

The United States National Committee on Vital and Health Statistics

Fiscal Year 1977

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NATIONAL CENTER FOR HEALTH STATISTICS

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service
Office of the Assistant Secretary for Health

ANNUAL REPORT OF

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

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**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 \$26,156. Estimate of annual man-years of staff support required is .85, at an estimated annual cost of \$15,400.

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 1977^a

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 (HEW) 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.

For many years the USNCVHS has been attached for administrative purposes to one of the subdivisions of the Public Health Service (PHS). As part of a PHS reorganization that included transferring the National Center for Health Statistics (NCHS) to the Office of the Assistant Secretary for Health (OASH) in December 1977, the USNCVHS was also moved to OASH and is staffed by the Office of Statistical Policy, OHPRS.

Public Law 93-353 gives the USNCVHS a broad mandate to assist and advise the Secretary of HEW 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. First among its duties is to assist the Secretary in "delineating the statistical problems bearing on health and health services which are of national and international interest".^b In view of these responsibilities and the improved opportunities for communication as a result of the Committee's reconstitution under Public

^aThis report covers the period July 1, 1976-December 30, 1977.

^bSee appendix I for full text of Section 306(i) in Public Law 93-353 pertaining to the USNCVHS.

Law 93-353, this year's Annual Report seeks to identify and comment on the basic issues that have occupied its attention, and to discuss its major activities and recommendations within the context of these issues.

The USNCVHS believes that the United States is probably one of the world's leaders with respect to the scope of its health data systems and the technical competence with which it acquires, processes, and tabulates data. It appears to be rather less advanced than certain other countries, however, with respect to some of the ways in which information can be analyzed, interpreted, and presented for the purposes of informing the public and illuminating political decisions. The basic problem may best be described as lack of a sufficiently well-planned and integrated approach to the acquisition and dissemination of health information across the Department. We have a wealth of data sources about the health of the population and the activities aimed at improving health, but we experience great difficulty in linking these sources together and translating data into the kinds of information needed by decision-makers. In some areas, there is duplication, different definitions for the same term, and other evidence of incomplete coordination causing confusion, unnecessary work for respondents, and excessive costs. In other areas the essential facts are missing.

The general problem of developing well-integrated and balanced health and other statistical systems for the country has been addressed by many external commissions and internal review bodies over the years. A certain amount of untidiness is inevitable in a political system that encourages diversity, decentralization, and the balancing of opposing interests. No statistics, especially health statistics, are value-free. Differences of opinions over the appropriate roles of the many private and public sectors in health affairs are inevitably reflected in differences of opinion over the kinds of health statistics the country needs, and how our data systems should be organized and controlled. In a sense, a country gets the health statistics it wants, and some of the present conflicts in health statistical policy may actually be constructive.

The effects of our political system on health statistics are

heightened at this time, however, by the fact that there is considerable uncertainty and indecision over the direction of Federal policy; under the circumstances, rational planning of an overall health statistics system is difficult. Also it is apparent that the rapid growth of the health care industry in the last decade, and of Federal involvement in its operations, has placed a severe strain on the existing statistical systems and its available resources. Finally, it should be noted that the means available to those responsible for planning our statistical systems for increasing the efficiency and effectiveness of the country's data systems are still largely the traditional ones of persuasion, communication, and coordination.

The following discussion shows that a number of constructive steps have been taken in the past year and that there are many opportunities for further improvements. The overall problem of developing, maintaining, and using a comprehensive, effective, and efficient data base for decision-making in health affairs is viewed in this Report from four interrelated perspectives: conceptual, organizational, technical, and legislative.

CONCEPTUAL OR PLANNING ISSUES

Efforts of the Department of Health, Education, and Welfare (DHEW) to rationalize existing data systems, to identify missing areas, and to transform statistics into a dynamic tool for planning and evaluating health policy clearly suffer from the lack of agreement on a common conceptual framework or set of guiding principles. Chief among these principles, in the view of the USNCVHS, is a population-based or epidemiological orientation. Important additional elements are comprehensiveness and balance in statistical coverage; comparability in the conventions, terms, 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 peer review of the quality and utility of established data systems.

In presentations made to the USNCVHS during 1977, it was obvious that many agencies with administrative responsibilities to health in DHEW and in other Federal departments collect the data they consider necessary for their own purposes without regard to their utility for others, and with little awareness of other data systems or sources that may duplicate or complement their own. There appears to be room in the Department for greater coordination and common purpose among the major surveys, inventories, and program specific data systems. Coordination of effort reduces isolation of data systems from each other and avoids isolation of those who collect the data from those who analyze and use them. Without such coordination there is risk that data systems may be continued indefinitely and at considerable cost, without a hard look at their utility.

