



---

# The National Committee on Vital and Health Statistics, 1992

---

From the CENTERS FOR DISEASE CONTROL AND PREVENTION/National Center for Health Statistics



# nchhs



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



---

The National  
Committee on  
Vital and Health  
Statistics, 1992

---



**ncvhs**

---

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service  
Centers for Disease Control and Prevention  
National Center for Health Statistics

Hyattsville, Maryland  
June 1993

# National Committee on Vital & Health Statistics

---

JUDITH MILLER JONES  
CHAIR

GAIL F. FISHER, Ph.D.  
EXECUTIVE SECRETARY

The Honorable Donna E. Shalala, Ph.D.  
Secretary, Department of Health  
and Human Services  
Washington, D.C. 20201

Dear Secretary Shalala:

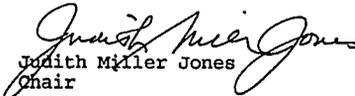
I am pleased to transmit to you the 1992 Annual Report of the National Committee on Vital and Health Statistics (NCVHS), as required by the Committee's Charter.

During 1992 the Committee completed and approved major reports recommending revision of the Uniform Hospital Discharge Data Set and assessing current public policy issues surrounding the release, disclosure, and confidentiality of health care data. These reports are included in the appendixes.

We also began to look more broadly at the data needed to inform the policy debate on health system reform; this matter is addressed in my Foreword. Finally, the Committee called attention to the importance of data on race/ethnicity and socioeconomic factors for understanding health status and health care utilization. The latter is the subject for the preamble to policymakers contained in the report.

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

Sincerely yours,

  
Judith Miller Jones  
Chair

# Foreword

As the National Committee on Vital and Health Statistics (NCVHS) reflects on its work during 1992, a new president has assumed office, one who made health systems reform a top priority for his administration. But while significant changes have been promised, much analytical work must take place, first as legislation is considered and then as new programs are implemented and assessed.

The need for analysis to inform the health policy debate presents new challenges to components of the Department of Health and Human Services (DHHS) that bear the responsibility for health data collection and dissemination. However, as the country seeks to define and implement new financing and payment schemes that will encourage more effective and efficient delivery of care, we are concerned that the demands for data collection and analysis will far outstrip current capacities. Plans for upgrading such capacities in the future must be evaluated and strengthened.

In setting our course for 1993 and beyond, NCVHS feels the coming months and years are an opportune time to focus attention on the need for a truly national health data system. With this in mind, we plan to highlight data-related issues and levels of support for improved data collection and analysis and to conduct the following outreach activities:

1. In order to sustain its ongoing work and take an expanded look at the policy-related data activities of the Department, the Committee will seek to enhance its working relationships with staff and the new leadership of DHHS agencies most involved in data collection and analysis. While a number of individuals have contributed very substantially to past Committee deliberations, sometimes on their own time, inadequate staffing in general and lack of other support has at times hampered our efforts. We are anxious to see this does not occur again.
2. Although senior Congressional health staff continue to demonstrate a keen interest in data issues, we recognize much turnover occurs every 2 years and newer staff may know relatively little about such matters. In the coming year, therefore, we intend to organize one or more educational programs for legislative staff. Using highly regarded researchers and other policy experts, these sessions will highlight the importance of data and ways existing capacities can be strengthened.
3. Because other executive and legislative agencies of government, such as the Office of Management and Budget, the Prospective Payment Assessment

Commission, and the Physician Payment Review Commission, are highly involved in policymaking that uses data sets maintained by the Department, we plan to involve representatives of these and other bodies in our deliberations from time to time.

4. The Committee routinely summarizes the conclusions of its deliberations in recommendations to the Secretary of the Department. Beginning in 1993 many of our recommendations will be squarely focused on specific data and statistical needs to guide health care financing and delivery reform.

### **Continuing Committee Concerns**

Our deliberations in recent years have already led us to call attention to certain issues. For example, we are concerned about the growing reliance on administrative data sets, which are generally confined to a specific group of beneficiaries and services covered by major insurance programs and largely limited to hospital settings. Most of the presently available data bases in the Department have evolved in ways that reflect concern about the operation of existing programs—not with an eye toward addressing the difficult policy choices inherent in system reform or in judging the impact of decisions that are made.

We also have noted that, for the most part, we are unable to track patients through the system as they enter and leave various care settings, whether it is over the course of an illness or over a longer time-frame. The lack of agreement on universal patient and provider identifiers and incompatible confidentiality provisions must be resolved.

At the same time, we are concerned about growing expectations that computerized patient records will “solve” many existing data inadequacies. Hardware and programming capacities are much in advance of agreement about content and operational procedures, with protection of confidentiality another major hurdle.

We know key staff in a number of agencies are trying to address such concerns. However, most of the data planning and coordinating mechanisms within the Department that could resolve them are simply not operating at a high enough level and in the strategic planning mode they should be.

The Committee plans to pursue these and other critical data policy issues that command our attention. But in our deliberations, we expect to focus much more on the larger context of systems reform and the kinds of data and information needed to better inform the developing debate and whatever programs materialize from it.

### **Health Systems Reform**

The new administration has yet to unveil its specific proposals for reforming health delivery and financing. But already we can see two somewhat competing

philosophies are at work in the political arena and will have to be reconciled. Taken together they seem certain to force attention to several important data concerns.

Those supporting a managed competition approach are looking to near universal deployment of managed care arrangements and counting on the development of outcome measures and risk adjuster technologies to empower purchasers and consumers to choose among competing plans.

Others are not certain managed competition is the best or only way to increase access to care, improve quality and effectiveness, or bring about the kinds of cost savings needed now. They are vitally concerned about ways to impose global budgets or administrative pricing systems, if not on their own, then perhaps somehow married to the managed competition efforts.

Whether and when consensus might evolve around a compromise proposal blending these philosophies is uncertain. But in our most recent deliberations, the Committee has begun to look at the Department's data tools and related analytical capacities to address the kinds of policy questions each of these philosophies raises. We are troubled by the inadequacy of data for choosing among alternative reform options and for gauging the outcomes associated with alternative delivery and financing choices.

For instance, what kinds of data will be needed from managed care organizations to be confident they provide appropriate, sufficient, and effective care? What data must the Department have to evaluate the implementation of a managed competition infrastructure? Without the kind of data now being collected in the fee-for-service environment, how in the future can we evaluate quality and sufficiency of care rendered?

Currently, administrative and quality review procedures for Medicare are geared to the dominant fee-for-service mode of payment. But with many private insurers and State Medicaid programs moving rapidly to implement managed care, it is important to encourage the development of data systems that can monitor quality and cost effectiveness in these environments.

How are we to assess the impact of delivery changes that come about, either as a result of the growth of managed care or the imposition of cost constraints? Do we have a good baseline from which to judge whether certain groups are harmed or benefitted? Will we have the capability to monitor trends and make program changes as they are needed? In looking at such questions, a major concern of our Committee is the marked disparities that exist in health status, access to care and use rates between minority populations and the white population, and between those with insurance and those without. Do we have the data and analytic means to determine whether differences in health status primarily reflect the way "care follows the dollar?" Are they the consequence of important racial, ethnic, and socioeconomic determinants that we do not yet fully comprehend or know how to

address? The Committee has intensified its efforts to shed light on these issues in the past year, as evidenced by the preamble for policymakers contained in this report.

At present, administrative data systems and some of the provider surveys or special studies tell us a good deal about the care being delivered to the elderly in hospitals or nursing homes. We have less knowledge, however, about care delivered to this population elsewhere, especially in the home, where costs are growing fastest. By comparison, we know relatively little about care rendered to the under-65 years of age population, especially nonacute care delivered to the poor and uninsured. As the country faces an ever-growing burden of chronic illness and behaviorally related diseases such as alcoholism and substance abuse, and as ever more care—even quite sophisticated care—is received outside the hospital, can it be tracked adequately? Are we devoting sufficient attention to determining what is appropriate from providers in these other settings and how to pay for it?

Such questions have already surfaced in the current debate about systems reform, because they are key to establishing risk adjusters and norms for appropriate care and levels of payment. They are also important to those worried that budget constraints might exacerbate existing discrepancies in use rates or health outcomes rather than alleviate them.

We recognize much of the current systems reform discussion really is about ways to control costs, while expanding and equalizing the financing burden. But when services or delivery considerations are being talked about, there is little to indicate coverage beyond the medical model of care—that which is currently offered under most indemnity or managed care versions of private insurance. Yet there is another model of care that could and should be considered, one that looks at disability, functional capacity, and well-being. To address these concerns data are needed to describe the kinds of chronic, rehabilitative, and attendant services encompassed in such a model.

There is also the public health model, which focuses on the prevention of illness and disability at the individual and community level. Will data systems be adequate to evaluate preventive and primary care services and to support the essential public health functions of health monitoring and assessment?

The NCVHS is cognizant these kinds of policy concerns for efficiency, quality, and equity in the delivery of health care will dominate more than they have to date. It is not clear, however, whether the Department has yet been able to step back and assess its overall capacities to delve into such issues.

We know a recent study by the Institute of Medicine recommended that an ad hoc external high-level committee undertake a comprehensive review of the health statistics activities throughout the Department. This study noted the role of the NCVHS as the principal advisory committee to the Secretary but indicated the Committee was not constituted for such a task. We strongly encourage the

Department to assess its overall data capabilities and are eager to work collaboratively with the Department in this endeavor. But we do not believe micromanagement of the Department's data collection activities by external advisory committees is appropriate. Instead, we believe a neutral body, such as ours, should help to define priorities for critical data needs and facilitate cooperation, while serving as an honest information broker and advocate for necessary or better targeted funding and new initiatives.

Improving the country's capacity to track the evolving structure and performance of the health care system is a task that deserves increased attention within government and among private sector interests. As an objective deliberative body, which oversees data-related activities of the Department, the National Committee will take whatever steps it can to solicit greater input from all relevant parties and facilitate the kinds of dialogue and interaction needed to enhance data collection and analysis in the future.

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

# Contents

Foreword . . . . .	v
Executive Summary . . . . .	1
Diversity in the Health Care Data Base: A Preamble for Policymakers . . . . .	3
Activities, Accomplishments, and Future Plans of the National Committee on Vital and Health Statistics . . . . .	20
Medical Classification Systems . . . . .	24
Long-Term Care Statistics . . . . .	26
Ambulatory and Hospital Care Statistics . . . . .	28
Health Statistics for Minority and Other Special Populations . . . . .	32
Mental Health Statistics . . . . .	35
State and Community Health Statistics . . . . .	37
Confidentiality . . . . .	39
<b>Appendixes</b>	
Appendix I. Legislative Authority for the National Committee on Vital and Health Statistics from the Public Health Service Act . . . . .	42
Appendix II. Charter . . . . .	44
Appendix III. Membership Roster of the National Committee on Vital and Health Statistics . . . . .	48
Meeting Dates . . . . .	49
Appendix IV. Subcommittees of the National Committee on Vital and Health Statistics, Rosters, Meeting Dates, and Charges . . . . .	50
Appendix V. Proposed Revision to the Uniform Hospital Discharge Data Set, June 1992 . . . . .	66
Appendix VI. Report of the Work Group on Confidentiality, December 1992 . . . . .	80

# Executive Summary

During 1992 the National Committee on Vital and Health Statistics (NCVHS), in its advisory capacity to the Department of Health and Human Services (DHHS), accomplished the following activities through the work of the full Committee, seven subcommittees, a work group, and several monitors:

- Completed a thorough and systematic review of the Uniform Hospital Discharge Data Set (UHDDS) and submitted its proposed revision of the UHDDS to the Assistant Secretary for Health. The UHDDS report is contained in appendix V.
- Developed a report affirming the ongoing commitment of the National Committee to seek solutions to the dual needs of assuring access to critical data and meeting the confidentiality requirements of the individual health care consumer. The report, which was submitted to the Assistant Secretary for Health, can be found in appendix VI.
- Stated in the report cited above the continued NCVHS support for the adoption of a unique personal identifier to enhance opportunities for interagency and research-related data linkages.
- Convened a meeting to discuss a proposed procedure classification system, developed for the Health Care Financing Administration (HCFA), to respond to the difficulties of maintaining and updating volume 3 of the clinical modification of the ninth revision of the *International Classification of Diseases (ICD-9-CM, Volume 3)*.
- Circulated a letter to organizations interested in medical classification systems, requesting written input regarding the feasibility and desirability of a single procedure classification system.
- Continued to provide an open forum for information on the progress of the 10th revision of *ICD (ICD-10)* and its implementation.
- Convened a meeting to discuss the adequacy of data on the needs for chronic care services and the extent to which these needs are being met.
- Supported the efforts in the public and private sectors to implement the Committee's recommendations on collection of external cause-of-injury codes (E-codes) as part of the UHDDS, improvement of the E-code classification system, and development of national guidelines for E-coding.

- Continued in its efforts to encourage HCFA and the Social Security Administration to improve current and future racial and ethnic identifiers in the Medicare administrative data bases.
- Participated in setting the research agenda for the National Center for Health Statistics (NCHS) Minority Health Statistics Grants Program and continued to monitor the implementation of the program.
- Reviewed and provided comments on the *Report of the PHS Task Force on Minority Health Data* issued in the spring of 1992.
- Monitored the impact of the Committee's report on medical indigence, which was submitted to the Assistant Secretary for Health in 1991.
- Collaborated with NCHS in developing appropriate mental health status measures for the National Health Interview Survey.
- Continued to address the quality, quantity, and availability of health and health care data at the State and community levels, and techniques for analyzing small area data.
- Maintained a strong interest in collaborative efforts with NCHS to strengthen the vital statistics system, and specifically, to improve cause-of-death reporting on the death certificate.
- Received an in-depth briefing from the Committee on National Statistics and the Institute of Medicine on the expert panel report on the National Health Care Survey and is continuing to follow responses to the report's recommendations.
- Commended the Secretary's leadership in creating a nationwide electronic health care information network and sought to support his efforts in defining data content and assuring data access and data confidentiality.
- Initiated an educational effort to explain to policymakers and program managers the importance and challenges of collecting meaningful data on race/ethnicity and socioeconomic factors for understanding health status and health care utilization.
- Developed a preamble for policymakers on diversity in the health care data base, which is included in this report.
- Reviewed and provided comments on the 1991 publication of *Health, United States*.

In 1993 the Committee will continue and expand efforts related to many of the above activities.

# Diversity in the Health Care Data Base: A Preamble for Policymakers

## Introduction: From "Race" to "Diversity"

The first vital statistics published by the Federal government reported that for the year 1900 the life expectancy of the United States white population was 48 years of age; for "all other races" (predominately the black population), life expectancy was 33 years of age (1). Race as a factor creating large disparities in mortality risk is rooted deep in American history.

Nearly a century later health care research demonstrates that persistent differences in key health indicators among racial groups in the United States reflect a complex chain of causality. Race alone no longer can be assumed to explain health status disparities like the following:

There is still a 100 percent gap between the infant mortality rates of African-American and white babies, even though both rates have dropped close to 1,000 percent since 1915 (2).

Low (<2,500g) and very low (<1,500g) birth weight is endemic among African-American births (more than double) compared with all other races (3).

African-American males are dying at a rate of 1,032 per 100,000 per year, while white males die at 644, black females at 586, and white females at 375 per 100,000 per year (4).

