privacy and confidentiality.
- Access and dissemination.

The primary objective of the project is to identify relevant functions involved in the coordination of the Federal statistical system and then to evolve a system to enhance coordination and maintain decentralization. The project is scheduled to be completed in 1 year. The USNCVHS expressed great interest in the findings of the project as they relate to health statistics.

4. *TCP on Statistical Systems for National Health Insurance*: During 1977 the USNCVHS initiated a technical consultant panel with the charge to delineate the essential features of a statistical system for national health insurance (NHI), to formulate the kinds of policy, function, and organization principles that would be useful in developing proposed legislation to coordinate statistics under national health insurance and to consider the relationship of a national health insurance system to currently operating data systems.

The TCP reported progress in the development of a statement of guiding principles for a national health insurance information system. These principles should provide the basis for the establishment of a statistical support system for national health insurance that will be sufficiently broad based to support long-range evaluation as well as daily operations.

The basic principles provide the foundation for development of data and information systems for NHI. Two essential features prevail—data should be *population*

based, and the structure and administrative organization of data activities should *promote efficiency and effectiveness* in the collection, processing, analysis, and dissemination of information. Several principles follow:

- The information system must have the capability to count the number of *persons* enrolled, the number served, and the services used and to link these measures to available resources, NHI revenues and expenditures, and health status.
- Data on the size, demographic characteristics, and health services received by the *whole population* should be available to the NHI information system in addition to data on population groups and services covered by NHI. This comprehensive scope is needed to maintain understanding of the experience of persons not covered by NHI and of the use of services not covered by NHI beneficiaries.
- The *privacy and confidentiality* of data on individual patients must be safeguarded while providing access by responsible users to information required for health planning, research, evaluation, and monitoring.
- There should be *clear designation of authority and responsibility* for data activities at Federal, State, and local levels and between the public and private sectors.
- Reporting requirements should *minimize the burden* imposed on data suppliers and processors while assuring sufficient amounts and types of data to serve NHI information needs.
- Data items and sources needed for planning, evaluation, and research as well as management should be clearly defined, taking into consideration existing data systems.
- *Uniform Minimum Data Sets* such as those currently available should be established and promulgated by the NHI authority to assure comparability and completeness of reporting.
- Reporting mechanisms should accommodate *multiple uses* and *minimize duplicate or repeated reporting* of invariable data.

- Mechanisms must be built into the information system to assure *accurate and timely collection, processing, and retrieval of data.*
- Emphasis should be placed on *meeting the information needs of providers and consumers of care* as well as NHI managers and policy analysts.

5. *Establishment of a Cooperative Health Statistics System*
 TCP: During 1978 the USNCVHS approved the formation of a TCP on the Cooperative Health Statistics System. The charge to the TCP is to provide the USNCVHS with assistance and advice on the program as follows:

- With respect to the design of the approval of health statistical and health information systems within DHEW which have as an objective the production of local, State, and national statistics.
- For the adoption or implementation by local, State, or national agencies of findings and proposals developed by other organizational agencies.

Specific charges to the TCP include making recommendations to the USNCVHS

- On general program policy and plans for research, development, implementation, and technical support of CHSS
- To assure that national, State, and local agencies are appropriately involved in formulating decisions regarding the definition of CHSS and its administration.
- With respect to reports and recommendations of the former Cooperative Health Statistics Advisory Committee such as the report on the designation and development or organizational structure and the report of the Task Force on Cost Sharing.
- To improve the access to and use by health program planners, directors, and researchers at the national, State, and local level of data collected by CHSS.
- With respect to technical issues of major import to cooperation and integration of health data systems such as confidentiality, geocoding, quality control, and model laws.

6. *Establishment of TCP on Mental Health Statistics:* During 1978 a TCP on Mental Health Statistics was established to make recommendations to the USNCVHS about the mental health aspects of Federal health surveys and statistical reporting systems. These recommendations should result in the maximal comparability of mental health data developed by NCHS, NIMH, and State and local mental health agencies to fulfill their respective general purpose statistical needs and program related data needs.

The specific charges assigned to this TCP are as follows:

- a. To examine the national, State, and local needs for mental health data.
- b. To assess which of these needs can now be met through existing data systems (such as those of NIMH and CHSS or other NCHS programs) and which needs require either new data programs or modifications to existing ones.
 - To recommend what, if any, changes are appropriate to enable needs for mental health data to be met by the existing systems.
 - To recommend the design and content of new mental health data programs to meet needs not being met by existing systems.
 - Specifically, in this context, to examine the feasibility of establishing a mental health component or subcomponents within CHSS and to make recommendations as appropriate.
- c. To examine the relationships of the current Mental Health Uniform Data Sets to other data sets and recommend any modifications needed to maximize the consistency of all uniform minimum data sets.
- d. To examine current practices at the State level of integrating the mental health and health data systems and recommend principles and alternative models for future cooperation at the State level.