The essential population perspective is often lacking in many of DHEW's data systems because of the fragmentation

of data responsibilities. The incidence and prevalence of specific diseases, disabilities, or use of services are recorded and reported without relating the findings to the total burden of illness and disability in the population and its subgroups. Health facilities and manpower, the use of services, and costs and expenditures for these services are measured separately so that the relationships among them, and the workings of the health care system as a whole, are obscured rather than illuminated. In turn the the impact of the overall health care system, or even the medical care component of it, is not systematically viewed in relation to health needs and health status of the population, so that the provision of medical services or containment of costs become ends in themselves. The larger physical, economic, and social environment in which people live is generally treated as a separate subject in which health statisticians have only a peripheral involvement. However, most health policy decisions depend upon being able to make these linkages.

The kinds of questions our statistical systems must help to answer center around the relative importance of health problems; the identification of high-risk or underserved groups in the population; the complicated interplay of resource distribution and resource mix on access, patterns of use, and cost; the outcome or impact on health status of specific programs, interventions, or resource combinations; and the cost-benefits of alternate courses of action, including primary prevention and improvements in the social and physical environment, as well as the provision of medical services.

Traditionally a distinction has been made in government circles between "general-purposes" or "baseline" statistics and "program" statistics. However, this would appear to be largely an anachronism, or at least counter productive. Most agencies produce some statistics of general interest as a byproduct of administering their special programs. Some are sufficiently comprehensive in their interest or coverage—for example Medicare, the National Institute of Mental Health, or the Center for Disease Control—to qualify as sources of "baseline" statistics. Data systems set up exclusively for the management of discrete programs are an expensive and often

transient luxury. Because they are not integrated into the mainstream of health statistics, they tend to develop their own terms of reference and limited measures of performance, making evaluation in relation to population-based measures of need, benefit, and satisfaction impossible. These special-purpose systems may demonstrate whether or not a program is administered efficiently and in compliance with the legislation without answering the more basic policy question of whether it is effective and efficacious. Also the systems are frequently immune to external review. An essential step in statistical coordination in DHEW, and at all levels of government, is formulation of a conceptual framework or matrix and relevant guidelines and conventions to integrate categorical and comprehensive data sources into an overall coordinated population-based health information system.

A final weakness in our statistical planning is insufficient appreciation of the value of cross-national comparisons. By means of internationally agreed terms, definitions, and classification systems, and by collaboration in the design and conduct of national surveys, we can greatly expand our understanding of our own health care system as well as benefit from technical cooperation.

Committee Actions During 1977

1. *Technical Consultant Panel on Organizing Principles for Health Information:* At its April 1977 meeting, the USNCVHS set up a general panel to coordinate the work in progress of its other panels on minimum basic data sets (see section on Technical Issues), to resolve problems common to all the data sets, and to develop a comprehensive conceptual framework for planning and organizing health information systems.
2. *Environmental health and fertility statistics:* The USNCVHS approved for publication two new reports prepared by its technical consultant panels: "Statistics Needed for Determining the Effects of the Environment on Health" (DHEW Publication No. (HRA) 77-1457, Series 4, No. 20, July 1977); and "Statistics Needed for

National Policies Related to Fertility" (DHEW Publication No. (PHS) 78-1455, Series 4, No. 18). It is hoped that these reports will promote better measurements and thereby better understanding of environmental, social, and personal determinants of health and of demand on the health services system.

3. *Health, United States, 1976-77*: One responsibility of the USNCVHS is to assist and advise in the preparation of this new series of annual reports. In addition to its primary purpose as a source of information for Congress, the President, and the public, it is viewed by the USNCVHS as an important contribution to the inter-agency collaboration and the evolution of a coherent statistical policy across DHEW. Plans and progress of the 1976-77 and 1978 reports were monitored during the year. The final draft of the 1976-77 report was reviewed in depth by a special task force of the Committee in October 1977. The Task Force on Reports was impressed with the overall excellence of the report and the accompanying chart book. It considered the special-emphasis chapters successful and well worth continuing and applauded the "people" orientation in the chapter on the health of the elderly and in the tables in general. Specific reservations about certain features that might have been interpreted as policy statements not supported in the data in one chapter and the need for a clinical perspective in another were discussed with the staffs of NCHS and the National Center for Health Services Research (NCHSR) and changes were made.