*Progress in epidemiology allows us to begin to go to another level of definition and understanding in relation to the heterogeneity of (our) society. (R. Cooper, Loyola U.)*

---

NOTE: This paper was written for the NCVHS by Lucy Johns, M.P.H., Consultant, Health Care Planning & Policy, San Francisco, CA., in consultation with David Williams, Ph.D., NCVHS member, and Judith Miller Jones, NCVHS Chair, and assisted by Marjorie S. Greenberg, NCVHS staff. Other NCVHS members and staff also contributed. The full Committee approved the paper and recommended that it be disseminated widely.

African-American males suffer the highest incidence rates for all types of cancer (524 per 100,000) and also the highest single incidence rate of any cancer by far, 142 per 100,000 for prostate cancer (5).

African-American females are dying of AIDS at nine times the rate for white females (6).

Whereas life expectancy for the white population had risen to 76 years by 1990, the comparable figure for the African-American population lagged a full 7 years, at 69 (7).

These and many similar differences are now known to mask a multiplicity of risk factors that influence, in non-uniform ways, health status and outcomes. Dozens of studies have delved beyond race to reveal that ethnicity, socioeconomic status (SES), environmental conditions, and psychosocial attributes constitute strong intervening variables affecting health. Race alone no longer "explains" current patterns of mortality, morbidity, and health behavior in the United States.

Development of effective policy to improve health status in the 21st century will be highly dependent on research findings that are sensitive to population diversity and causal complexity. Such research can only be accomplished with a data base that reflects and quantifies multiple influences on health status. The National Committee on Vital and Health Statistics (NCVHS), charged to advise the Secretary of the Department of Health and Human Services (DHHS) on issues related to collection and analysis of health data, provides this preamble as a first step to strengthening the national data base to support such research.

## Key Issues in Defining and Measuring Diversity

The desire to understand complexity and diversity does not automatically specify the data needed or justify their collection. A symposium in late 1992 on "Race/Ethnicity, Socioeconomic Status and Health: Data Needs and Data Challenges," organized by the NCVHS, revealed several issues pertinent to development of data policy. These include:

- evolving meaning of "race" and "ethnicity";
- implications of socioeconomic indicators;

*Race is a poor substitute for socioeconomic status because the large majority of blacks, 69 percent, are not below poverty (and) two-thirds of all Americans who are below poverty are white. (D. Dutton, Stanford U.)*

*Analysis may reveal that opportunities for prevention (of) and intervention (in) poor health outcomes may lie beyond the traditional purview of the health care system. (P. Golden, NCHS)*

- value of additional data;
- currently available SES data; and
- problems of collection and analysis.

A copy of the symposium agenda is included in attachment A.

## Evolving Meaning of "Race" and "Ethnicity"

A distinction long assumed to represent irreducible genetic differences within the human species, "race" has been collected as part of official U.S. mortality and morbidity statistics since 1900. Modern molecular biology, however, now reveals that there is sometimes more variation *within* traditional racial categories than *among* them. "African" is becoming the model case: Africans appear to show far more variety in the characteristics of certain genetic markers than has been measured in other racial groups. How much underlying genetic variance should be included within a single racial designation based on phenotypic (visible) characteristics? African-Americans also present this challenge. The technology of organ transplantation has revealed degrees of genetic difference within the group "African-American" greater than those found in other racial groups. From a scientific perspective, the concept of race itself is becoming less meaningful for understanding differences among population groups.

The notion of "ethnicity," associated with but not identical to "race," appears to many health researchers to add significant meaning to health statistics. "Ethnicity" begins to represent the "cultural evolution" that is unique within the human species (8), complementing and complicating—for purposes of any taxonomic scheme—"genetic evolution." Ethnicity, however, has to be defined in considerable detail to reveal useful differences, as these two examples illustrate:

- Puerto Rican mothers give birth to low-birth weight (LBW) babies (<2,500g) at much higher rates than Mexican-American mothers, whose rates of LBW births equal those of (non-Hispanic) white mothers, *despite* low use of prenatal care by these Hispanic mothers, as shown in table 1. The simple grouping "Hispanic" would have obscured these differences, which in themselves suggest more questions and possible refinements of prenatal programs.

*Please continue to use race/ethnicity data, don't just replace it with ... socioeconomic status because we continue to find (race) differences ... within (socioeconomic) categories. (O. Carter-Pokras, OASH)*

Table 1. Low birth weight live births, according to first trimester and Hispanic ethnicity of mother: selected states, 1980, 1985, and 1989

Ethnicity	1980		1985		1989	
	Low birth weight	Prenatal care	Low birth weight	Prenatal care	Low birth weight	Prenatal care
Mexican . . . . .	5.6%	60%	5.8%	60%	5.6%	57%
Puerto Rican . . .	9.0	55	8.7	58	9.5	63
Cuban . . . . .	5.6	83	6.0	83	5.8	83
Non-Hispanic						
White . . . . .	5.7	81	5.6	81	5.6	83

NOTES: Only available for states with Hispanic-origin on their birth certificates. Over 90 percent of the U.S. Hispanic population lived in these states in 1988.

SOURCE: National Center for Health Statistics. Health, United States, 1991. Hyattsville, Maryland: Public Health Service. Tables 7 and 8. 1992.

- Figure 1 shows the variance in blood pressure (BP) obtained from three populations of “West African” origin. Clearly, ethnic origin affects blood pressure and provokes further questions about causality.

Contemporary government policy on group identification began to move beyond race in 1981 when the Office of Federal Statistical Policy and Standards defined the

*The (federal) standard for racial and ethnic groups . . . has really been a force for good in that it has created standardization . . . imperfect, but at least (things) stand still for a while. (N. Zill, Child Trends)*

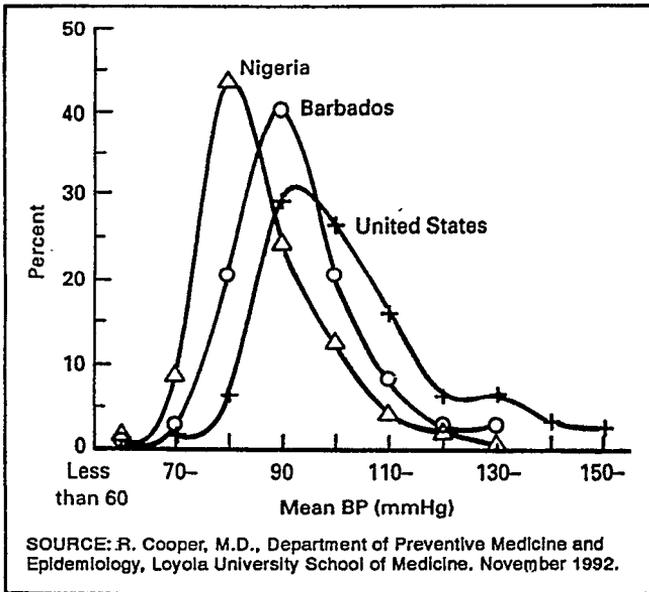


Figure 1. Blood pressure in three populations of West African origin: Men, aged 35–54 years

classification scheme for federal data collection activities to include five "racial" groups: White, Black, Asian or Pacific Islander, American Indian or Alaskan Native, and Other; and two "ethnic" groups: Spanish Origin/Hispanic or Non-Spanish Origin/Non-Hispanic. While this classification "was not intended to be scientific or anthropological in nature (9)," it nevertheless defines the racial/ethnic data now collected in the Uniform Hospital Discharge Data Set (UHDDS)(10) and other uniform health care data sets. The NCVHS, in a report to the Secretary of DHHS (11), recommended a revision of the UHDDS that would continue to require these standard groupings, but urges programs "whenever possible" to collect greater detail on Asians and Pacific Islanders and on the Hispanic population (12).

## Implications of Socioeconomic Indicators

Much as can be learned about health from race and ethnicity data, studies since the 1950's in many countries of Europe and North America show an independent, strong and consistent relationship between SES and health status (13). When statistics for mortality, infectious disease, chronic illness, disability days, and self-perceived health status are disaggregated by income, level of education, or occupation, those of lower SES typically have or report worse health than those of higher SES.(14) Figure 2 shows one of dozens of possible examples of this phenomenon: Americans with less education and less income report poorer health than those with more.

This is true *within* races in the United States as well, for example:

- in five American family income groups ranging from \$2,000 to more than \$15,000, (age-adjusted) mortality rates decline from lower to higher incomes for both black and white families, but at every income level black mortality exceeds white, as shown in figure 3;
- heavy smoking during pregnancy decreases with level of education, with the least educated white mothers smoking the most, while alcohol consumption during pregnancy increases with more education (15).

*Risk factors do not always go the way that you think they do. (O. Carter-Pokras, OASH)*

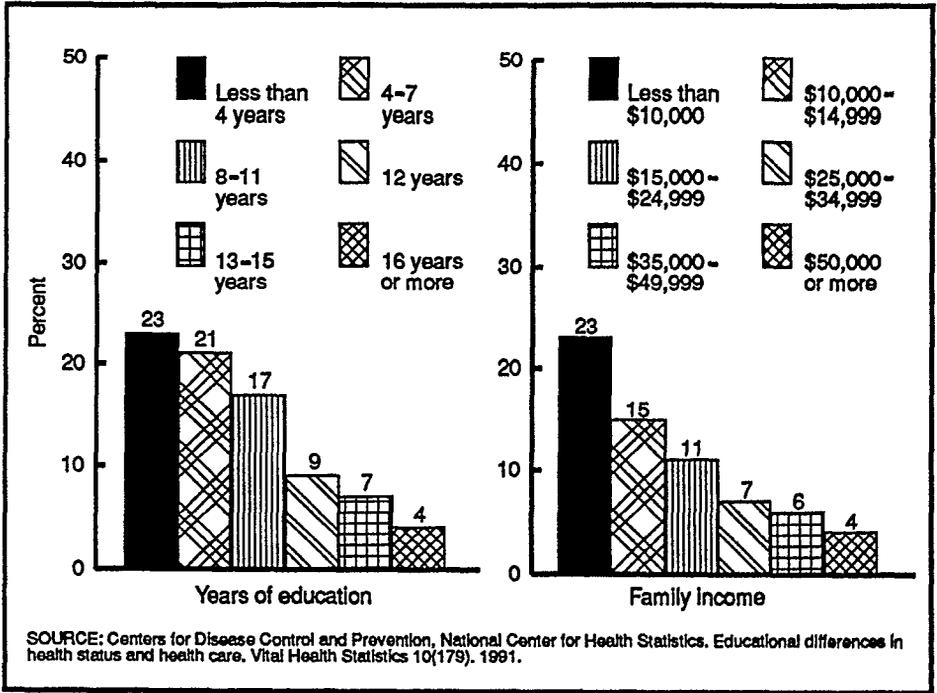


Figure 2. Age-adjusted percent of persons of all ages reported to be in fair and poor health by education and family income: United States, 1989

SES factors also appear to influence use of in-hospital resources in the United States, even after age, diagnosis, and severity have been accounted for (16).

The precise mechanisms through which income and education affect health status have yet to be discovered. That the observed associations may be artifacts does not appear a valid possibility, nor is it accepted as plausible that “downward drift” (illness causes poverty and so poverty will appear with illness) explains the phenomenon (17). Even improvement in access to health services does not eliminate health status differences among SES groups, as data from Europe and the United States, since Medicare and Medicaid show. There is some evidence that psychosocial factors—environmental stressors, health practices, social ties and attitudes—“mediate” and interact with SES to create health status. However, the mechanism is unclear and it is even proposed that psychosocial factors themselves derive from SES, rather than being independent variables subject to direct interventions (for example,

*Most of the . . . available data which relate socioeconomic status to minority populations only describe the marked differences between the poor and the non-poor . . . We have little data that really tell us exactly how . . . socioeconomic and sociocultural factors . . . interact in maintaining health. (P. Golden, NCHS)*

*I think . . . let's put it plainly . . . we have always had . . . this view that (we are) a melting pot and racism is going away. It is not fashionable to acknowledge its*

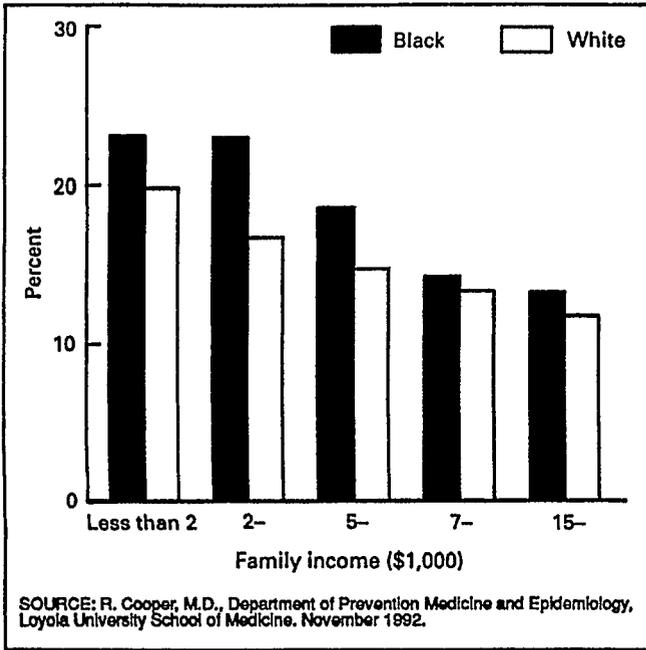


Figure 3. Age-adjusted mortality by income and race (NHEFS)

through health education) (18). A recent study asserts that “the structural elements of inequality in society” that create the SES associated with health status may have to be altered if health is ultimately to be improved (18).

Whatever the exact relationships, government policy may also have measurable effect on health status by prompting changes in SES. A number of indicators—access to prenatal care, life expectancy, infant mortality—worsened among groups increasingly disadvantaged during the 1980’s, years associated with reduction or withdrawal of federal support for community and health service programs initiated in the 1960’s. The poor, minorities who often are poor (especially African-Americans), children, and women with children, have all been disproportionately affected by declining SES in the last decade and therefore by declining health status (14).

In sum, measured differences in health status indicators among racial/ethnic groups can be reduced, that is, “explained,” by the addition of SES factors (although effects of race are not eliminated) (19). It may be true that, as the

*permanent structural existence within our society. (R. Cooper, Loyola U.)*

*The pattern I kept seeing . . . (was that) health trends among the disadvantaged improved markedly during the 1970’s and then slackened or worsened during the eighties. Clearly, the relationship between socioeconomic level and health . . . seemed to be responding to changing social policies. . . . At least, that is my interpretation. (D. Dutton, Stanford U.)*

*In every income (and) educational category, blacks have somewhat worse health than whites. However, the*

former dean of the School of Public Health, University of California-Berkeley, recently stated: "Poverty is the number one factor that influences health (20)."

*differentials associated with race are much smaller. (D. Dutton, Stanford U.)*

## Value of Additional Data

Additional national data on ethnicity and socioeconomic status could serve two very important purposes.

First, such data would improve the ability of researchers to detect, analyze, and suggest means for diminishing disparities in health status. Such data would be especially significant, for example, for planning at national, State, and local levels for services for pregnancy and early childhood. Many studies have found that poor health status early in life generates a burden of developmental disability, susceptibility to illness, and behavioral problems that cumulates over time (19). Programs to prevent unwanted pregnancy, to nurture pregnancy, and to enhance health in early childhood should promote better health throughout life. A more informative data base could pinpoint, for example, why 30 percent of American women do not use contraceptives and why 25 percent of U.S. women still lack prenatal care in the first trimester (21).