TECHNICAL ISSUES

There is unanimity in the concept that there must be widespread agreement on the basic terms, definitions, and classifications employed in order for health statistics to be useful as expressions of trends or variations in health. In keeping with this concept, the USNCVHS in 1978 vigorously pursued its objective of developing and promulgating, through DHEW, minimum basic data sets for reporting various modes of patient care in ambulatory, hospital, and long-term care, as well as data sets for classifying health manpower and facilities. With respect to the responsibility of USNCVHS to advise the Secretary on statistical activities related to international activities, the Committee reviewed, followed, and made recommendations on the progress and development of the Ninth Revision of the International Classification of Diseases Clinical Modification (ICD-9CM) in 1978. During the same time, the Committee continued its ongoing review of the various DHEW data systems.

Committee Actions During 1978

1. *International Classification of Diseases*: The USNCVHS in 1978 received several briefings on the progress and development of the Ninth Revision of the International Classification of Diseases (ICD-9) and ICD-9CM. The ICD-9CM is a clinical modification of ICD-9 and is collapsible to the fourth-digit level of ICD-9. There is in reality single classification, the clinical modification being a more detailed version of ICD-9. It is generally accepted that mortality coding does not require the specificity found in the clinical modification version. DHEW is supporting the use of ICD-9 for mortality purposes and ICD-9CM for morbidity uses. This concept was approved by the Committee.

The WHO Center for Classification of Diseases in North America, located in NCHS, is developing a new conceptual framework for the Tenth Revision. The proposal is based on the use of a single core classification with a series of modules related to the core. The modules could be developed to various levels of complexity and specificity to cover a variety of different but related classification needs. This flexibility would permit the use of these modules in both the developing and developed countries. This proposal was presented to the Heads of WHO Centers meeting in Brazil in January 1978. The concept was generally accepted by the other centers and by WHO Headquarters Office in Geneva.

2. *Minimum basic data sets*

a. Ambulatory Medical Care Data Set

The Chairman of the Ambulatory Medical Care TCP reviewed the status of the final report. The data set proposed by the TCP will be patient oriented rather than provider oriented. It will also clarify the role of the provider and will capture a greater proportion of the services provided by nonphysicians. The data set will be minimum, and the information obtained will aid the provider in recall of problems, diagnoses, and treatments; document encounter content; facilitate data reporting for reimbursement purposes; and facilitate the abstraction of data by Federal, State, and third-party users.

The data set will be divided into four modules: (1) the registration module containing patient characteristics, provider characteristics, and specific patient-provider encounter characteristics, (2) the encounter content module describing services provided the patient at the time of the encounter, (3) the patient's reason for encounter module describing the patient's view of the need for the encounter, and (4) the charges module describing the charges made for services provided during the encounter. The TCP also recommended that the USNCVHS encourage

a direct effort to develop a comprehensive classification scheme for all types of problems presented by ambulatory care patients; consider the need to establish guidelines for recording data; monitor the quality of the data reported by users of the Uniform Ambulatory Medical Care Data Set; and support research to assess the extent of use of the data set over time. The TCP also recommended that the problems of confidentiality, geocoding, and definition of costs of health care be reviewed and specifically defined in all data sets.

The Ambulatory Medical Care Data Set will be mailed to more than a thousand individuals in Health Systems Agencies (HSA's), PSRO's, schools of medicine and public health, and other organizations concerned with ambulatory care for review and comment. A compilation of the comments and recommendations will be reviewed by the TCP before the final report is submitted to the USNCVHS.

b. Long-Term Care Data Set

The Chairman of the TCP reported that the TCP has settled on the elements to be included in the data set and has agreed to the rationale for inclusion of each item.

The data set has been mailed by NCHS to 1,400 individuals in HSA's, PSRO's, schools of medicine and public health, and other organizations involved in long-term care for review and comment. The response has been excellent and a compilation of the comments will be reviewed and analyzed by several members of the TCP. Comments and recommendations will be incorporated in the final report presented to the USNCVHS.

c. Manpower and Facilities Data Sets

During 1978 the Manpower and Facilities TCP moved to a final review of the Manpower Minimum Data Set

proposed by the TCP. There are a few outstanding issues still to be resolved on several items of the data set. A rationale has been developed for each item in the Manpower Minimum Data Set and will be circulated to all TCP members before the next meeting of the TCP.

A draft revision of the Facilities Minimum Data Set has been completed with several items modified, others added, and some deleted. This draft will be reviewed and discussed by the TCP. A draft of the rationale for each of the items in the Facilities Minimum Data Set has been prepared. However, if substantial changes are approved by the TCP in the data set as suggested, additional work will be required on the rationale.