The Task Force recommended improvements in the review process in the coming year and urged that more staff be made available for this important undertaking. It also noted the need for developing more information on the environment and on personal determinants of health in future editions, and recommended continuity in the basic tables to allow the development of trends over time. On the strength of the Task Force's report and the subsequent changes made, the USNCVHS approved and

endorsed the 1976-77 edition and chart book, and complimented its designers and authors. The Committee also urged that more staff be made available for this important undertaking.

4. *Review of other reports:* Other major reports pertaining to statistical policy and planning reviewed and commented on by the USNCVHS Task Force on Reports, and individual members were: the draft chapter on health statistics in *A Framework for Planning U.S. Federal Statistics, FY 1978-89* prepared by the Statistical Policy Division of the Office of Management and Budget; the *Public Health Service Forward Plan for Health, FY 1978-82*; and the *Health Statistics Plan, FY 1978-82*, prepared by the Health Data Policy Committee (HDPC) in the Office of the Assistant Secretary for Health. The latter report was considered an especially valuable contribution to the coordination of health statistical activities. Further work was recommended on the rudimentary conceptual framework in the *Health Statistics Plan*. The USNCVHS adopted a resolution recommending that the Report's inventory assembled by HDPC, and included in the report, of the 282 health data systems operated by DHEW (as well as 12 maintained by the Veterans Administration and the Department of Defense) be computerized; that it be expanded in regard to key words, lists of specific tables, and plans for dissemination; that clearance mechanisms for data systems be strengthened; and that adequate staff be provided to HDPC for these purposes. The USNCVHS further recommended that steps be taken to insure better coordination between the *Health Statistics Plan*, the *PHS Forward Plan for Health*, and the annual report to Congress, *Health, United States*.
5. *International collaboration:* In addition to reviewing technical problems and plans connected with the International Classification of Diseases (ICD) and discussed below, the USNCVHS heard progress reports from the NCHS Office of International Statistics and visiting WHO representatives. In view of the importance of interna-

tional collaboration and extensive NCHS involvement in the ICD, the Committee expressed concern over the lack of statistical representation in the U.S. delegation to the World Health Assembly and at meetings of the WHO Executive Board, and recommended to the Assistant Secretary for Health that this omission be corrected. The Committee further moved that the United States support with Public Law 480 ("Food for Peace" Act) funds in Egypt, and with technical participation, two new WHO projects to develop Health Indicators and to broaden the conceptual framework for the international classification of diseases and health problems to guide the creation of the Tenth Revision of the ICD. It also expressed support for NCHS participation in the work being done by the Organization for Economic Cooperation and Development on Social Indicators in general, including Health Indicators.

ORGANIZATIONAL ISSUES

It is clear from the issues brought before the USNCVHS during 1977 that organizational arrangements and authorities in DHEW and the Federal Government are in part responsible for the present fragmentation, redundancy, confusion, and dissension in health statistics, not only at the national level but also at State and local levels. Reorganization in the Public Health Service in December 1977, as well as the negotiation of a number of new interagency cooperative arrangements, could help to improve efficiency and narrow the gap between special-purpose and general-purpose data systems. The elevation of the National Center for Health Statistics to the Office of the Assistant Secretary for Health places it in a somewhat more advantageous position to serve as the 'lead' agency for health statistics. Bringing together NCHS, NCHSR, and the external advisory committee, the USNCVHS, under a newly created Deputy Assistant Secretary for Health Policy, Research, and Statistics should also be a constructive move. However, these changes do not affect the Department as a whole. Insofar as coordination of Federal health statistics policy is concerned, the confusion may not have been entirely dissipated by recent organizational changes.

At the heart of the present debate is the Cooperative Health Statistics System (CHSS) and the principles it embodies of voluntary cooperation among private and public users of statistics and decentralization of statistical activities. The CHSS, to which PHS is committed, was established by Congress with Public Law 93-353. It is designed to meet the concerns and needs of State and local planning agencies (Health Services Administration), cost and rate review commissions, and other State agencies, voluntary associations, and Professional Standards Review Organizations, as well as those of the Federal Government. The CHSS has been

evolving slowly, in part because of potentially conflicting Federal policies and limited Federal funding. Concerns are expressed that the voluntary decentralized approach may not meet short-range needs and that CHSS, for example, will be unable to supply the data needed to carry out specific responsibilities. A very real danger exists that a unilateral imposition of new reporting requirements on the providers of care could materially retard the entire long-range development of a cooperative system. Equally serious in the long run, assuming that some form of a national health plan, with the probable inclusion of national health insurance will emerge, is the prospect that the choice of data on health services manpower and facilities, use of services, and costs and expenditures will be determined almost exclusively by the needs of the current payment mechanisms. Thus the data collected will be effectively divorced from population-based measures of health status that should be both the starting point for planning health services and the end point for evaluating them; and that it will not be readily available to State and local planners and the private sector.