Second, SES could be used to refine measures of hospital outcomes and formulas for payment of health care providers. As the concept of (medical) "severity adjustment" is increasingly accepted as a modifier for outcome indicators and payment methodologies, researchers now propose the concept of "social severity" as a further refinement (22). For example, preliminary evidence indicates that patients of lower SES use more hospital resources (23). This has implications for risk-adjusting outcomes and payment formulas, techniques for which are gaining sophistication (24). Absent adjustment for SES, outcome results may be misleading, and a disincentive to accept poor patients could be created. Hospitals completing UHDDS-based forms should be interested in documenting the SES of their patients for just these reasons.

*We have been concerned about outcomes data and comparisons ... among hospitals because we are trying to assess ... the best buy for the dollar ... Unless institutions know that they are treating the same severity of illness and the same kinds of patients, those comparisons are hokey. (J. Jones, NCVHS)*

Hospitals or other providers could also use SES data to justify translator services, better targeted patient education and home care resources, and to enhance the multicultural dimension of teaching and clinical research.

## Currently Available SES Data

Some SES data are now available from several sources within the Public Health Service, creating precedents and suggesting benefits and difficulties.

The experience of the National Center for Health Statistics (NCHS) shows (25) that:

- collection of "race" data has been recommended nationally since 1900 and now occurs uniformly in all registration areas for birth and death certificates;
- the "occupation" item on the standard birth certificate since 1900 was dropped in 1968 because it was not generally used, and "education" was substituted with few problems;
- "education" was added in 1989 to the death certificate without dropping "occupation" 10 years after being first recommended and only after experience in two States showed that the data could be collected and would be used; and
- the rationale for race and SES data on vital records was originally and remains primarily research, with no pretense of utility for funeral directors or health care providers.

The standard certificates for vital statistics thus seem to present a contrast to the UHDDS, which was based (1969) on information generally already being collected, that is, used, by hospitals and that continues to be revised with utility for the hospital as an important criterion.

A number of programs sponsored by DHHS have collected or will soon collect a variety of SES data (26). These include Healthy Start, the National Health Interview Survey, the National Maternal and Infant Health Survey, the National Health and Nutrition Examination Surveys, and the National Medical Expenditure Survey (NMES). Selected findings from these sources, some of which are very recent, include the following:

- Data that are coded are not necessarily used by analysts.
- Analysis shows that race cannot be considered a "surrogate" for SES measures.
- Health status differentials *within* educational and income levels of heads of household can now be documented.

- SES from the 1987 NMES are not predictive of (self-reported) hospital expenses, after age, insurance, race, and ethnicity are taken into account (27), although they provide substantial descriptive information about variations by SES in the use of health services.

A report describing a desirable “common core” of “socio-demographic descriptors,” is available to assist in decisions about further collection efforts (28).

## Problems of Collection and Analysis

Although SES data collected in the UHDDS could be useful, the NCVHS is aware of several problems in the way of smooth implementation.

Because the UHDDS reflects federal policy concerning collection of hospital discharge data, its use is voluntary State by State. This means uneven reporting and therefore potential bias in aggregated statistics. The Agency for Health Care Policy and Research (AHCPR) reports that of the 20 States that in 1991 had statewide, publicly available data sets, only 4 were based specifically on the UHDDS and only 9 (representing 45 percent of hospitals in the United States) report on race/ethnicity (29). Non-reporting of race/ethnicity is especially prevalent in northern, southern, and mid-western States. Adding variables to the UHDDS for SES data will not of itself produce a reliable national data set.

Second, numerous questions of definition and scope must be answered precisely. Which data should be sought, assuming not all can be? The NCVHS’ preliminary assessment is that education, rather than income or occupation, may be the most feasible SES indicator to collect in the UHDDS (11). If education, it must be defined such that a clerk can ask and record an answer. “Years completed,” rather than “degrees,” seems to be preferred here, although certain ambiguities would need to be clarified (include trade school? vocational rehabilitation? if for a child, use the parents’? or one parent? which?).

Third, requests for SES data from patients or family members at the time of hospital admission are unlikely to

*We added ethnicity (to UHDDS) . . . and we know how that has turned out. We are not getting it . . . It has been 10 years and we still just . . . get horrible information out of the hospitals. (E. Bacon, NCHS)*

*No new data gets collected in California from hospitals unless the legislature says this has to be done. And the legislature only says this has to be done if the hospital industry can be persuaded . . . It is not just a matter of this Committee . . . understanding the rationale. (L. Johns, Health Care Planning and Policy)*

*Whenever feasible, income, education and race should all be included since each makes a separate contribution to . . . differences. The biggest problem with income is . . . more and more people are refusing to provide (it). (D. Dutton, Stanford U.)*

*We take care of whoever comes to us, so . . . it can*

be welcome. In the context of illness, distress, pain, or fear and in a country where access to care is not guaranteed, questions concerning SES at time of admission could be considered an invasion of privacy, might raise concerns about confidentiality, and may even be perceived as a threat. (This may be less of a problem if education instead of income is requested.)

Fourth, patient demographic data fed into the UHDDS are collected at the hospital level by clerks who require training and motivation. While SES data may seem only a marginal increment to an already lengthy form, even addition of a single SES question would mean increased expense for hospitals. More training and motivation than ever could be needed. Hospitals may be willing to test the costs of collection (30) but these should not be underestimated.

Finally, biostatistical methods must be continually refined to untangle the correlations among race, health status, and indicators of SES. Meaningful analysis must be rigorous to avoid the statistical artifacts that bedevil highly correlated data (31).

Researchers, always eager for more data, must reckon with these problems. Does the value of additional SES data—possibly fairly crude, not universally collected, or truthfully answered—outweigh the expense and burden the relevant questions might cause?

## The Role of NCVHS

Statistics now collected on the UHDDS have yet to reflect a contemporary awareness of the population diversity and causal complexity affecting health status. The symposium held in late 1992 confirmed the NCVHS's concern that the national data base must be expanded to yield accurate information for design and evaluation of imminent health system reforms.

The NCVHS recommends that the Secretary support a program of research to address the problems noted above in order to facilitate future addition and collection of SES factors on the UHDDS. Such research should focus on the following goals:

*be counter-cultural for a hospital to collect income data. (Staff) people were offended . . . in our hospitals when I said, have we ever . . . It is like, NO. (M. Lademberger, Daughters of Charity National Health System)*

*We have to have clearly articulated data definitions for people to . . . work from . . . (and) where does it need to be collected? . . . up front? . . . during? . . . on discharge? (M. Lademberger, Daughters of Charity National Health System)*

*I guess I am not convinced yet that incurring the additional expense of gathering . . . socioeconomic status data (is) going to allow us to have a data base that will permit us to improve the health of the population or to make the system more fair in its reimbursement . . . or structure. (J. Ashley, NCVHS)*

### *Universal reporting*

- Develop incentives and technical assistance to States to increase the number collecting the complete UHDDS-based discharge data set.

### *Optimal specification*

- Create precise definitions of SES indicators based on state-of-the-art survey research, epidemiological experience, and current work of PHS agencies, including but not limited to such variables as "education of head of household," ZIP Codes, and income.

### *Protection of confidentiality*

- Design technically reliable mechanisms to assure policymakers and the citizenry that solicitation of SES information will not result in abuse of privacy. Likewise, that linkage of UHDDS data to census or other national data sets (which will require patient identifiers) will not result in the same.

### *Feasible collection*

- Study the requirements, costs, and benefits of collection of SES data by hospitals and organized delivery systems.

### *Appropriate application*

- Explore uses of SES data to understand and improve health status, health care outcomes, health financing, and related social policy, and to strengthen the link between research findings and policymaking.

This set of research recommendations expands on NCVHS' previous recommendation to the Secretary, that "research should be initiated on adding socioeconomic factors to the UHDDS, in particular a patient's years of education completed, no later than the revision to the UHDDS following this one (11)."

The NCVHS expects to continue its discussion of increasing diversity in the national health statistics data base. The potential of such data to indicate more effective interventions to enhance health requires this Committee to continue

*Many people are struggling right now in terms of confidentiality and privacy and ability to link records . . . Keeping information in discrete segments has been a protection . . . Secondary use of information . . . is . . . more scary than the primary designated use. (D. Ganzer, NCVHS)*

*I am of two minds. One . . . says we jolly well need this information and we ought to have it . . . The other . . . says we ain't nowhere near telling the world it ought to go collect this because I do not think we understand what it would cost (or) what we would do with it. (J. Jones, NCVHS)*

*(The Public Health Service Task Force on Minority Health Data) urges PHS agencies to support research into the*

its own education and to raise the consciousness of others in the health field concerning diversity in the health care data base.

*relationship (of) socio-economic and other risk factors to minority health. (P. Golden, NCHS)*

*... We are a committee that is looking at more than the hospitals' perspective ... (We need to) keep in mind whether or not these (are) good predictors of health status and better our understanding of disparities ... We have a national interest in hand. (R. Lavizzo-Mourey, AHCPR)*

---

The marginal quotations included in this paper illustrate key points made by individual participants during the symposium. They are not intended to represent a consensus reached by the participants or the NCVHS.

# Tentative Agenda

## National Committee on Vital and Health Statistics

November 4, 1992  
Room 703A, Hubert H. Humphrey Building  
200 Independence Avenue, SW.  
Washington, DC

### Wednesday, November 4

1:00 p.m.	Call to order Welcome and introductions	Ms. Jones Chair
-----------	--	--------------------

1:15 p.m.	Race/ethnicity, socioeconomic status, and health: Data needs and data challenges
-----------	--

Richard Cooper, M.D.  
Editor, *Ethnicity and Disease*  
Department of Preventive Medicine  
and Epidemiology  
Loyola University School of  
Medicine

Diana Dutton, Ph.D.  
Research Associate, Stanford University  
School of Medicine  
Associate Director of Robert Wood  
Johnson Clinical Scholars Training  
Program at Stanford and University  
of California, San Francisco

#### Panel of discussants:

Rosanna Coffey, Ph.D.  
Director, Division of Provider  
Studies  
Center for Intramural Research,  
Agency for Health Care Policy and  
Research (AHCPR)

Beth Hahn, Ph.D.  
Service Fellow  
Division of Medical Expenditure  
Studies  
Center for Intramural Research,  
AHCPR

Wednesday, November 4 (con.)

Edward Bacon, Ph.D.  
Director, Division of Health Care  
Statistics  
National Center for Health  
Statistics (NCHS)

Mr. George Gay  
Chief, Registration Methods Branch  
Division of Vital Statistics, NCHS

3:00 p.m.

Break

3:15 p.m.

Continuation of panel discussion

Patricia Golden  
Co-Chair of PHS Task Force on  
Minority Health Data  
National Center for Health  
Statistics (NCHS)

Olivia Carter-Pokras  
Office of Minority Health  
Office of the Assistant Secretary for  
Health

Marsha Ladenburger  
Director, Quality and Utilization  
Management  
Daughters of Charity National  
Health System

Barbara Clements, Ph.D.  
Council of Chief State School  
Officers

Lucy Johns, M.P.H.  
Consultant, Health Care Planning  
and Policy

5:00 p.m.

Adjourn

## References

1. National Center for Health Statistics. Vital statistics of the United States, 1988, vol II, mortality, part A. Washington: National Center for Health Statistics. Table 6-5. 1991.
2. National Center for Health Statistics. Health, United States, 1991. Hyattsville, Maryland: Public Health Service. 15 p. 1992. Rogers E. Human ecology and health. New York: The McMillian Company. Table 49. 1960.
3. National Center for Health Statistics. Health, United States, 1991. Hyattsville, Maryland: Public Health Service. Tables 10 and 11. William Rand Wroblewski R. 1984-88 maternal and child data base: Descriptive narrative. Santa Barbara, California: University of California. 39-46. 1991.
4. National Center for Health Statistics. Health, United States, 1991. Hyattsville, Maryland: Public Health Service. Table 27. 1992.
5. National Center for Health Statistics. Health, United States, 1991. Hyattsville, Maryland: Public Health Service. Table 57. 1992.
6. National Center for Health Statistics. Health, United States, 1991. Hyattsville, Maryland: Public Health Service. Table 30. 1992.
7. National Center for Health Statistics. Advance report, final mortality statistics, 1990. Monthly vital statistics report; vol 41 no 7, suppl. Hyattsville, Maryland: National Center for Health Statistics. 1993.
8. Cooper R. Department of Preventive Medicine and Epidemiology, Transcript, National Committee on Vital and Health Statistics symposium. "Race/ethnicity, socioeconomic status and health: Data Needs and data challenges." Loyola University School of Medicine. 17 p. 1992.
9. Public Health Service Task Force on Minority Health Data. Improving minority health statistics. Washington: Public Health Service. ii p. 1992.
10. The Uniform Hospital Discharge Data Set was first developed in the 1970's and has received widespread use in the public and private sectors as a minimum, common core of data for programs that require data on individual hospital discharges on a continuing basis.
11. Subcommittee on Ambulatory and Hospital Care Statistics. Proposed revision to the Uniform Hospital Discharge Data Set. National Committee on Vital and Health Statistics. June 1992.
12. For Asian or Pacific Islander, the Committee recommends use of the following groupings collected by the U.S. Bureau of the Census: Filipino, Chinese, Japanese, Asian Indian, Korean, Samoan, Vietnamese, Hawaiian, Guamanian, and Other Asian and Pacific Islanders. For the Hispanic population, NCVHS recommends, at a minimum, differentiation among Mexican Americans, Cubans, Puerto Ricans, and other persons of Spanish/Hispanic origin.
13. Williams D. Socioeconomic differentials in health: A review and redirection. *Social Psychology Quarterly* 53:81-99. 1990.

14. Dutton D. Social class, health, and illness. In Aiken L, Mechanic D, eds. *Applications of Social Science to Clinical Medicine and Health*. New Brunswick, New Jersey: Rutgers University Press. 1986.
15. Carter-Pokras O. Office of the Assistant Secretary for Health, Transcript. National Committee on Vital and Health Statistics symposium, Race/ethnicity, socioeconomic status and health: Data needs and data challenges. 132 p. 1992.
16. Epstein A, Weissman J. Case mix and resource utilization by uninsured hospital patients in the Boston metropolitan area. *JAMA*, 261:3572-6. 1989.
17. Williams D. Socioeconomic differentials in health: A review and direction. *Social Psychology Quarterly* 53:85. 1990.
18. Williams D. Socioeconomic differentials in health: A review and direction. *Social Psychology Quarterly*. 53:95. 1990.
19. Schoendorf K, et al. Mortality among infants of blacks as compared with white college-educated parents. *N Engl J Med* 326:1522-6. 1992.
20. Lashof J. Quoted in Russell S. Hawaii ranks first in health care. *San Francisco Chronicle*. November 10, 1992.
21. National Center for Health Statistics. *Health, United States, 1991*. Hyattsville, Maryland: National Center for Health Statistics. Tables 8 and 15. 1992.
22. Johns L. Health care data: Sources, uses, needs—a conference summary for policymakers. Sacramento, California: California Association of Hospitals and Health Systems. 1991.
23. Epstein A, et al. Do the poor cost more? A multihospital study of patients' socioeconomic status and use of hospital resources. *N Engl J Med* 322:1122-8. 1990.
24. For risk-adjusting outcomes, see Blumberg M. Risk-adjusting health care outcomes: A methodologic review. *Medical Care Review* 43: 357-93. 1986; for payment, see Robinson J, et al. A method for risk-adjusting employer contributions to competing health insurance plans. *Inquiry* 28:107-16. 1991.
25. Gay G. Transcript, National Committee on Vital and Health Statistics symposium. Race/ethnicity, socioeconomic status and health: Data needs and data challenges. National Center for Health Statistics. 111-8. 1992.
26. Carter-Pokras O. Office of the Assistant Secretary for Health. Transcript, National Committee on Vital and Health Statistics symposium. Race/ethnicity, socioeconomic status and health: Data needs and data challenges. 125-33. 1992.
27. Hahn B. Agency for Health Care Policy and Research. Transcript, National Committee on Vital and Health Statistics symposium. Race/ethnicity, socioeconomic status and health: Data needs and data challenges. 80-7. 1992.
28. The Interagency Board for Nutrition Monitoring and Related Research. *Improving comparability in the National Nutrition Monitoring and Related Research Program*. 1992.
29. Coffey R. Agency for Health Care Policy and Research. Transcript, National Committee on Vital Health Statistics symposium. Race/ethnicity, socioeconomic status and health: Data needs and data challenges. 72 p. 1992.
30. Ladenburger M. Daughters of Charity National Health System. Transcript, National Committee on Vital Health Statistics symposium. Race/ethnicity, socioeconomic status and health: Data needs and data challenges. 139-41. 1992.
31. Cooper R. Department of Preventive Medicine and Epidemiology. Transcript, National Committee on Vital and Health Statistics symposium. Race/ethnicity, socioeconomic status and health: Data needs and data challenges. Loyola University of Medicine. 11-17, 24. 1992.