It is planned to disseminate both the Manpower and Facilities Minimum Data Sets to the field for review and comment in the manner used for Long-Term Care and Ambulatory Medical Care Data Sets. A draft report is being written and will be reviewed by the TCP in early 1979 and later by the USNCVHS.

d. Uniform Hospital Discharge Data Set

At the May 1978 meeting of the USNCVHS, a report was given of the UHDDS "Procedures" data items. The Committee agreed to adopt in principle the UHDDS procedures classification and to recommend that DHEW modify it as necessary and promulgate it promptly. The earlier UHDDS TCP report was modified to reflect this action and forwarded to the Secretary and NCHS for publication and dissemination.

3. *Review of data systems:* In keeping with its view that routine surveys and data systems should be periodically assessed, the USNCVHS established a TCP to review the Health Interview Survey (HIS) and reviewed the activities of the National Ambulatory Medical Care Sur-

vey (NAMCS) and the statistical activities of the Center for Disease Control (CDC).

a. Health Interview Survey

The charge to the Panel is to review and revise HIS through expansion and revision of the questions; collection of subnational data by altering the sample size and survey design; and development of new methods of survey research including mail and telephone interviews.

The TCP has concentrated on the following issues: the possibility of redesigning the survey to produce subnational data as well as national data by using new methods such as random digit dialing telephone interviews; exploration of new methods for the collection of data; and development of planned approaches for the collection of supplemental data to provide greater consistency with the core data and with other NCHS surveys.

b. National Ambulatory Medical Care Survey

The USNCVHS reviewed the current status of NAMCS, a continuing survey of a national probability sample of office-based physicians who, in turn, report on a sample of the patients they see for a period of 7 days. The aggregated reporting period is 1 year, and the response rate is over 80 percent.

Two major evaluation studies have been carried out in relation to NAMCS. One examined the possibility of collecting data from hospital outpatient departments, and the other attempted to measure the understanding of NAMCS by physicians and their staff as an index of the quality of data received in the survey. A new proposed study will evaluate the feasibility of collecting data from hospital emergency rooms and from physicians who are not office based.

Staff reported that data from NAMCS have been similar from year to year in terms of diagnosis and types of care provided; there has been little change in the trends. It may be important, therefore, to add the data from outpatient departments, emergency rooms, and other ambulatory medical care clinics to the survey so that total national estimates for ambulatory care can be developed.

c. Statistical activities of CDC

The Director of CDC reported on the statistical activities of that agency. The mission of CDC is to reduce preventable morbidity and mortality. The major functional areas of the Center for Disease Control are epidemiology, surveillance, Federal grant disease programs, occupational safety and health, laboratory support, training programs, and operational research.

The statistical activities of CDC include detecting unusual occurrences, studying epidemics, assessing control measures, and monitoring activities.

CDC publishes the *Morbidity and Mortality Weekly Report* (MMWR) which is a summary of reportable diseases in each State. These reports include summarized data that display trends over time on specific reportable conditions. Periodic surveillance reports are also issued on special conditions. Currently there are 30 conditions and diseases reported in MMWR. Other statistical activities of CDC include international surveillance of disease of foreign origin; participation in the reporting network of WHO and the Pan-American Health Organization; and administration of federally supported programs for control of venereal diseases, lead poisoning prevention, urban rat control, influenza reporting, surveillance of vaccine distribution, investigation of epidemics, and investigation of individual cases in States.

The Director of CDC emphasized that access to identifiable patient records is essential to the functions of surveillance, which requires conducting interviews and related investigations to determine origins and sources of epidemics.

LEGISLATIVE ISSUES

The Health Services Research, Health Statistics, and Health Care Technology Act of 1978 renews the legislative mandate for the USNCVHS and adds several significant modifications to the language of the previous legislation establishing the Committee. The name of the Committee is changed to the National Committee on Vital and Health Statistics, (NCVHS), United States, being dropped from the title. In addition, the Committee's functions are expanded to include assisting and advising the Secretary with respect to the requirements of the Cooperative Health Statistics System set forth in the law. It adds health planning as a field from which persons may be appointed to NCVHS.

Committee Actions During 1978

1. *Confidentiality issues: status of DHEW review of the report of the Commission on Privacy:* In 1977 the Committee reviewed the proposed legislation Public Law 95-142 dealing with hospital care data and specifically the Crane Amendment to that bill which would prohibit Federal employees and their agents from having access to medical records. The Committee instructed its Chairman to write the Assistant Secretary for Health and all members of the Ways and Means and Commerce Committees of the House urging them to postpone passage of Section 1125 (Crane Amendment) of the Social Security Act (Public Law 95-142) on the grounds that (1) they should await the results of the full Department study of the Privacy Protection Study Commission, (2) the interests of all citizens need to be safeguarded equally, and (3) the USNCVHS and the Assistant Secretary for Health need to

be made aware of all outside reviews of and comments pertaining to this bill.