Present organizational arrangements in DHEW do not appear equal to the task of resolving the conflicts that arise between the specific and centralized responsibilities of Health Care Financing Administration (HCFA) and the more diffuse and decentralized responsibilities of PHS. As part of PHS, NCHS is limited in its ability to serve as the focal point for all DHEW health statistics as mandated by Public Law 93-353. Plans to replace the internal DHEW Health Data *Policy* Committee by a Health Data *Advisory* Committee suggest that coordination among the health-related agencies of DHEW will continue to present problems. In addition, the potential that exists in an external advisory body like the USNCVHS to see that all interests are represented is not being realized because it does not report directly to the Secretary; instead it reports indirectly through the Assistant Secretary for Health.

In regard to coordination of DHEW statistical activities with those of other Federal agencies, the only change made during the year was relocation of the Office of Statistical Policy, Office of Management and Budget (OMB) to the Department of Commerce. However, OMB continues to coor-

dinate health and other statistics by means of its control over the preparation of the budget and by its responsibility for clearing Federal data collection forms. It is not yet clear what the effects of this change will be. At the Federal level, too, there is evident need for better coordination mechanisms, especially in regard to data systems on environmental and occupational health, which are presently scattered throughout the government and of little practical assistance to policymakers.

Committee Actions During 1977

1. *Implementation of the Uniform Hospital Discharge Data Set (UHDDS)*: The USNCVHS has continued to work in every way possible to resolve differences between HCFA and the Health component of DHEW over the UHDDS, but so far without success. The UHDDS, as the first of a recent series of minimum basic data sets, had its origins in a conference of public and private users and providers of information on short-stay hospital inpatients at Airlie House in 1969. It was subsequently refined, tested, and promulgated by the USNCVHS in 1974, endorsed by the then Secretary of HEW and by national organizations like Blue Cross, the Health Insurance Association of America, and the American Hospital Association, and adopted by most hospital discharge abstracting systems. Disagreement among the affected agencies in DHEW and inaction on the part of DHEW leadership concerning the UHDDS led to further review by a technical consultant panel of the USNCVHS, with special attention to methods of implementation. In early 1976 a second set of recommendations and resolutions were forwarded to the Assistant Secretary for Health, and they still await action.

At issue is the data set itself, the importance of collecting it, and whether HCFA, Medicare, Medicaid, and the PSRO programs will participate in shared data systems in keeping with public Law 93-353, the policies of CHSS, and the recommendations of the USNCVHS, or will set up their own direct method of data collection. Proposed regulations by Social Security Administration (SSA), now

HCFA, that a special form be used to report the UHDDS elements, that the data be collected as part of the billing process, and that the Social Security number be used as the unique identifying number for patients and physicians are examples of the procedural issues that have been exhaustively debated. Although these measures may be expedient for HCFA, they make it extremely difficult to implement the model of a single, statewide "data broker" system which has been endorsed by the USNCVHS to cover *all* hospital inpatients and supply data to *all* qualified users. For example, current restrictions on public use of the Social Security number, its possible limitations as a universal identifier, and confidentiality restrictions preclude its use in shared data systems and direct reporting on special forms to HCFA contravenes the principle of one-time data collection.

The problem is further compounded by uncertainty about whether HCFA has the legislative authority (either directly under Public Law 95-142 or indirectly under Public Law 93-641) to require or contract for discharge data on all patients in participating hospitals or only on the recipients of Medicare, Medicaid, and Title V payments. At the October 1977 meeting of the USNCVHS, representatives of the two largest States, New York and California, and of the Health Insurance Association of America, appeared before the Committee to urge resolution of this debate. In the case of New York, the head of a statewide consortium supported by funds from CHSS reported that a competing grant was being awarded by HCFA to the State Department of Health in New York. In the case of California, the State Health Facilities Commission reported that it has the legal authority to establish a common data base on hospital patients but is reluctant to proceed until Federal regulations and policies are clarified. In view of USNCVHS, current efforts at coordination between PHS and HCFA to promote the collection of hospital statistics is encouraging and should be pursued vigorously. This should help to promote the development of the national, State, and local statistical

systems to collect ambulatory care, long-term care, resources, and cost data, as well as hospital data. Nevertheless, the discussion indicated that HCFA has substantially more funds for data collection at its disposal than CHSS and is able to purchase directly the data it seeks. It would further enhance the development of CHSS if HCFA would channel some of its data collection funds into this system.