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

The National Committee on Vital and Health Statistics (NCVHS) continued to play a lead role in defining critical data elements for national health policy during 1992. In this capacity it worked actively with agencies within the Department of Health and Human Services (DHHS), as well as with other public and private sector organizations, to promote comparability and availability of high quality health data.

In 1992 the Committee carried out substantive activities in the following areas through its subcommittee and work group structure:

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

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

Some subcommittee and full Committee activities had to be curtailed during the first nine months of 1992 due to significant restrictions on Federal travel. The March NCVHS meeting was canceled, and several subcommittees met less frequently than planned. However, a number of significant accomplishments were realized during the year.

The full Committee and NCVHS Executive Subcommittee continued to promote communication and dialogue with departmental policymakers and agency staffs to assure NCVHS responsiveness to Department programs and needs. The Chair of the DHHS Data Planning and Analysis Working Group met with the Committee at its November meeting to discuss the agenda and activities of the Working Group and explore ways in which the NCVHS can be of assistance to the Group. The NCVHS shares the concern of the Working Group that the Department must have the ability to rationalize and coordinate health data collection and to fill health data gaps as well as reduce redundancies in critical areas. Subsequent to the meeting, the Working

Group Chair shared with the NCVHS an analysis of departmental needs for health care utilization and expenditure data in the 1990's, which it had commissioned.

The full Committee receives regular reports on major health data activities and policies from the National Center for Health Statistics (NCHS), which provides Executive Secretary support to the NCVHS; and from the Health Care Financing Administration (HCFA) and the Agency for Health Care Policy and Research (AHCPR), both of which have principal liaisons working with the Committee and Executive Subcommittee. Staff from NCHS, HCFA, and AHCPR serve as staff on most of the NCVHS subcommittees and work group, and other agencies also are represented, as appropriate. This year, as in the past, the Committee provided comments to NCHS on the development of *Health, United States*, the Secretary's annual report on the health of the Nation.

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

### **Strengthening Vital Statistics**

The NCVHS, through the Executive Subcommittee, continued to maintain a strong interest in collaborative efforts with NCHS to strengthen the vital statistics system and, specifically, to improve cause-of-death reporting on the death certificate. The Committee and NCHS cosponsored two invitational workshops on improving cause-of-death statistics with representation from Federal, State, local, and private sector organizations in 1989 and 1991. An educational exhibit addressed to physicians also was developed by NCHS, NCVHS, and the Association for Vital Records and Health Statistics (AVRHS) in 1991 and was taken to additional professional meetings in 1992.

At the June NCVHS meeting, the NCHS Director and staff provided reports on an evaluation of the medical certification process for the death certificate, which has been awarded by NCHS as an outgrowth of the two national workshops, and on the revision of the Model State Vital Statistics Act and Regulations, also supported by NCHS. In May the Executive Subcommittee and Subcommittee on State and Community Health Statistics had reviewed the draft revision of the act and regulations, which are designed to improve the quality and uniformity of State data by establishing standard reporting requirements, definitions, and procedures for reporting vital events. The revision was necessitated by a variety of advances in technology, including electronic transmission of data, and issues related to confidentiality of records and their use for research. At the end of June, the revision was endorsed by the AVRHS.

### **National Health Care Survey**

Another area followed with great interest by the Committee has been NCHS development of the integrated National Health Care Survey, which involves

restructuring existing provider surveys and expanding coverage to a fuller range of health care providers and service settings. At the recommendation of the NCVHS, in 1989 NCHS requested the National Academy of Sciences and the Institute of Medicine (IOM) to convene a panel of experts to evaluate its plans for the National Health Care Survey. Staff from the Committee on National Statistics and IOM presented the panel's final report and recommendations at the June NCVHS meeting, and the NCHS Director reported at the November NCVHS meeting on NCHS plans to implement many of the recommendations. The latter include far-reaching proposals that NCHS develop and implement a continuous, longitudinal survey of health care utilization and expenditures, using cohorts of individuals selected from among National Health Interview Survey (NHIS) respondents and their health care providers; and that NCHS explore whether the reporting of service providers in the NHIS can form a sampling frame for providers not currently surveyed. The NCVHS will continue to follow these developments.

### **Computer-Based Patient Record**

The NCVHS had received a briefing on the IOM report, *The Computer-Based Patient Record: An Essential Technology for Health Care*, at its November 1991 meeting. A broad range of issues concerning public and private sector input, record content, access, and confidentiality were identified that were of interest to the full Committee, several subcommittees, and the Work Group on Confidentiality. Each has incorporated the relevant issues into its ongoing agenda. In addition, an NCVHS member serves on the Board of the Computer-Based Patient Record Institute and has provided regular reports to the NCVHS on the Institute's activities.

At the November 1992 NCVHS meeting the Committee voted to send a letter to the Secretary of DHHS, commending his leadership to the public and private sectors in creating a nationwide electronic health care information network and seeking to support his efforts in the work that lies ahead. As currently envisioned, the network will include standardized electronic health care billing, as well as computerized patient health records. Noting its past and current efforts to define uniform health data sets and appropriate health data policies, the NCVHS seeks to be an active participant in the processes for defining the content of these systems and appropriate data access while protecting personal confidentiality.

### **Race/Ethnicity and Socioeconomic Status**

During the June 1992 NCVHS meeting the members identified the critical need to explain to policymakers and program managers the important role of data on race/ethnicity and socioeconomic factors in understanding health status and health care utilization. Strong concern was expressed that the analysis of racial and ethnic information without socioeconomic indicators is limited and can be misleading.

Specifically, the NCVHS recommended to the Department that studies be undertaken to examine the feasibility of collecting as part of the Uniform Hospital Discharge Data Set a patient's years of education completed, a discrete socioeconomic indicator that has been found to be highly predictive of health status and health care use. Further, the members agreed to initiate an educational effort on these issues by devoting a session at the November 1992 NCVHS meeting to the importance and challenges of collecting meaningful information on race, ethnicity, and socioeconomic status and developing a commentary on this topic for inclusion in the 1992 NCVHS annual report.

The November session included presentations by Dr. Richard Cooper of Loyola University School of Medicine and Dr. Diana Dutton of Stanford University School of Medicine on the role of and interaction between race/ethnicity and socioeconomic status in understanding and explaining health status and health care utilization. This was followed by a panel discussion with representatives of several DHHS components and private sector organizations. With this session and the resulting preamble for policymakers included in this annual report, the NCVHS hopes to advance the broader understanding of these issues and stimulate a research agenda that will address the data challenges and concerns.

# Medical Classification Systems

During 1992 the Subcommittee on Medical Classification Systems continued to address issues surrounding the use of the *International Classification of Diseases (ICD)* in the United States focusing on the status, development, and implementation of *ICD-10*; issues concerning implementation and maintenance of the current classification; and activities relating to the development of a revised classification system for procedures. In April 1992 the Subcommittee convened a meeting to discuss a proposed procedure classification system developed for the Health Care Financing Administration (HCFA) to respond to the difficulties of maintaining and updating the *ICD-9-CM Volume 3*. In September 1992 the Subcommittee circulated a letter to its mailing list requesting written input regarding the feasibility and desirability of a single procedure classification system.

## Background

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

## Current Year's Activities

In April 1992 the Subcommittee convened a meeting to discuss a proposed procedure classification system developed by 3M Health Information System under contract for HCFA to respond to the difficulties of maintaining and updating the *ICD-9-CM Volume 3*. Representatives from major end user organizations who had had the opportunity to pilot test at least one of the chapters of the proposed procedural classification were asked to participate in the discussion. Subsequently, the Subcommittee pursued the issue regarding the benefits and implications for instituting a single procedure classification system and invited its constituents to participate in the written review. Many substantive comments have been received from respondents. To facilitate review of these comments, staff developed a matrix, which aggregates the constructive and insightful information received. The Subcommittee is in the process of deliberating its recommendation on the need for a single procedure classification system and agreeing upon a common definition of procedure classification boundaries.

The Subcommittee held one meeting and three working sessions during 1992.

## **Continuing Work Plan**

The Subcommittee's work plan for 1993 will focus on the following areas:

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

# Long-Term Care Statistics

During 1992 the Subcommittee on Long-Term Care Statistics focused its efforts on the need to improve data collection on disability, initially focusing on the elderly. The Subcommittee convened a meeting in March to discuss the adequacy of data on the current status and trends in the needs for chronic care services and the availability of data to assess the extent to which the needs are being addressed.

## Background

The Subcommittee on Long-Term Care Statistics was formed in 1987 as a successor to the Subcommittee on Uniform Minimum Health Data Sets. In 1991 the Subcommittee revised its charge to focus on identifying the data gaps in disability, particularly as they relate to the elderly, with the view of improving the coordination and the collection of disability data for policy development.

## Current Year's Activities

The March meeting laid the groundwork for the Subcommittee's review on the need for policy relevant data about long-term care. The Subcommittee agreed to address the needs for long-term care by focusing on the following data sets supported by the National Center for Health Statistics (NCHS), the Agency for Health Care Policy and Research (AHCPR), the Health Care Financing Administration (HCFA), and the National Institute on Aging (NIA):

- 1993-94 National Health Interview Survey Disability Supplement (NCHS)
- 1996 National Medical Expenditure Survey (AHCPR)
- Medicare Current Beneficiary Survey (HCFA)
- Health and Retirement Survey (NIA)
- Assets and Health Dynamics Among the Oldest Old (NIA)
- National Long-Term Care Survey (NIA)
- Longitudinal Survey on Aging II (NCHS)

The Subcommittee identified several cross-cutting questions for each of the surveys to help facilitate a possible evaluation of these major long-term care surveys with respect to the adequacy of the data and how the long-term care needs are being met. Alternatively, the Subcommittee may use the information gathered to identify policy issues and assess the adequacy of current data to address them.

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

The Subcommittee held one meeting, two working sessions, and a conference call in 1992.

### **Continuing Work Plan**

The Subcommittee intends to carry out the following work plan in 1993:

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

# Ambulatory and Hospital Care Statistics

The Subcommittee on Ambulatory and Hospital Care Statistics completed a thorough and systematic review of the Uniform Hospital Discharge Data Set (UHDDS) and submitted its proposed revision of the data set to the National Committee on Vital and Health Statistics (NCVHS) in June 1992. Since its inception in the 1970's, the UHDDS has received widespread use as a minimum, common core of data for programs that require data on individual hospital discharges on a continuing basis. The last revision of the UHDDS took place in 1984. The Subcommittee's report was the result of 2 years of study and deliberation, which included review of extensive testimony from public and private sector collectors and users of the UHDDS received by the Subcommittee and the Interagency Task Force on the UHDDS. At the June 1992 NCVHS meeting, the full Committee approved the Subcommittee's report, with modifications, and submitted the report to the Assistant Secretary for Health for consideration by the Department and the Interagency Task Force. The report also was disseminated to other organizations and individuals interested in the work of the Subcommittee. The Assistant Secretary for Health commended the NCVHS on its report and forwarded the document to the Interagency Task Force. The Task Force plans to make its recommendations in 1993.

## Recommendations

The report on the Proposed Revision to the UHDDS is contained in appendix V and includes the following recommendations:

- Unique and universal identifiers should be collected for the patient, the attending and operating physicians, and the hospital.
- Total charges billed by the hospital for the hospitalization, excluding professional charges by physicians, should be added as a new element to the UHDDS.
- Several other new elements are recommended that will contribute to risk-adjusted outcome studies; these include an item for type of admission (scheduled or unscheduled), a qualifier indicating whether the onset of each additional (other) diagnosis preceded or followed admission to the hospital, and newborn birth weight.
- The Committee's June 1991 recommendation to require collection of external cause-of-injury codes as part of the UHDDS is reaffirmed.
- In lieu of five-digit ZIP Code, the patient's full address with nine-digit ZIP Code, if available, should be collected, with appropriate and essential safeguards for maintaining confidentiality. This would allow researchers to

aggregate data to any level of geographic detail and insure the availability of small area data.

- The application of outpatient diagnosis coding guidelines to the inpatient setting is proposed. The implications of this change would be that conditions qualified at discharge as “probable,” “suspected,” or “still to be ruled out” would be coded to the highest degree of certainty, rather than as if they existed or were established.
- Modified and expanded categories for disposition of patient and patient’s expected source of payment are recommended.
- Whenever possible, greater detail should be collected for the Asian or Pacific Islander racial category and the Hispanic ethnicity designation.
- The Department should begin investigating how to add socioeconomic indicators to hospital discharge data, without which analysis of racial and ethnic information is limited and can be misleading.
- The UHDDS, as revised, should continue to be a common core of data elements with uniform definitions recommended for collection on all inpatient hospital discharges.
- The ability to link records is considered an essential aspect of the data set. This ability is strengthened by the recommendations on unique identifiers.
- Programs and other organizations collecting and using health data, such as hospital discharge data, must assume the responsibility for safeguarding these data and seek solutions where inadequate safeguards exist.
- Implementation of a revised UHDDS must be preceded by adequate educational programs for the recorders, collectors, and users of hospital discharge data. Additional field testing and evaluation may be required for some items.

## **Background**

The Subcommittee on Ambulatory Care Statistics was formed at the June 1987 NCVHS meeting as a direct outgrowth of the Subcommittee on Statistical Aspects of Physician Payment Systems, which had begun as a work group in 1984. In June 1989 the Subcommittee and an Interagency Task Force completed work on a revised Uniform Ambulatory Care Data Set. At the November 1989 NCVHS meeting the Subcommittee amended its charge and changed its name to the Subcommittee on Ambulatory and Hospital Care Statistics to reflect an expanded focus on hospital care data.