2. *Proposed legislation—Cancer Prevention Act of 1978, H.R. 10190*: Representative Andrew Maguire addressed the Committee on H.R. 10190, The Cancer Prevention Act, and the specific provisions of a study of the feasibility of establishing a national registry or data base which were subsequently incorporated into H.R. 12584, the Health Service Research and Health Statistics Amendments of 1978.

Representative Maguire stated that data are needed on the effects of environmental factors on the population. He reported that the National Institute for Occupational Safety and Health has estimated that 16,500 chemicals are toxic. Approximately 1,500 of these are suspected carcinogens. CDC estimates that there are probably 100,000 excess deaths annually due to occupational exposures to toxic substances. The magnitude of this health hazard makes it imperative that agencies obtain data on employers' use of toxic chemicals and other hazardous substances, the number of workers exposed, and the effects of such exposures on workers' health.

Representative Maguire outlined the objectives of his proposed study which relates directly to several specific amendments to the National Cancer Act. The objectives are to facilitate studies of the effects of hazardous substances on humans and to assist Federal, State, and other entities in locating individuals who have been or may have been exposed to hazardous substances, to determine the effects on their health, and to assist them in obtaining appropriate medical care and treatment. Representative Maguire referred to the report of the USNCVHS TCP on *Statistics Needed for Determining the Effects of the Environment on Health*. The recommendations of this report offer a starting point from which the study might begin. He said that the results of this TCP report suggest that the USNCVHS is well suited to coordinate the study proposed in his amendment.

Representative Maguire discussed how this proposed study fitted in with the statistical activities of NCHS and NCHSR and the need to evaluate medical technologies. He indicated that the Subcommittee on Health and Environment is revising the authorities for the two Centers and that specific provisions included would require NCHS to conduct a study of the cost associated with environmentally related diseases and would mandate that NCHS promulgate and implement guidelines for the collection of statistics necessary for determining the extent to which environmental factors cause or contribute to disease and other adverse health effects.

The Committee unanimously approved the following motion:

“To establish a TCP to conduct a study of the feasibility of creating a national tumor registry to deal with generic issues of reporting all tumors, other than discrete registers for specific disease entities, and to relate this activity to the National Death Index, and the activities of the National Cancer Institute.”

APPENDIX I

Public Law 93-353 Section 306(i)

“There is established in the Office of the Secretary a committee to be known as the United States National Committee on Vital and Health Statistics (hereinafter in this subsection referred to as the ‘Committee’) which shall consist of fifteen 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, epidemiology, and the provision of health services. Except as provided in subparagraph (B), members of the Committee shall be appointed for terms of three years.

“(B) Of the members first appointed—

“(i) five shall be appointed for terms of one year,

“(ii) five shall be appointed for terms of two years, and

“(iii) five shall be appointed for terms of three years, as designated by the Secretary at the time of appointment. Any member appointed to fill a vacancy occurring prior to the expiration of the term for which his predecessor was appointed shall be appointed only for the remainder of such term. A member may serve after the expiration of his term until his successor has taken office.

“(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, Education, and Welfare, (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, Education, and Welfare;
 - “(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 improve-

ment of the Nation's health statistics and health information systems.

“(5) In carrying out health statistics under this part, the Secretary shall consult with, and seek the advice of, the Committee and other appropriate professional advisory groups.”

APPENDIX II

TECHNICAL CONSULTANT PANELS

CONSULTANTS ON AMBULATORY MEDICAL CARE DATA SET

Maurice Wood, M.D., Director of Research, Department of Family Practice, Medical College of Virginia, Richmond, Va., Chairperson

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Carmalt B. Jackson, Jr., M.D., Associate Director, M.D., Anderson Hospital and Tumor Institute, Texas Medical Center, Houston, Tex.

Carol A. Lewis, Medical Records Administrator, Pan American Health Organization, Washington, D.C.

Nora Piore, Professor of Health Administration and Associate Director, Center for Community Health Systems, School of Public Health, Columbia University, New York, N.Y.

Sam Shapiro, Director, Health Services Research and Development Center, Baltimore, Md.

Doris H. Thompson, M.D., Director, City of New Orleans Health Department, New Orleans, La.

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Karen Davis, Ph.D., Deputy Assistant Secretary for Planning, Evaluation/Health, Designate, Washington, D.C.

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Anne A. Scitovsky, Chief, Health Economics Division, Palo Alto Medical Research Foundation, Palo Alto, Calif.

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Allen J. Manzano, Vice President, American Hospital Association, Chicago, Ill.

Vergil N. Slee, M.D., President, Commission on Professional and Hospital Activities, Ann Arbor, Mich.

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APPENDIX III

FISCAL YEAR 1978

NATIONAL COMMITTEE MEETINGS

October 12-13, 1977

January 11-12, 1978

May 3-4, 1978

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