2. *Statistical systems for national health insurance:* At its April 1977 meeting, the USNCVHS set up a new technical consultant panel to delineate the essential features of a statistical system for national health insurance; to formulate the kinds of policy, functional, and organizational 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 systems. Given the present uncertainty about the main outlines of national health insurance, the panel is taking into consideration the differing requirements of centralized and decentralized payment mechanisms. At its initial meetings, the panel conducted a review of the activities of DHEW and other Federal agencies and bureaus in regard to planning for national health insurance. It then drafted a short but important statement of principles and issues to guide its deliberations, which summarizes many of the conceptual and practical standards for health statistics advocated by the USNCVHS.^c The USNCVHS considers it essential to plan in advance the statistical support system for national health insurance and to insure that this system will be sufficiently broad-based to support long-range evaluation as well as daily operation. The Committee also hopes to avoid the kind of conflicts that have arisen among Federal, State, and local interests over UHDDS and CHSS.
3. *Status of the USNCVHS:* In a letter to the Secretary of HEW April 7, 1977, the USNCVHS requested clarifi-

^cSee appendix IV for text of this statement.

cation of its role in regard to the statistical activities of agencies outside the Health part of DHEW, pointing out that the enabling legislation (Public Law 93-353) establishes the Committee in the Office of the Secretary, while the present charter of the Committee specifies that it report to the Assistant Secretary for Health. Current progress in the revision of the charter for the USNCVHS should facilitate its capacity to advise the Secretary directly on DHEW statistical activities.

4. *Status of the CHSS and its advisory committee:* During 1977 the USNCVHS increasingly assumed the role of *locum tenens* for the Cooperative Health Statistics Advisory Committee, which was disbanded as part of the overall reduction of government external advisory bodies. The USNCVHS expressed concern over this decision and urged that the Assistant Secretary for Health establish an alternative mechanism for involving outsiders, especially State and local representatives, in the planning and monitoring of this important enterprise. Subsequently, the Committee was advised that a new Technical Consultant Panel could be established to provide advice and assistance for CHSS.

In reviewing CHSS progress generally, the USNCVHS strongly recommended that first priority be given at this time to the designation, perhaps through the Planning Act mechanism, of a central authority, such as State Centers for Health Statistics in each State for CHSS. It requested that a report prepared for the former Advisory Committee on "Component Integration and Organizational Structure" be circulated to Committee members for future discussion.

5. *Interagency cooperation:* The USNCVHS reviewed a number of cooperative arrangements between PHS agencies in the field of health statistics, and commented favorably on the increasing reliance within PHS on the basic surveys conducted by NCHS and its technical resources to provide some of the data needed for operating special programs. The cooperative arrangements include:

- a. A joint work plan by NCHS and the Bureau of Health Planning and Resources Development to assist State and local planning agencies in developing the extensive data base and statistical expertise required by Public Law 93-641.
- b. The Medical Care Expenditure Survey, jointly sponsored by NCHS and the National Center for Health Services Research, which will provide detailed data on use of services and associated expenditures and insurance coverage for a representative sample of U.S. households and individuals, including those in the age group 65 years and over formerly surveyed by SSA.
- c. Use of the basic Health Interview Survey conducted on a continuing basis by NCHS to provide the Center for Disease Control with weekly estimates of the incidence of influenza-like illness and influenza immunizations during the 1976-77 Swine Influenza Immunization Program.
- d. A pilot project by NCHS and the National Institutes of Health to test the feasibility of using the annual Hospital Discharge Survey to collect data on the incidence and prevalence of selected neurological and other diseases.
- e. The establishment of an interagency manpower committee by NCHS and the Bureau of Health Manpower to jointly develop the extensive data base mandated in Public Law 94-484.
- f. Negotiation of a memorandum of understanding between NCHS and the National Institute of Mental Health (NIMH) to coordinate their data collection activities.

In connection with the negotiations between NCHS and NIMH, the USNCVHS considered it sounder in theory and both more efficient and useful to design, insofar as practical, one statistical system that integrated data about mental illness and associated services and facilities with the general flow of other health data. It recommended that the projected NIMH State and local reporting systems be incorporated in the overall design of CHSS and

mental health data sets and definitions be coordinated with those covering health services and patients in general. A technical consultant panel is to be set up to advise and assist in the coordinating of NIMH and CHSS statistical systems.