The Subcommittee subsequently recommended to the NCVHS in June 1990 that a thorough and systematic review of the UHDDS should be undertaken, working in close cooperation with the Department and the National Uniform Billing Committee. The Department responded by establishing an Interagency Task Force on the UHDDS, chaired by the Health Care Financing Administration (HCFA). The Subcommittee began its review of the UHDDS by receiving testimony on external cause-of-injury coding (E-coding), because during the Subcommittee’s informal inquiry into the adequacy of the UHDDS, the additional item most frequently recommended for collection was the E-code associated with an injury diagnosis.

After a year of study and deliberation, in June 1991 the Subcommittee presented a report to the full Committee strongly supporting the inclusion of E-codes in the UHDDS.

### **Current Year's Activities**

The Subcommittee met on January 13–14 and February 12–13 to carry out its review of all current elements of the UHDDS and all new items recommended for inclusion in a revised UHDDS. At both meetings, progress reports were received from the Chairman of the Interagency Task Force.

During the January meeting testimony was received from HCFA and the American Medical Association on a unique identifier for physicians. Representatives of the National Center for Health Statistics (NCHS), HCFA, the American Health Information Management Association (AHIMA), and Massachusetts General Hospital provided testimony on the current UHDDS definitions for principal and other diagnoses. The Subcommittee staff representative from the Agency for Health Care Policy and Research (AHCPR) provided perspectives from the Agency's Hospital Cost and Utilization Project on the collection of disposition status, admission type, and newborn birth weight.

Following the January meeting a work group of Subcommittee staff and the AHIMA representative developed recommendations on revision of the UHDDS element for disposition of patient. This recommendation was adopted by the Subcommittee at its February meeting. The February meeting also included further testimony on the diagnosis definitions from NCHS, the American Hospital Association, and Medicus Systems Corporation. The Subcommittee then heard from the HCFA Health Standards and Quality Bureau about hospital data needs of Peer Review Organizations and AHCPR and the co-chair of an AHCPR guidelines panel on data needed to benefit outcomes research. Finally, the Executive Director of the National Association of Health Data Organizations reported on the data collected by State health data organizations and the importance of adding charge data to the UHDDS.

The Subcommittee reached closure on a revised UHDDS and presented its recommendations at the June NCVHS meeting. The full Committee accepted the Subcommittee's report with two additions. First, language was added to the recommendation on race and ethnicity encouraging the collection of greater detail than the current standards whenever possible. Second, the Committee agreed that data collectors should begin investigating how to add socioeconomic indicators to hospital discharge data and voted to recommend to the Department that studies be undertaken to examine the feasibility of collecting as part of the UHDDS a patient's years of education completed, a discrete socioeconomic indicator that has been found to be highly predictive of health status and health care use. The Committee further recommended that this element be added to the UHDDS as soon as it is deemed feasible, but no later than the revision to the UHDDS following this one. In support of these areas of concern, the NCVHS devoted a half-day session at its

November meeting to the importance and challenges of collecting meaningful information on race, ethnicity, and socioeconomic status.

The Subcommittee met in working session at the June and November NCVHS meetings and agreed at the latter to continue the Committee's inquiry into collecting socioeconomic indicators in hospital discharge data in cooperation with the Subcommittee on Health Statistics for Minority and Other Special Populations.

During its meetings and working sessions the Subcommittee also received updates on implementation of its recommendations concerning external cause-of-injury coding. Staff attended the March meeting of the National Uniform Billing Committee, where agreement was reached on the instructions for recording E-codes on the revised Uniform Bill for hospitals (UB-92), scheduled for implementation in October 1993. In November the Subcommittee was gratified to learn that NCHS had awarded a contract to evaluate the E-code classification system, recommend revisions to the tabular list and alphabetic index, and develop and test national coding guidelines and prototype training materials for E-coding. This contract responds specifically to the recommendations contained in the Subcommittee's 1991 report.

The Subcommittee also continues to follow the Department's review and finalization of the Uniform Ambulatory Care Data Set and to maintain liaison with NCHS, HCFA, AHCPR, and the Health Resources and Services Administration concerning the statistical aspects of physician payment systems and other data systems and research concerned with encounters between patients and providers and with the outcome of care.

## **Continuing Work Plan**

The Subcommittee will pursue the following work plan in 1993:

- Review the report of the Interagency Task Force on the UHDDS, when it becomes available, as well as comments received concerning the Subcommittee's proposed revision to the UHDDS, and determine whether any modifications should be made to its original recommendations.
- Follow departmental data systems and related data activities in ambulatory and hospital care by receiving periodic updates, having an opportunity to react to developments and, where appropriate, framing recommendations concerning their future course.
- Follow and contribute to the work of the Department and the private sector in developing and promoting standards for electronic receipt and transmission of health insurance information and for an automated patient medical record.
- Consider the needs for data to inform the discussion of various health care reform proposals, to establish a baseline, and to monitor the impact of reform proposals as they are implemented. This will include looking at ways to obtain necessary health data from managed care systems.

# Health Statistics for Minority and Other Special Populations

During 1992 the Subcommittee on Health Statistics for Minority and Other Special Populations continued in its efforts to encourage the Health Care Financing Administration (HCFA) and the Social Security Administration (SSA) to improve current and future racial and ethnic identifiers in the Medicare administrative data bases. The Subcommittee was involved in setting the research agenda for the National Center for Health Statistics (NCHS) Minority Health Statistics Grants Program and continues to monitor the implementation of the program. The Subcommittee continued to follow the activities of the U.S. Public Health Service (PHS) Task Force on Minority Health Data, and Subcommittee members reviewed and provided comments on the *Report of the PHS Task Force on Minority Health Data* issued in the spring of 1992.

## Recommendations

During the November 1992 meeting of the National Committee on Vital and Health Statistics (NCVHS), the Subcommittee made the following recommendations to the full Committee:

- The 1995 redesign of the National Health Interview Survey sample, which is to include oversampling of minority populations allowing for more stable estimates, should be fully funded to allow the full scope of the survey to be carried out.
- Continued support should be sought for the maximum authorized level of funding for the NCHS Minority Health Statistics Grants Program.

The full Committee agreed to revisit these recommendations at the March 1993 NCVHS meeting in the context of broader consideration of Committee mechanisms for focusing attention on priority health data needs.

## Background

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

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

### **Current Year's Activities**

The Subcommittee has continued to monitor the impact of its report on medical indigence, which was submitted to the Assistant Secretary for Health in 1991. The report was forwarded to the Department's Data Planning and Analysis Working Group and has been integrated into several documents.

In June 1991 Dr. Carlos Moreno became the chair of the Subcommittee, when Dr. Risa Lavizzo-Mourey resigned from the NCVHS to assume the position of Deputy Administrator of the Agency for Health Care Policy and Research (AHCPR). The Committee and Subcommittee expressed appreciation for Dr. Lavizzo-Mourey's contributions to the NCVHS and welcomed the opportunity to work with her in her new capacity, which includes serving as AHCPR liaison to the NCVHS.

The Subcommittee held two meetings and one conference call during 1992 with a continuing main focus on efforts to improve data on the race and ethnicity of current and future Medicare beneficiaries. The original emphasis of the Subcommittee's inquiry was to identify a mechanism through which health researchers could gain access to Medicare data with enhanced racial and ethnic identifiers. During the course of its investigation, the Subcommittee discovered that a 1990 provision for assigning Social Security Numbers (SSN's) at birth has resulted in a cohort of people for whom no racial and ethnic identifiers are obtained. This omission is a consequence of an agreement between the States and the SSA stipulating that race would not be required by hospitals as a mandatory part of the SSN application because reporting race is not mandatory for obtaining an SSN. The information also cannot be obtained from the birth certificate because the data on race are located in the confidential section of that document. As a result, when the SSA administrative data files are linked to other data sets, including Medicare files, there will be no information on race or ethnicity for this cohort.

The Subcommittee is pursuing the creation of an ad hoc working group under the auspices of the Subcommittee, but including representatives of other concerned agencies such as the SSA, HCFA, AHCPR, and the States, to address this problem.

The Subcommittee was involved in setting the research agenda for the NCHS Minority Health Statistics Grants Program and continues to monitor the implementation of the program.

The Subcommittee continued to follow the activities of the PHS Task Force on Minority Health Data through periodic reports made to the Subcommittee by Task

Force members. The Task Force was established to make specific recommendations to the Assistant Secretary for Health for improving health data for public health assessment, policy development, and programmatic purposes. Subcommittee members reviewed and provided comments on the *Report of the PHS Task Force on Minority Health Data* issued in the spring of 1992.

### **Continuing Work Plan**

- Continue to pursue various avenues to encourage HCFA and SSA to improve current and future data on race and ethnicity in the Medicare administrative data bases.
- Continue to monitor the NCHS reauthorization provisions with regard to the mandate to improve minority health statistics and the grants program to public and nonprofit entities for the conduct and/or analysis of special surveys and methodological studies on the health of racial and ethnic populations.
- Maintain liaison with the Department's working groups established to identify data needs within the Department for health care utilization and expenditures information.
- Meet periodically with the Office of Minority Health and collaborating agencies.
- Explore minority data collection in other Federal agencies, including the Bureau of the Census (Race and Ethnicity Statistics Branch and Estimates and Projections Branch).

# **Mental Health Statistics**

In 1992 the Subcommittee on Mental Health Statistics conducted its third year of activities. The Subcommittee continued to address the following issues: the integration of priority mental health topics into national health care surveys; the creation of a forum for mental health statistical concerns within the Department of Health and Human Services; and the provision of liaison with other committees and activities concerned with data on mental health epidemiology, services, and clients, within and outside of the Department. Continuing with work begun in 1991, the Subcommittee collaborated with the National Center for Health Statistics (NCHS) in developing appropriate mental health status measures for the National Health Interview Survey (NHIS).

## **Background**

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

In 1991 the Subcommittee prepared a report on incorporating mental health status measures in national surveys and commended NCHS for initiating steps to include appropriate measures in the NHIS.

## **Current Year's Activities**

A primary accomplishment in 1992 was the integration of mental health measures into the NHIS. Representatives of the Subcommittee, the National Institute of Mental Health (NIMH) and consultant staff were invited to a meeting in North Carolina to discuss mental health statistics measures for the NHIS. The group recommended that a two-fold approach be employed: (1) use of general measures of depression and anxiety and (2) use of measures to determine specific disorders. This recommendation was accepted by NCHS. Dr. Ronald Kessler of the University of Michigan is currently in the process of developing the approach to be used in the field test for the 1995 NHIS, the first year in which mental health status measures will be integrated into the core instrument.

In 1992 the Subcommittee received testimony in two meetings with representatives of key Federal agencies regarding developments in the area of disability statistics. Primary emphasis was placed on the applicability of disability measures utilized with other populations to mentally ill individuals. The ultimate objective is to develop measures that assess dimensions of functioning specific to mentally ill populations. The Subcommittee provided technical consultation to NCHS on the development of the screener and follow-up survey forms for the 1993-94 disability supplements. This work will address major issues of children and adults, ensuring that mental and emotional health measures are implemented.

Although the number of mentally ill children and adolescents is sizeable, mental health statistics on these populations remain underdeveloped at present. In 1992 the Subcommittee received testimony on the status of epidemiological, service, and client statistics for these populations at two meetings. As a result, the Subcommittee identified content, scope, and data integration gaps that will require attention in the future.

At the closing meeting of the year, presentations were made by representatives of the new Center for Mental Health Services of the new Substance Abuse and Mental Health Services Administration (SAMHSA) regarding the status of existing data systems. The Office of Applied Studies was highlighted, which will be coordinating data collection efforts and evaluation activities across the Agency. Discussion focused on the need to develop a national mental health data policy, upgrading State data capacity, and coordinating and integrating data collection efforts among various national centers and components within the Department.

### **Continuing Work Plan**

In 1993 the Subcommittee will continue to pursue unfinished activities initiated in 1992. Particular attention will be given to:

- The further identification and development of disability measures for mentally ill persons and development of the statistical field for mentally ill children and adolescents.
- Emphasis on the inclusion of mental health measures in drug abuse, alcoholism, and various disability surveys.

Members of the group also expressed concern that future endeavors should facilitate development of a system-wide data collection effort with adequate funding support and dissemination to health care policymakers with appropriate technical assistance.

# State and Community Health Statistics

During 1992 the Subcommittee on State and Community Health Statistics continued its efforts to address the availability of health and health care data at the State and community levels. Testimony received by the Subcommittee and discussions of the Subcommittee focused on data that are currently available for States and communities, sources of data, gaps in data as well as analyses, and anticipated future developments. The Subcommittee in its deliberations addressed issues of improving the quality and quantity of health data, access to data at the State and community levels, and techniques for analyzing small area data.

## Background

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

## Current Year's Activities

Due to travel restrictions the Subcommittee held only one meeting during 1992. At that meeting the Subcommittee continued to hear testimony about issues that affect the availability and utility of data at the State and local levels. A draft report outline was prepared for consideration by the Subcommittee and the Subcommittee conducted extensive discussions of its planned report and recommendations to the full Committee.

## Continuing Work Plan

The Subcommittee will pursue the following work plan in 1993:

- Continue to monitor progress towards achieving the Surveillance and Data Systems objectives in *Healthy People 2000*.

- Continue to work with Federal and State agencies and organizations to identify gaps in health statistics at the State and community levels.
- Review and monitor the annual *Healthy People 2000 Review* to appear in *Health, United States*.
- Prepare a report, for consideration by the full Committee, that outlines major issues with respect to health data at the State and community levels, and make recommendations for improvement in the collection, tabulation, analysis, and access to State- and community-level health data.

# Confidentiality

**During 1992 the Work Group on Confidentiality focused on its two main objectives: an open meeting in January to discuss issues of data access, confidentiality, and unique identifiers; and a final report of its progress and recommendations. The final report was presented by the Work Group Chair at the November meeting, and the recommendations were accepted by the full Committee and transmitted to the Assistant Secretary for Health.**

## Recommendations

The Report of the Work Group on Confidentiality, which can be found in appendix VI, recommended the following:

Systematic and comprehensive data access, through mandated linkages and the universal adoption of unique personal identifiers, would greatly enhance the ability of policymakers to analyze options available to them and make informed decisions. To that end, the Work Group presents these specific recommendations:

- The continuation of the Work Group as a monitor of the current national activities and studies related to data sharing and confidentiality issues.
- Continued support by the National Committee on Vital and Health Statistics (NCVHS) for the adoption of a unique personal identifier to enhance opportunities for interagency and research-related data linkages.
- The ongoing commitment of the National Committee to represent the need for a solution to the problem of data requirements in support of critical research that will inform public policy and the national health care agenda *and* meet the confidentiality requirements of the individual health care consumer.

## Background

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

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

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

## **Current Year's Activities**

In January the Work Group on Confidentiality held an open meeting in Washington, DC, that included broad representation from the private and public sectors. The meeting was designed as a fact-finding mission to obtain input in the areas of data disclosure, data security, and data linkage. A written summary of that meeting was prepared for the full Committee. Following that meeting the Work Group prepared and presented an interim report at the June meeting of the full Committee. The full Committee recommended that a final written report be prepared for the November meeting.

The Work Group held a working session in June to plan for the final report. Budget constraints kept the Work Group from meeting again, but draft reports were circulated for input and comment.

At the November meeting of the full Committee, the Work Group Chair presented the final report of the Group with the recommendations described above. The report was approved by the full Committee at that meeting.

During the year the Work Group Chair and/or key staff participated in the following meetings where issues of confidentiality were explored:

- The First Annual Confidentiality Symposium held in Washington, DC, sponsored by the American Health Information Management Association.
- The Annual Meeting of the National Association of Health Data Organizations, Washington, DC.
- Meetings of the DHHS Task Force on the Privacy of Private Sector Health Records.