6. *Federal statistical coordination:* After reviewing the relevant correspondence between members of Congress, DHEW, and the Department of Commerce, the USNCVHS passed a formal motion recommending that the Assistant Secretary for Health take every action possible to promote the inclusion of health questions in the 1980 Census. The Committee believes that adequate evidence exists of the need, validity, and reliability of the health questions proposed by DHEW, and that the opportunity afforded by the Census for collecting highly valuable information on perceived health status on a small-area basis should not be wasted. So far, however, the Bureau of the Census has not acceded to this request.

The statistical activities of other Federal agencies reviewed by the USNCVHS during 1976 and 1977 included: the Commission on Federal Paperwork; the Inter-agency Committee on Occupational Classification, which is seeking to reconcile systems used by the U.S. Bureau of the Census, U.S. Employment Services, the National Science Foundation, PHS, and the Office of Education; the Committee on National Statistics of the National Research Council and its expert panels on a variety of statistical issues; and the Office of Management and Budget. Although the USNCVHS strongly supports the development of Federal statistical guidelines by OMB, it noted that there has been much adverse reaction to the new OMB regulations on the reporting of race and ethnicity and recommended that OMB institute procedures for eliciting comments and periodically reviewing its guidelines.

TECHNICAL ISSUES

In order for health statistics (and social statistics generally) to be useful in providing comparisons over time and place, expressed as trends or variations, it is essential that there be widespread agreement on the basic terms, definitions, and classifications employed. The USNCVHS has a long tradition of encouraging such work through its participation in the evolution of the International Classification of Diseases. For the past 9 years the USNCVHS also has worked on a series of uniform minimum data sets for reporting various modes of patient care, including ambulatory, hospital, and long-term care, as well as data sets for classifying health manpower and facilities. The first of these data sets promulgated in 1974 by the USNCVHS was the Uniform Hospital Discharge Data Set. Essentially they are an extension of the well-established procedures for uniform reporting of deaths and other vital events. They define the core data needed by the majority of users and are suitable for inclusion in a wide variety of data systems. They are fundamental to the concept of CHSS and, in addition, have proved to be an effective means of coordination—or at least communication—within DHEW and between data collectors and users at different levels of government.

A recent study sponsored by HDPC graphically illustrates the need for such standards. The study found considerable variability that could not be justified by special circumstances in the terms, definitions, classifications, age intervals, and other groupings used in the major DHEW data systems and many unwarranted departures from census definitions and conventions. Individually and collectively these idiosyncratic practices seriously limit the analytical capacity of DHEW data systems.

As the foregoing discussion of implementation of the UHDDS illustrates, however, the success of the uniform data

set approach depends upon the willingness of private and public data collectors to incorporate the agreed-upon core elements in their data systems rather than devise their own specialized terms and definitions. Use of the data sets is also dependent upon the adoption of mechanisms acceptable to the public and the providers of health care for ensuring confidentiality. Finally, it is important that they, as well as the major data collection systems that incorporate them, are reviewed and revised periodically so that they are responsive to the policy issues of major public concern.

Committee Actions

1. *International Classification of Diseases*: Discussion of the Ninth Revision of the ICD, which was completed under WHO auspices in 1975, centered around the clinical modification being prepared for use in the United States starting January 1, 1979. In the case of ICD-8, two competing and incompatible adaptations were developed and widely used (as well as several specialized systems), one sponsored by PHS and other by the Commission on Professional and Hospital Activities (CPHA). Considerable effort has been made by the USNCVHS, PHS, and others to avoid this confusing and self-defeating situation in the case of ICD-9, and a single version (ICD-9CM) is now ready for publication. Although work on the clinical modification was guided by a steering committee composed of representatives from professional societies and PHS, the substantial time and costs of development were largely met by CPHA in the absence of adequate PHS funding. As a result there is some dispute about its copyright, ownership, and "official" status. The USNCVHS believes that this kind of fundamental classification system should be in the public domain and is working to remedy the situation in regard to the clinical modification of ICD-9.

NCHS has been designated the WHO Center for Classification of Disease for North America (one of six such centers) and is already working on plans for ICD-10 as well as on implementation of ICD-9. With the strong sup-

port of the USNCVHS, NCHS is proposing for ICD-10 an interrelated family of classifications built upon a central core, which will encompass lay-reported symptoms, classifications of health problems as seen in primary care, and classifications of disability and impariment, as well as the more traditional biomedically oriented systems and their refinements used in hospital care, specialty medicine, and pathology. The initial reaction of the ICD-10 working groups to this much broader concept of health problems and disease has been favorable.

2. *Minimum basic data sets:* The technical consultant panels charged with developing or redesigning multiple-purpose core data sets for health manpower and facilities, ambulatory health care, and long-term health care all reported substantial progress in 1977 and expect to present final reports in 1978. Government officials in agencies and bureaus affected by these data sets have for the most part participated actively in the work of these panels, which may help to avoid the kind of conflict that has arisen over implementation of the Uniform Hospital Discharge Data Set. The USNCVHS has asked its Technical Consultant Panel on Organizing Principles for Health Information (discussed earlier) to make sure that these data sets use compatible terms and conventions and are capable of being used in combination, and also to propose solutions to problems common to them all such as geocoding, confidentiality procedures, and unique identification of individuals and providers. The USNCVHS has further requested that a central office be designated in DHEW to exchange information on the basic data sets and monitor their implementation.

The next project in this series planned by the USNCVHS is development of standard cost accounting procedures for health facilities. However, the project is being held in abeyance because of uncertainty about HCFA plans in this area and the possibility of competing efforts. Also under consideration when more funds are available is the design of standard health indicators.

3. *Model State Statistics Law:* The USNCVHS reviewed NCHS progress on the Model State Law for Collection, Sharing, and Confidentiality of Health Statistics and subsequently endorsed it. The Committee recommended that expanded commentaries be prepared on the legal connotations of alternative options for organizing State statistical activities. Because of growing State interest in this area, it urged that the Model Law be published as soon as possible in the Federal Register and widely circulated by DHEW. Concern was expressed that present variation among Federal agency regulations on confidentiality as well as proposed regulations on the transfer of PSRO data would affect the availability of aggregated statistics, and possible individual data to multiple users, and therefore be more restrictive than general procedures outlined in the Model Law.
4. *Review of data systems:* In keeping with its view that routine surveys and data systems should be periodically reassessed, the USNCVHS has established a Technical Consultant Panel to review the Health Interview Survey (HIS). This important national survey has been conducted continuously (with some modifications) since 1956, and is the basic source of annual population-based estimates of perceived health problems and needs and the related use of health services. In addition to reviewing the total survey design and the contents of the core and supplemental questionnaires, the panel is considering new methods of data collection, the relation of HIS to other national and international surveys, and the options for providing the State and small-area estimates that are being sought by health planning agencies.

The National Hospital Discharge Survey (HDS) has also been reviewed, in this case by an independent contractor, with special attention to the technical problems of phasing in the hospital discharge data that are gradually becoming available from State components of CHSS. The USNCVHS urged that the revisions necessary to incorporate the Uniform Hospital Discharge Data Set in HDS be made promptly.

The Committee heard presentations on the Medicaid Management Information System (MMIS) and the data collection systems of the Developmental Disabilities Office, Office of Human Development. It noted that both systems should be critically reviewed, and questioned whether the technical skills and experience in statistics available in DHEW are being effectively shared among the various agencies. It also noted with concern the enormous cost of MMIS (an estimated \$250 million annually).

LEGISLATIVE ISSUES

At the root of many of the problems and issues that have occupied the USNCVHS in 1977 is the health legislation that has been passed in recent years. The underlying legislative process is confusing with regard to legislative mandates created by seemingly contradictory congressional instructions. Four congressional committees have primary responsibilities for health legislation, as well as the two appropriations committees. The basic act, passed in 1974 (Public Law 93-353), that renews and extends the authority of the Secretary of Health, Education, and Welfare to collect and disseminate health statistics, to coordinate Federal statistical policies, and to set up CHSS is sufficiently broad to cover the gamut of specific needs of Congress, the public, and DHEW health programs. However, Congress has included a number of highly detailed reporting requirements in subsequent acts, especially those dealing with health planning (Public Law 93-641), health manpower (Public Law 94-484), and the Medicare-Medicaid Anti-fraud and Abuse Act (Public Law 95-142).

There are many inconsistencies among these laws, but each contributes essentially to the data on health and health services that are needed by everyone and collected by many. It is within the Secretary's authority to assign specific requirements of these laws in accordance with overall Department plans for health statistics. In practice this is difficult because there are strong interest groups with their own constituencies both within and without DHEW. This difficulty, however, must be overcome. The Secretary should strongly encourage the sharing of data collection activities and funds. Where close working relationships have not been established between officials in different DHEW agencies and when ample funds are available, the incentive to cooperate is

weak and the effect of separately mandated requirements is divisive. Collaborative arrangements should be worked out within PHS, for example, in connection with the planning and manpower data requirements.