## **Continuing Work Plan**

The Work Group intends to carry out the following limited work plan in 1993:

- Monitor the current national activities and studies related to data sharing and confidentiality issues, including the February 1993 Conference on Health

Records: Social Needs and Personal Privacy, sponsored by the DHHS Task Force on the Privacy of Private Sector Health Records.

- Assist other NCVHS subcommittees in areas related to data sharing, confidentiality, and unique identifiers.

# **Appendix I.**

## **Legislative Authority for the National Committee on Vital and Health Statistics From the Public Health Service Act**

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

- (1) There is established in the Office of the Secretary a committee to be known as the National Committee on Vital and Health Statistics (hereinafter in this subsection, referred to as the "Committee") which shall consist of sixteen members.
- (2) (A) The members of the Committee shall be appointed by the Secretary from among persons who have distinguished themselves in the fields of health statistics, health planning, epidemiology, and the provision of health services. Except as provided in subparagraph (B), members of the Committee shall be appointed for terms of four years.
  - (B) (i) In the case of membership terms on the Committee under this subsection (as in effect prior to January 1, 1988) which expire in calendar year 1988, the appointments to three such terms in such calendar year shall be for a period of four years and the appointments to two such terms in such calendar year shall be for a period of three years, as designated by the Secretary.
  - (ii) In the case of membership terms on the Committee under this subsection (as in effect prior to January 1, 1988) which expire in calendar year 1989, one such term shall be extended for an additional consecutive one-year period, as designated by the Secretary.
  - (iii) In the case of membership terms on the Committee under this subsection (as in effect prior to January 1, 1988) which expire in calendar year 1990, two of such terms shall each be extended for an additional consecutive one-year period, as designated by the Secretary.
- (3) Members of the Committee shall be compensated in accordance with section 208(c).
- (4) It shall be the function of the Committee to assist and advise the Secretary—
  - (A) to delineate statistical problems bearing on health and health services which are of national or international interest;
  - (B) to stimulate studies of such problems by other organizations and agencies whenever possible or to make investigations of such problems through subcommittees;
  - (C) to determine, approve, and revise the terms, definitions, classifications, and guidelines for assessing health status and health services, their distribution

and costs, for use (i) within the Department of Health and Human Services, (ii) by all programs administered or funded by the Secretary, including the Federal-State-local cooperative health statistics system referred to in subsection (e), and (iii) to the extent possible as determined by the head of the agency involved, by the Veterans' Administration, the Department of Defense, and other Federal agencies concerned with health and health services;

- (D) with respect to the design of and approval of health statistical and health information systems concerned with the collection, processing, and tabulation of health statistics within the Department of Health and Human Services, with respect to the Cooperative Health Statistics System established under subsection (e), and with respect to the standardized means for the collection of health information and statistics to be established by the Secretary under subsection (j)(i);
  - (E) to review and comment on findings and proposals developed by other organizations and agencies and to make recommendations for their adoption or implementation by local, State, national, or international agencies;
  - (F) to cooperate with national committees of other countries and with the World Health Organization and other national agencies in the studies of problems of mutual interest; and
  - (G) to issue an annual report on the state of the Nation's health, its health services, their costs and distributions, and to make proposals for improvement of the Nation's health statistics and health information systems.
- (5) In carrying out health statistical activities under this part, the Secretary shall consult with, and seek the advice of, the Committee and other appropriate professional advisory groups.

# Appendix II. Charter



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

## CHARTER

### NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

#### PURPOSE

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

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

#### AUTHORITY

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

FUNCTION

It shall be the function of the Committee to assist and advise the Secretary:

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

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

(C) to determine, approve and revise the terms, definitions, classifications, and guidelines for assessing health status and health services, their distribution and costs, for use:  
(i) within the Department of Health and Human Services;  
(ii) by all programs administered or funded by the Secretary;  
and (iii) to the extent possible as determined by the head of the agency involved, by the Department of Veterans Affairs, the Department of Defense, and other Federal agencies concerned with health and health services;

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

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

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

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

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

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

## STRUCTURE

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

Members shall be invited to serve for overlapping four-year terms. Terms of more than two years are contingent upon the renewal of the Committee by appropriate action prior to its termination. Any member appointed to fill a vacancy occurring prior to expiration of the term for which their predecessor was appointed shall be appointed only for the remainder of such term. A member may serve after the expiration of their term until a successor has been appointed.

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

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

## MEETINGS

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

Meetings of the subcommittees shall be held at the call of the Chair with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all subcommittee meetings. All subcommittees shall report their findings to the Committee.

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

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

COMPENSATION

Members who are not full-time Federal employees shall be paid at the rate of \$188 per day, plus per diem and travel expenses in accordance with the Standard Government Travel Regulations.

ANNUAL COST ESTIMATE

Estimated annual cost for operating the Committee, including compensation and travel expenses for members but excluding staff support, is \$147,723. Estimated annual man-years of staff support required is 2.5, at an estimated annual cost of \$133,650.

REPORTS

An annual report shall be submitted to the Secretary through the Assistant Secretary for Health, not later than January 31 of each year, which shall contain as a minimum a list of members and their business addresses, the Committee's functions, dates and places of meetings, and a summary of committee activities and recommendations made during the fiscal year. A copy of the report shall be provided to the Department Committee Management Officer.

TERMINATION DATE

The duration of the National Committee on Vital and Health Statistics is continuing, and a new charter shall be filed no later than July 23, 1994, 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:

JUL 23 1992

\_\_\_\_\_  
Date



\_\_\_\_\_  
Louis W. Sullivan, M.D.  
Secretary

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

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

## *Chair*

Judith Miller Jones (1996)  
Director  
National Health Policy Forum  
2021 K Street, NW., Suite 800  
Washington, DC 20052

School of Public Health  
University of Alabama at Birmingham  
University Station  
Birmingham, AL 35294

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

## *Ex Officio*

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

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

## *Executive Secretary*

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

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

## *Current Membership*

### *(Date Appointment Expires)*

John T. Ashley, M.D. (1994)  
Associate Vice President  
University of Virginia  
Health Sciences Center  
Box 236 Jefferson Avenue  
Charlottesville, VA 22908

Judith D. Kasper, Ph.D. (1996)  
Associate Professor  
Department of Health Policy  
and Management  
The Johns Hopkins University  
Room 689 Hampton House  
624 North Broadway  
Baltimore, MD 21205-1901

William F. Bridgers, M.D. (1994)  
Professor of Public Health

Sister Irene V. Kraus (1993)  
President and CEO  
Sacred Heart Hospital  
5151 North 9th Avenue, P.O. Box 2700  
Pensacola, FL 32513-2700

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

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

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

James W. Thompson, M.D. (1996)  
Associate Professor of Psychiatry  
University of Maryland at Baltimore  
School of Medicine  
IPHB, 645 West Redwood Street  
Baltimore, MD 21201

George H. Van Amburg (1993)  
State Registrar and Chief  
Office of the State Registrar and  
Center for Health Statistics  
Michigan Department of Public Health  
4323 North Logan Street, Box 30195  
Lansing, MI 48909

Thomas T.H. Wan, Ph.D. (1995)  
Professor and Chair  
Department of Health Administration  
Medical College of Virginia  
Virginia Commonwealth University  
520 North End 12th Street, Box 203  
Richmond, VA 23298-0203

David R. Williams, Ph.D. (1996)  
Associate Research Scientist  
Associate Professor of Sociology  
Institute for Social Research  
University of Michigan  
P.O. Box 1248  
Ann Arbor, MI 48106

Nicholas Zill, Ph.D. (1996)  
Vice President  
Westat, Inc.  
1650 Research Boulevard  
Rockville, MD 20850-3129

#### *Members Retired During 1992*

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

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

Risa J. Lavizzo-Mourey, M.D.  
(Resigned)  
Deputy Administrator  
Agency for Health Care Policy  
and Research  
Executive Office Center, Room 600  
2101 East Jefferson Street  
Rockville, MD 20852

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

#### **Meeting Dates**

*All meetings held in Washington, DC*

June 2-4, 1992

November 4-6, 1992

# Appendix IV. Subcommittees of the National Committee on Vital and Health Statistics, Rosters, Meeting Dates, and Charges

## Executive Subcommittee

*Ex Officio*

### Current Roster

#### *Chair*

Judith Miller Jones (1996)  
Director  
National Health Policy Forum  
2021 K Street, NW., Suite 800  
Washington, DC 20052

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

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

George H. Van Amburg (1993)  
State Registrar and Chief  
Office of the State Registrar and  
Center for Health Statistics  
Michigan Department of Public Health  
4323 North Logan Street, Box 30195  
Lansing, MI 48909

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

#### **Staff**

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

John R. Cotter, HCFA

Risa Lavizzo-Mourey, M.D., AHCPR

#### **Meeting Dates**

*Meetings held in Washington, DC*

January 14, 1992

April 14, 1992

August 7, 1992

## Functions and Process for the Executive Subcommittee, NCVHS

### *Background*

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

### *Purpose*

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

### *Composition*

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

### *Functions*

Specific responsibilities of the Executive Subcommittee are to:

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

### *Procedures and Process*

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

Specific activities include:

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

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

## Subcommittee on Medical Classification Systems

### Current Roster

#### *Chair*

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

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

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

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

James W. Thompson, M.D. (1996)  
Associate Professor of Psychiatry  
University of Maryland at Baltimore  
School of Medicine  
IPHB, 645 West Redwood Street  
Baltimore, MD 21201

#### Staff

Lynnette Araki, NCHS  
Perrienne Lurie, M.D., NCHS  
Sue Meads, NCHS

Patricia Brooks, HCFA

Kathleen A. Weis, Dr.P.H., AHCPR

#### Meeting Dates

*Meetings held in Washington, DC*

April 21-22, 1992

June 3, 1992 (working session)

November 4, 1992 (working session)

November 5, 1992 (working session)

December 21, 1992 (conference call)

## Charge to the Subcommittee on Medical Classification Systems

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

- The progress of decisions regarding *ICD-10* with particular attention to the feasibility of development and necessity of an *ICD-10-CM*, including alternative mechanisms and suggested time tables for a clinical modification.
- The progress towards implementation of *ICD-10* including ongoing dissemination of information; the development and dissemination of educational materials; the implementation of operational systems and programs to serve the whole of the user community, providers (physicians, hospitals, ambulatory care), payers, researchers, etc.
- The development and use of derivative applications of the *ICD*, including specialty-specific compendia.

- The continuing process of the *ICD-9-CM* Coordination and Maintenance Committee and related activities since they are expected to serve as the prototype for ongoing maintenance of *ICD-10*, including national and international activities.
- The progress of activities relating to the development and improvement of classification systems for procedures in the United States.
- The ongoing refinement of Diagnosis Related Groups (DRGs), including non-Medicare applications.
- The progress towards improvement of data quality and coding accuracy, systems for automated coding of medical diagnoses, and patient record documentation.

## Subcommittee on Long-Term Care Statistics

### Current Roster

#### *Chair*

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

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

Judith D. Kasper, Ph.D. (1996)  
Associate Professor  
Department of Health Policy  
and Management  
The Johns Hopkins University  
Room 689 Hampton House  
624 North Broadway  
Baltimore, MD 21205-1901

Judith Miller Jones (1996)  
Director  
National Health Policy Forum  
2021 K Street, NW., Suite 800  
Washington, DC 20052

Thomas T.H. Wan, Ph.D. (1995)  
Professor and Chair  
Department of Health Administration  
Medical College of Virginia  
Virginia Commonwealth University  
520 North End 12th Street, Box 203  
Richmond, VA 23298-0203

### Staff

Lynnette Araki, NCHS  
Evelyn Mathis, NCHS

Marvin Feuerberg, Ph.D., HCFA  
Mary Waid, HCFA

### Meeting Dates

*Meetings held in Washington, DC*

March 4-5, 1992  
June 2-3, 1992 (working session)  
October 8, 1992 (conference call)  
November 5, 1992 (working session)

## Charge to Subcommittee on Long-Term Care Statistics

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

There is a link between disability and long-term care, and the causes of disability are varied: developmental, injury-related, chronic disease-related including mental

health conditions, related to aging or frailty, or to conditions secondary to a primary disability. Disabilities often dictate the need for assistance in the activities of daily living (ADL's) or instrumental ADL's (IADL's). However, care of the disabled or those at risk in the disabling process is not limited to that resulting from ADL and IADL limitations; rather, it requires a complete and integrated system of longitudinal care.

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

## Subcommittee on Ambulatory and Hospital Care Statistics

### Current Roster

#### Chair

John T. Ashley, M.D. (1994)  
Associate Vice President  
University of Virginia  
Health Sciences Center  
Box 236 Jefferson Avenue  
Charlottesville, VA 22908

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

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

Judith Miller Jones (1996)  
Director  
National Health Policy Forum  
2021 K Street, NW., Suite 800  
Washington, DC 20052

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

George H. Van Amburg (1993)  
State Registrar and Chief  
Office of the State Registrar and  
Center for Health Statistics  
Michigan Department of  
Public Health  
4323 North Logan Street, Box 30195  
Lansing, MI 48909

#### Staff

Marjorie S. Greenberg, NCHS  
Jim Delozier, NCHS  
Linda Lawrence, NCHS

William Sobaski, HCFA

Judy Ball, Ph.D., AHCPR

#### Meeting Dates

*Meetings held in Washington, DC*

January 13-14, 1992

February 12-13, 1992

June 3, 1992 (working session)

November 5, 1992 (working session)

## Charge to Subcommittee on Ambulatory and Hospital Care Statistics

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

Health by the NCVHS and the Interagency Task Force. Monitor any implementation plans that are developed by the agencies.