Moreover, the piecemeal legislation of health data requirements, which may or may not be supported by adequate appropriations, disrupts the efforts in DHEW to establish priorities and plan a balanced and comprehensive health information system. It leaves in doubt the fate of CHSS, which is mentioned in passing in most of the legislation but is not being adequately funded. If the Secretary finds that the present authority is inadequate to achieve the essential coordination required to implement a department-wide health statistics plan, the USNCVHS recommends that he seek appropriate authority from the Congress.

Committee Actions

1. *Conflicting provisions in recent health legislation:* The USNCVHS reviewed the sections on health facilities financial data in amendments being proposed to the Social Security Act during 1977 and recommended to congressional sponsors that the legislation not specify the establishment of new data "systems," since they would in all likelihood lead to duplication by HCFA of the activities of NCHS and CHSS mandated in Public Law 93-353. The Committee further called attention to the fact that the National Health Planning and Resources Development Act of 1974 (Public Law 93-641) already directs the Assistant Secretary for Health to establish uniform cost accounting procedures, although in somewhat different language. It recommended that a thorough study be made of the conflicting and redundant statistical provisions of recent health legislation.
2. *Protection of Privacy:* The USNCVHS, in concert with NIH and the research community, strongly opposed in letters to congressional committee members the proposed Crane Amendment to H.R. 3, which would have prohibited access to medical records by Federal employees,

contractors, and grantees. It recommended instead that the guidelines of The Report of the Privacy Protection Study Commission be followed and noted that PHS procedures are in general in conformity with these guidelines and provide adequate protection against disclosure of personal records while permitting the acquisition of information of public interest.

3. *Health manpower reporting requirements:* The USNCVHS voiced reservations about the usefulness in practice of all the manpower data called for in the Health Professions Educational Assistance Act (Public Law 94-484) and about the tendency on the part of Congress to spell out data collection and reporting in considerable detail in health legislation. It noted that no funds were appropriated in connection with the data provisions in the Act, and that conformance with the Act would require a disproportionate share of the staff and funds currently available to NCHS and to the Bureau of Health Manpower. It recommended to the Assistant Secretary for Health that special funds be provided for the current year to avoid disruption of NCHS statistical activities, and that steps be taken to secure appropriation authorization in future years. The Committee also recommended that only the highlights of the required data on manpower be included in *Health, United States*, so that this annual report to Congress would not become unmanageably large and unbalanced.

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 STATISTICS NEEDED FOR FORMULATION AND EVALUATION OF NATIONAL POLICIES ON FERTILITY

Mary G. Powers, Ph.D., Department of Sociology and Anthropology, Fordham University, Bronx, N.Y., Chairperson

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Donald W. Dunn, Director, Iowa Hospital Association, Des Moines, Iowa.

Paul Y. Ertel, M.D., Research Scientist, Health Services Research Center, University of Michigan, Ann Arbor, Mich.

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APPENDIX III

NATIONAL COMMITTEE MEETING
DATES FOR FISCAL YEAR 1977

October 12-13, 1976

January 11-12, 1977

May 3-4, 1977

APPENDIX IV

INFORMATION NEEDS FOR NATIONAL HEALTH INSURANCE: A STATEMENT OF PRINCIPLES^d

A set of basic principles provides the foundation for development of data and information systems for National Health Insurance (NHI). Two essential features prevail. First, data should *be population-based*, and second, 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 a) count the number of persons enrolled, the number served, and the services used, and b) 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 noncovered services by NHI beneficiaries.

^dPrepared by Technical Consultant Panel on Statistical Systems for National Health Insurance, April 1978.

- 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 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.

**Published Reports of the
United States National Committee on Vital and Health Statistics**

**ANNUAL REPORT OF THE UNITED STATES NATIONAL
COMMITTEE ON VITAL AND HEALTH STATISTICS
FISCAL YEARS 1975-1976, DHEW Publication No. (HRA)
78-1206, November 1977**

**STATISTICS NEEDED FOR DETERMINING THE
EFFECTS OF THE ENVIRONMENT ON HEALTH, DHEW
Publication No. (HRA) 77-1457, Series 4-No. 20, 1977**

**STATISTICS NEEDED FOR NATIONAL POLICIES
RELATED TO FERTILITY, DHEW Publication No. (PHS)
78-1455, Series 4-No. 18, January 18, 1978**

DHEW PUBLICATION NO. (PHS) 78-1205

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