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

## **Subcommittee on Health Statistics for Minority and Other Special Populations**

### **Current Roster**

#### *Chair*

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

Sister Irene V. Kraus (1993)  
President and CEO  
Sacred Heart Hospital  
5151 North 9th Avenue  
P.O. Box 2700  
Pensacola, FL 32513-2700

Thomas T.H. Wan, Ph.D. (1995)  
Professor and Chair  
Department of Health Administration  
Medical College of Virginia  
Virginia Commonwealth University  
520 North End 12th Street, Box 203  
Richmond, VA 23298-0203

David R. Williams, Ph.D. (1996)  
Associate Research Scientist  
Associate Professor of Sociology  
Institute for Social Research  
University of Michigan  
P.O. Box 1248  
Ann Arbor, MI 48106

#### **Staff**

P. Ellen Parsons, Ph.D., NCHS  
Diane Makuc, Ph.D., NCHS  
Patricia M. Golden, NCHS

Frank Emerson, HCFA  
David Gibson, HCFA

Harvey A. Schwartz, Ph.D., AHCPR

#### **Meeting Dates**

*Meetings held in Washington, DC*

June 3, 1992 (working session)  
November 5, 1992 (working session)

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

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

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

## Subcommittee on Mental Health Statistics

### Current Roster

#### *Chair*

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

Judith D. Kasper, Ph.D. (1996)  
Associate Professor  
Department of Health Policy  
and Management  
The Johns Hopkins University  
Room 689 Hampton House  
624 North Broadway  
Baltimore, MD 21205-1901

James W. Thompson, M.D. (1996)  
Associate Professor of Psychiatry  
University of Maryland at Baltimore  
School of Medicine  
IPHB, 645 West Redwood Street  
Baltimore, MD 21201

Thomas T.H. Wan, Ph.D. (1995)  
Professor and Chair  
Department of Health Administration  
Medical College of Virginia  
Virginia Commonwealth University  
520 North End 12th Street, Box 203  
Richmond, VA 23298-0203

David R. Williams, Ph.D. (1996)  
Associate Research Scientist  
Associate Professor of Sociology  
Institute for Social Research  
University of Michigan  
P.O. Box 1248  
Ann Arbor, MI 48106

Nicholas Zill, Ph.D. (1996)  
Vice President  
Westat, Inc.  
1650 Research Boulevard  
Rockville, MD 20850-3129

#### **Staff**

Ronald Manderschied, Ph.D., NIMH

Peggy Barker, NCHS

Thomas Hoyer, HCFA

Tamra J. Lair, Ph.D., AHCPR

#### **Meeting Dates**

*Meetings held in Washington, DC*

February 14, 1992

May 22, 1992

June 3, 1992 (working session)

October 29, 1992

November 5, 1992 (working session)

### Charge to Subcommittee on Mental Health Statistics

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

- Identify major gaps in mental health statistics;
- Explore the feasibility of filling existing gaps with ongoing data collection efforts; to explore how ongoing efforts might be supplemented;
- Examine areas of measurement development necessary to meet national goals or priorities;

- Work with PHS and other DHHS agencies to identify areas of needed initiatives and opportunities for coordination of efforts; and to bring in other relevant federal agencies;
- Examine how major data sources (e.g., Medicare and Medicaid data) can be used to help meet mental health data needs;
- Explore opportunities for data linkage relevant to data bases collected by NCHS, HCFA, and other federal agencies;
- Increase the availability, quality, and utility of data dealing with mental illness including the provision of public use data tapes; and
- Coordinate the NCVHS review of the biennial publication, *Mental Health, United States*.

## Subcommittee on State and Community Health Statistics

### Current Roster

#### *Chair*

George H. Van Amburg (1993)  
State Registrar and Chief  
Office of the State Registrar and  
Center for Health Statistics  
Michigan Department of  
Public Health  
4323 North Logan Street, Box 30195  
Lansing, MI 48909

John T. Ashley, M.D. (1994)  
Associate Vice President  
University of Virginia  
Health Sciences Center  
Box 236 Jefferson Avenue  
Charlottesville, VA 22908

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

Sister Irene V. Kraus (1993)  
President and CEO  
Sacred Heart Hospital  
5151 North 9th Avenue  
P.O. Box 2700  
Pensacola, FL 32513-2700

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

Nicholas Zill, Ph.D. (1996)  
Vice President  
Westat, Inc.  
1650 Research Boulevard  
Rockville, MD 20850-3129

### Staff

Mary Anne Freedman, NCHS

Kathleen A. Weis, Dr.P.H., AHCPR

### Meeting Dates

*Meetings held in Washington, DC*

June 3, 1992 (working session)

October 21-22, 1992

November 5, 1992 (working session)

## Charge to Subcommittee on State and Community Health Statistics

### *Background*

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

*The committee recommends that every public health agency regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health, needs, and epidemiologic and other studies of health problems.*

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

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

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

The charge of the Subcommittee shall be to:

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

## References

1. Institute of Medicine. The future of public health. Washington: National Academy Press. 1988.
2. U.S. Department of Health and Human Services. Healthy people 2000: National health promotion and disease prevention objectives. Washington: Public Health Service. 1990.

## Work Group on Confidentiality

### Current Roster

#### *Chair*

Nancy L. Cannon, Ph.D. (1993)

Vice President

Private Health Care Systems

20 McGuire Road

Lexington, MA 02173

William F. Bridgers, M.D. (1994)

Professor of Public Health

School of Public Health

University of Alabama at Birmingham

University Station

Birmingham, AL 35294

George H. Van Amburg (1993)

State Registrar and Chief

Office of the State Registrar and

Center for Health Statistics

Michigan Department of

Public Health

4323 North Logan Street, Box 30195

Lansing, MI 48909

### Staff

Mary A. Moien, NCHS

Glenn Martin, HCFA

Harvey Schwartz, Ph.D., AHCPR

### Meeting Dates

*Meetings held in Washington, DC*

January 15, 1992

June 3, 1992 (working session)

## Charge to Work Group on Confidentiality

### *Background*

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

The charge of the Work Group shall be:

The Work Group on Confidentiality has two objectives for 1991-92:

- The exploration of current public policy issues surrounding the release and disclosure of data and,

- The development of a strategic approach to the long-term management of these critical issues. In setting a course of the Work Group, the basic assumption was that the National Committee members have a common goal. Health care data should be made available to researchers and policy analysts (at the appropriate levels of disaggregation), with the correct safeguards in place to protect confidentiality.

# **Appendix V. Proposed Revision to the Uniform Hospital Discharge Data Set June 1992**

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

### **Background**

A Uniform Hospital Discharge Data Set (UHDDS) was promulgated by the Secretary of the U.S. Department of Health, Education, and Welfare in 1974 as a minimum, common core of data on individual hospital discharges in the Medicare and Medicaid programs. Its purpose was to improve the uniformity and comparability of hospital discharge data. Promulgation of the UHDDS was the culmination of a number of developmental activities involving the public and private sectors.

The current 1984 revision of the UHDDS was published by the Department of Health and Human Services (DHHS) in the July 31, 1985, issue of the *Federal Register*. The purpose of the revision was to update and improve the original version in the light of current needs and developments.

Since it was first promulgated, the UHDDS has achieved widespread use as a minimum, common core of data within the Department in programs that require data on individual hospital discharges on a continuing basis. The data set is also used within other Federal agencies and has gained use as a standard in the non-Federal public and private sectors, such as in the operations of State health data organizations and hospital discharge abstracting services.

The National Committee on Vital and Health Statistics (NCVHS), the principal advisory body to the Secretary of DHHS on health statistical matters, has been involved with the development, assessment, and modification of the UHDDS since the data set's inception. In June 1990 the NCVHS recommended to the Department that once again a thorough and systematic revision of the UHDDS was warranted and should be undertaken by the NCVHS and the Department, working in close collaboration with the National Uniform Billing Committee (NUBC). The NUBC is responsible for maintaining the uniform bill for hospitals, which is a principal vehicle for collecting the UHDDS elements.

The NCVHS review of the UHDDS has been carried out by the Subcommittee on Ambulatory and Hospital Care Statistics. A roster of Subcommittee members and staff is presented at the end of this report. The Subcommittee held meetings

throughout 1990, 1991, and the first half of 1992 to receive and evaluate testimony from public and private sector organizations on proposed modifications to the UHDDS elements and definitions. Concurrently, an Interagency Task Force has been meeting to review the UHDDS from the perspective of departmental needs for hospital discharge data. The task force was established by the Department in January 1991 in response to the NCVHS recommendations and is chaired by the Health Care Financing Administration.

The following recommendations for revision of the UHDDS, which were developed by the NCVHS Subcommittee on Ambulatory and Hospital Care Statistics, have been approved by the full Committee for consideration by the Department and the Interagency Task Force. As in the past, it must be emphasized that the data set is a common core of data elements with uniform definitions to be collected on individual hospital discharges and is not intended to serve the entire data needs of a program or activity. The items recommended are considered to be those most likely to be needed by a variety of users for multiple applications. Individual programs and data collectors may choose to obtain additional data elements in accordance with their particular requirements and may obtain additional detail within the UHDDS items, provided that the detail can be aggregated to the UHDDS items, definitions, and categories.

The items in this data set are recommended for inclusion in the records of all inpatient hospital care but do not themselves define a complete medical record. Some items may be recorded in records other than the individual patient medical record, for example, registration or billing records. In such instances, the capability should exist to link data from the various data sources. This ability to link records is considered an essential aspect of the data set.

Confidentiality represents a continuing concern, which extends beyond the activities of the Subcommittee. It must be acknowledged that, wherever health or other personal data are collected, there is always the risk of inappropriate disclosure and invasion of personal privacy. The absence of such information, however, presents other serious risks. Programs and other organizations collecting and using health data must assume the responsibility for safeguarding those data and protecting citizens' rights under applicable laws and regulations and must modify approaches or seek solutions where inadequate safeguards exist.

Implementation of a revised UHDDS must be preceded by adequate educational programs for the recorders, collectors, and users of hospital discharge data to assure that new definitions and elements are properly understood and reported. Finally, research should be initiated on adding socioeconomic factors to the UHDDS, in particular a patient's years of education completed, no later than the revision to the UHDDS following this one.

## Recommendations

The Subcommittee on Ambulatory and Hospital Care Statistics of the National Committee on Vital and Health Statistics recommends the following core set of items for inclusion in a revised Uniform Hospital Discharge Data Set. These items are recommended for inclusion in the medical records of all inpatient hospital care and for uniform abstraction from existing records into hospital care data bases:

1. Personal identification
2. Date of birth
3. Sex
4. Race and ethnicity
5. Residence
6. Hospital identification
7. Admission date
8. Type of admission
9. Discharge date
10. Physician identification: attending
11. Physician identification: operating
12. Principal diagnosis
13. Other diagnoses
14. Qualifier for other diagnoses
15. External cause-of-injury code
16. Birth weight of newborn
17. Procedures and dates
18. Disposition of patient
19. Expected sources of payment
20. Total charges

The following list contains an identification and definition of each UHDDS element and comments, as appropriate. The recommendations represent the outcome of Subcommittee deliberations as informed by consultation with the broader community of data users. Differences in content or definition from the 1984 Revision are described.

### 1. Personal Identification

A unique number identifying the patient, applicable to the individual regardless of health care source or third-party arrangement. The Subcommittee considers the social security number (SSN), with a modifier, as necessary, for patients without their own number, the best option currently available for this unique and universal patient identifier.

Comment: The ability to link services for the individual across health care systems and reimbursement mechanisms is considered an extremely important goal. The 1984 Revision of the UHDDS specified as the patient identifier "The unique number assigned to each patient within a hospital that distinguishes the patient and his or her hospital record from all others in that institution." The Subcommittee considers such

an identifier, limited to the confines of the individual hospital, totally inadequate for the information requirements of 1992 and beyond. At the same time, the Subcommittee recognizes the vital importance of maintaining patient confidentiality and emphasizes that any public uses of the SSN should be in an encrypted form. Further, the Subcommittee notes that it will be necessary to improve the SSN as a truly unique and universal identifier. Nonetheless, alternative constructions for unique identification of all individuals are unlikely and would require a new bureaucracy and considerable additional expense.

## **2. Date of Birth (month, day, and year)**

Comment: A minimum of three digits are required for year. If birth date is not known, compute year of birth from age. The current UHDDS recommends four digits for year, but three are considered adequate to capture the century.

## **3. Sex**

- Male
- Female

Comment: No change from current UHDDS definition.

## **4. Race and Ethnicity**

- Race
  - (1) American Indian/Eskimo/Aleut
  - (2) Asian or Pacific Islander
  - (3) Black
  - (4) White
  - (5) Other Race
  - (6) Unknown
- Ethnicity
  - (1) Spanish/Hispanic Origin
  - (2) Not of Spanish/Hispanic Origin
  - (3) Unknown

Comment: Whenever possible, greater detail should be collected on Asians and Pacific Islanders (API) and on Hispanic populations. Specifically, the National Committee on Vital and Health Statistics recommends use of the following API categories collected by the U.S. Bureau of the Census: Filipino, Chinese, Japanese, Asian Indian, Korean, Samoan, Vietnamese, Hawaiian, Guamanian, and Other Asian and Pacific Islanders. For the Hispanic population, the Committee recommends, at a minimum, differentiation among Mexican Americans, Cubans, Puerto Ricans, and other persons of Spanish/Hispanic origin. The Subcommittee notes that the ethnicity identifier is an indication of Hispanic origin rather than a generic classification of ethnicity and that some localities may want to collect additional information on ethnic origin.

The basic six categories for race and three categories for ethnicity, with the exception of unknown, are those currently used by the Department in the Uniform Hospital Discharge Data Set and parallel those specified in 1981 by the Office of Management and Budget (OMB) with an additional exception. Whenever finer distinctions are made within a particular racial or ethnic group, as recommended above, it should be possible to aggregate such categories into the basic OMB categories.

The Department uses the category American Indian/ Eskimo/Aleut rather than the OMB category of American Indian or Alaskan Native, because Alaskan Native can include American Indians and could also be considered anyone born in Alaska. The Subcommittee recommends the final option of unknown for race and ethnicity, recognizing that there often are serious problems collecting accurate racial and ethnic identifiers for health care records. Additional research is needed to improve the collection of this information.

The OMB states that a person's racial and/or ethnic background is determined by the way in which the person chooses to be identified in his or her community. The race and ethnicity recorded for a newborn or other minor should be that designated by the parent(s). The National Center for Health Statistics analyzes vital record data on newborns according to the race and ethnicity of the mother.

Finally, the NCVHS recommends that the Department begin investigating how to add socioeconomic indicators to hospital discharge data. The analysis of racial and ethnic information without these indicators is limited and can be misleading. Specifically, the NCVHS recommends that studies be undertaken to examine the feasibility of collecting as part of the UHDDS a patient's years of education completed, a discrete socioeconomic indicator that has been found to be highly predictive of health status and health care use. The Committee further recommends that this element be added to the UHDDS as soon as it is deemed feasible, but no later than the revision to the UHDDS following this one.

##### **5. Residence (usual residence, full address and ZIP Code - nine digit ZIP Code, if available)**

Comment: This recommendation is in accord with the June 1989 recommendations of the NCVHS and an Interagency Task Force on the Uniform Ambulatory Care Data Set, as well as recommendations to this Subcommittee by the NCVHS Subcommittee on State and Community Health Statistics. The latter determined at its December 11-12, 1991, meeting that residential street address has the advantage of enabling researchers to aggregate the data to any level of geographic detail (block, census tract, ZIP Code, county, etc.) and that it is "the best alternative . . . (to) insure the availability of small area data." The current UHDDS requirement to collect ZIP Code, only, is considered inadequate for these purposes. Because the full residential address could serve as a proxy personal identifier, confidentiality of the complete information must be safeguarded in public use of the data.

## **6. Hospital Identification**

A unique institutional number across data systems, to allow for tracking and linkage of multiple records, preferably the Medicare provider number. The Subcommittee concurs with the American Hospital Association (AHA) that this capability is important and that any of three options, the Medicare provider number, the federal tax ID number, or the AHA number would be preferable to creating a new number. The current UHDDS definition of “A unique institutional number within a data collection system” is considered too limiting and would not permit linkage across data systems.

## **7. Admission Date (month, day, and year of admission)**

Comment: The current UHDDS specifies that “An inpatient admission begins with the formal acceptance by a hospital of a patient who is to receive physician, dentist, or allied services while receiving room, board, and continuous nursing service.” The Subcommittee provides further clarification that for emergency room and observation patients, the time that the physician signs the order for admission is a guide to admission date.

## **8. Type of Admission**

*Scheduled*—Defined as an arrangement with the admissions office at least 24 hours before the admission

*Unscheduled*—All other admissions

Comment: The Subcommittee recommends this element as a new element in the UHDDS. Documentation of this element, as defined above, should be available in the medical record. Testimony was received that supported the importance of differentiating between truly unscheduled and scheduled admissions for severity analysis and study of patient outcomes. Other distinctions (for example, among urgent, emergency, and elective) were considered too difficult to define uniformly across institutions.

## **9. Discharge Date (month, day, and year of discharge)**

Comment: As specified in the current UHDDS, “An inpatient discharge occurs with the termination of the room, board, and continuous nursing services, and the formal release of an inpatient by the hospital.”

## **10–11. Physician Identification**

Each physician should have a universal unique number across all hospitals and data systems. The Medicare Unique Physician Identification Number (UPIN) is recommended for this purpose. The attending physician and the operating physician (if applicable) are to be identified.

Comment: The current UHDDS states that “Each physician must have a unique identification number within the hospital.” The Subcommittee considers this requirement too narrow as it does not permit following a physician’s practice across

hospitals or linking records across hospitals and with records from other settings. The UPIN has been assigned to over 600,000 physicians who bill for Medicare services. In those cases when a physician does not currently have a UPIN, one should be obtained, or another unique number should be used. One possibility is the physician's social security number (SSN), although in earlier deliberations the Department decided not to use the SSN for this purpose. The Subcommittee explored the possibility of using the Medical Education Number maintained by the American Medical Association, but this approach was not deemed as feasible.

#### **10. Attending Physician**

The UPIN for the clinician of record at discharge who is responsible for the discharge summary.

Comment: The current UHDDS definition refers to "The clinician who is primarily and largely responsible for the care of the patient from the beginning of the hospital episode." The Subcommittee determined that it was most important to know which physician was responsible for the discharge summary and attestation statement and this might not be the same as the admitting physician, who was responsible for the patient at the beginning of the hospital episode.

#### **11. Operating Physician**

The UPIN for the clinician who performed the principal procedure (see item 17 for the definition of a principal procedure).

Comment: No change from current UHDDS definition of an operating physician.

#### **12-13. Diagnoses**

All substantiated diagnoses that affect the current hospital stay. Code to the highest degree of certainty.

Comment: The current UHDDS states "All diagnoses that affect the current hospital stay." Coding guidelines for inpatient cases printed in *Coding Clinic for ICD-9-CM* (March-April 1985) state, "If the diagnosis documented at the time of discharge is qualified as 'probable,' 'suspected,' 'likely,' '?,' 'possible,' or 'still to be ruled out,' code the condition as if it existed or was established. The bases for this guideline are the diagnostic workup, arrangements for further workup or observation, and initial therapeutic approach that correspond most closely with the established diagnosis."

Alternatively, the guidelines for outpatient coding instruct coders to code the condition(s) or symptom(s) to the highest degree of certainty for that encounter and not to code diagnoses documented as "probable," "suspected," "questionable," or "rule-out" as if they are established (see 1989 report on Uniform Ambulatory Care Data Set). The Subcommittee considers it problematic to have different guidelines on this element for inpatient and outpatient coding and also believes that the outpatient guidelines result in more accurate data and should apply in both settings. The

Subcommittee further recognizes that the responsibility for specifying the certainty of a diagnosis belongs to the attending physician and should not be borne by the coder. When qualifying terms are used, the coder should seek a definite diagnosis or other clarification from the attending physician.

Before implementation of this revision, educational efforts will be necessary for the recorders, collectors, and users of hospital discharge data.

## **12. Principal Diagnosis**

The condition established after study to be chiefly responsible for occasioning the admission of the patient to the hospital for care.

Comment: Aside from the commentary provided above on all diagnoses, there is no change recommended for this definition, which is widely used and understood by hospitals.

## **13. Other Diagnoses**

All conditions that coexist at the time of admission, or develop subsequently, which affect the treatment received and/or the length of stay. Diagnoses that relate to an earlier episode that have no bearing on the current hospital stay are to be excluded.

Conditions should be coded that affect patient care in terms of requiring:

- Clinical evaluation; or
- Therapeutic treatment; or
- Diagnostic procedures; or
- Extended length of hospital stay; or
- Increased nursing care and/or monitoring.

*(Coding Clinic for ICD-9-CM, Second Quarter 1990)*

Comment: The definition provided in the first paragraph above corresponds to the definition for Other Diagnoses in the original UHDDS. The current UHDDS definition from the 1984 revision defines other diagnoses as "all conditions that coexist at the time of admission, that develop subsequently, or that affect the treatment received and or the length of stay. Diagnoses that relate to an earlier episode that have no bearing on the current hospital stay are to be excluded." This rewording of the first sentence from the original UHDDS definition has led to confusion about whether any diagnosis that coexists at the time of admission or develops subsequently should be coded, whether it affects the treatment received and/or the length of stay. The final qualifying sentence does not totally alleviate the problem. The Subcommittee received considerable testimony about the value of removing this ambiguity and returning to the original definition.

## **14. Qualifier for Other Diagnoses**

A qualifier for each diagnosis coded under Other Diagnoses to indicate whether the onset of the diagnosis preceded or followed admission to the hospital. The option of uncertain also would be permitted. This is recommended as a new element for the

UHDDS in response to testimony that such a qualifier would contribute significantly to quality assurance monitoring, risk-adjusted outcome studies, and reimbursement strategies. Mayo Clinic affiliated hospitals implemented this coding modification in July 1990 and have reported a modest additional cost (under 2 minutes per abstract) and considerable consistency in reabstracting studies (*Quality Assurance in Health Care*, Vol. 3, No. 4, pp. 257-62, 1991). The New York State hospital data system also adopted this coding modification in 1991. The alpha qualifier, as specified below, could also accommodate the *voluntary* reporting of whether one of the other diagnoses was the primary diagnosis. Primary is defined as the diagnosis chiefly responsible for the major part of the patient's hospital length of stay, as identified by the physician. Several studies have indicated that, in some cases, this is a different diagnosis than the principal diagnosis.

If only the first qualifier is reported, the following schema can be used:

- A. Onset prior to admission
- B. Onset not prior to admission
- C. Onset uncertain

If both qualifiers are reported, the following is recommended:

- A. Onset prior to admission, uncertain whether primary diagnosis
- B. Onset not prior to admission, uncertain whether primary diagnosis
- C. Onset uncertain, uncertain whether primary diagnosis
- D. Onset prior to admission, primary diagnosis
- F. Onset not prior to admission, primary diagnosis
- G. Onset uncertain, primary diagnosis
- H. Onset prior to admission, not primary diagnosis
- J. Onset not prior to admission, not primary diagnosis
- K. Onset uncertain, not primary diagnosis

Implementation of one or both qualifiers should be preceded by appropriate educational efforts for the recorders, collectors, and users of hospital discharge data.

## 15. External Cause-of-Injury Code

The *ICD-9-CM* code for the external cause of an injury, poisoning, or adverse effect. Hospitals should complete this item whenever there is a diagnosis of an injury, poisoning, or adverse effect. The priorities for recording an E-code are:

- Principal diagnosis of an injury or poisoning
- Other diagnosis of an injury, poisoning, or adverse effect directly related to the principal diagnosis
- Other diagnosis with an external cause

When it is necessary or desirable to record more than one E-code, the first E-code should be recorded in this item. Additional E-codes may be entered in item 13., as space permits. The qualifier in item 14. would not apply; although the nature of the injury could be the primary diagnosis, the external cause could not.

Comment: The inclusion of a separate item for recording of an E-code is an addition to the current UHDDS. The information that will be provided on hospitalized injury patients with this item is considered essential for the development of intervention, prevention, and control strategies for injuries. Currently, E-codes can be recorded among the other diagnoses in the UHDDS; however, the Subcommittee concluded in its June 1991 report on the Need to Collect External Cause-of-Injury Codes in Hospital Discharge Data, that one or more separate fields for E-codes are most desirable in hospital discharge data and should be the goal for all systems. In response to the Subcommittee's recommendations, the revised uniform bill for hospitals (UB-92) will include a separate labeled form locator for an E-code. Further details on the need for improvements in the *ICD-9-CM* E-coding classification and for development of national guidelines and training materials for coders and physicians are contained in the Subcommittee's report.

## 16. Birth Weight of Newborn

The specific birth weight of the newborn, preferably recorded in grams.

Comment: Although recording in grams is preferred, the data collector should report whatever is recorded in the newborn's record with an indicator as to whether the birth weight is in pounds or grams. This is a new element recommended by the Subcommittee for the UHDDS. Testimony received by the Subcommittee supported that the information is readily available in the medical record and has singular importance for risk-adjusted outcome studies and health policy development related to maternal and infant health. Collection of birth weight in ranges for low-birth weight babies through *ICD-9-CM* coding is considered inadequate for these purposes.

## 17. Procedures and Dates

All significant procedures are to be reported.

- A significant procedure is one that is:
  - (1) Surgical in nature, or
  - (2) Carries a procedural risk, or
  - (3) Carries an anesthetic risk, or
  - (4) Requires specialized training.

Surgery includes incision, excision, amputation, introduction, endoscopy, repair, destruction, suture, and manipulation.

- The date must be reported for each significant procedure.
- When more than one procedure is reported, the principal procedure is to be designated. In determining which of several procedures is principal, the following criteria apply:

The principal procedure is one that was performed for definitive treatment rather than one performed for diagnostic or exploratory purposes, or was necessary to take care of a complication. If there appear to be two procedures that are principal, then

the one most related to the principal diagnosis should be selected as the principal procedure.

- The UPIN must be reported for the person performing the principal procedure (see item 11. above).

Comment: This item and definition are congruent with those currently used in the UHDDS. Further definition and guidelines on “procedural risk,” “anesthetic risk,” and “specialized training,” as described in the 1984 Revision, can be provided with UHDDS training materials. The current UHDDS definition states that “For significant procedures, the identity (by unique number within the hospital) of the person performing the procedure and the date must be reported.” The recommended revision clarifies that the identity of the person performing the procedure is only required for the principal procedure. Further, a universal and unique number, specifically the UPIN, is required for this person. Dates are required for all significant procedures.

## **18. Disposition of Patient**

- Discharged to home or self care

(This category includes discharged to a prison, orphanage, or other nonmedical custodial care facility. It does not include patients referred to a home health service.)

- Discharged to acute care (medical/surgical) hospital

(This category includes general, ob/gyn, children’s general, ENT, etc.)

- Discharged to a nursing facility

(This category includes skilled nursing and intermediate care facilities, freestanding and hospital-based units.)

- Discharged home to be under the care of a home health services agency

(This category includes hospice care provided in the home.)

- Discharged to other health care facility

(This category includes, for example, rehabilitation, psychiatric, chemical dependency, veterans facilities, and hospice facilities.)

- Left against medical advice
- Alive, other/alive, not stated
- Died

Comment: The above categories are a modification to the categories currently used in the UHDDS for Disposition of Patient. The current categories are (1) discharged to home, (2) left against medical advice, (3) discharged to another short-term hospital, (4) discharged to a long-term care institution, (5) died, and (6) other. The Subcommittee concluded that the distinction between short-term and long-term facilities, based on average length of stay, was less useful than a distinction between acute medical/surgical care and other care. For example, the hospital discharging a

patient to another facility may not know the average length of stay of that facility. The Subcommittee also considered it important to add a separate category for home health care and to provide a list of examples for other health care facilities.

Feasibility studies should be conducted on how future data collectors can capture greater detail about the setting to which the patient returns, specifically whether there are caretakers in the home.

## **19. Patient's Expected Sources of Payment**

- Primary source

The primary source that is expected to be responsible for the largest percentage of the patient's current bill.

- Other source(s)

Other sources, if any, that are expected to be responsible for a portion of the patient's current bill. More than one can be identified.

The categories for primary and other sources are as follows:

- Blue Cross and Blue Shield
- Other health insurance companies
- Other liability insurance
- Medicare
- Medicaid
- Workers compensation
- Self-insured employer plan
- Health Maintenance Organization (HMO)
- CHAMPUS
- CHAMP VA
- Other government payers
- Self pay
- No charge (free, charity, special research, or teaching)
- Other

Comment: The above categories are those recommended in 1989 for the Uniform Ambulatory Care Data Set. They are consistent with those used in the current UHDDS for "Expected Payer for Most of This Bill" with a further breakout for other liability insurance, self-insured employer plan, health maintenance organization, CHAMPUS, and CHAMP VA. The addition to the data set of other expected sources of payment in addition to the expected primary source reflects the increasing interest among private and public insurers in coordination of benefits. HMO can be a payment source and a payment mechanism. When the specific payment source (for example, Blue Cross and Blue Shield or Medicare) is known, that source should be selected rather than HMO.

This information is more likely to be available from registration forms and billing records than from the patient's medical record. It is recognized that as the expected

source(s) at the time of the hospitalization, this information has limitations and may overstate some categories and understate others. However, it is still considered useful to collect for trend purposes and for some indication of patient's coverage by third-party payers.

## **20. Total Charges**

All charges billed by the hospital for this hospitalization. Professional charges for individual patient care by physicians are excluded.

Comment: The Subcommittee recommends Total Charges as a new item in the UHDDS. The item already is collected by most State health data organizations collecting hospital discharge information and has been recommended by a variety of data collectors and users. The following commentary parallels that found in the recommended Uniform Ambulatory Care Data Set.

Patient medical records, from which most other items in the UHDDS can be captured, do not usually include fiscal information. However, information on charges associated with the hospitalization can be obtained as a byproduct of the billing process, offering the only readily available information on the fiscal dimensions of hospital care and the relative cost of different types of cases. The latter is particularly important for targeting scarce resources for medical effectiveness research. Previous work related to recalibration of the payment weights for Diagnosis-Related Groups (DRG's) found a high correlation of hospital costs and charges.

Charge data, linked with information on patient characteristics, provider characteristics, and the hospitalization could, if uniformly and systematically collected, yield substantially improved aggregate information on the scope, characteristics, and distribution of hospital care charges.

It is recognized that this item is difficult to capture in a uniform way and often will involve linkage of records. The Subcommittee encourages research and developmental work that will enhance the utility of the data collected.

**Roster:**  
**National Committee on Vital and  
Health Statistics Subcommittee on  
Ambulatory and Hospital Care  
Statistics**

*Chair* (June 1988–June 1991)

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

*Chair* (June 1991–)

John T. Ashley, M.D.  
Associate Vice President  
University of Virginia  
Health Sciences Center  
Box 236 Jefferson Avenue  
Charlottesville, VA 22908

*Members*

Paul Y. Ertel, M.D.  
Clinical Professor  
University of Michigan, Pediatrics  
Applied Medical Data  
400 Maynard Street, Suite 11A  
Ann Arbor, MI 48104

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

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

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

Mr. George H. Van Amburg  
State Registrar and Chief  
Office of the State Registrar  
and Center for Health Statistics  
Michigan Department of Public  
Health  
4323 North Logan Street, Box 30195  
Lansing, MI 48909

*Staff*

Marjorie S. Greenberg  
National Center for Health  
Statistics (NCHS)  
6525 Belcrest Road  
Hyattsville, MD 20782

Jim Delozier, NCHS  
Linda Lawrence, NCHS

William Sobaski  
Health Care Financing  
Administration  
6325 Security Blvd.  
Baltimore, MD 21207

Judy K. Ball, Ph.D.  
Agency for Health Care Policy  
and Research  
2101 East Jefferson  
Rockville, MD 20852

# Appendix VI. Report of the Work Group on Confidentiality

December 1992

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

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

The roster of the Work Group membership and staff is contained in attachment A.

## Background

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

## Activities

From the outset, the Work Group recognized that there was a renewed interest in the issue of health data confidentiality. After what may be termed a hiatus since earlier enactment of national privacy legislation, there was a growing demand for reconsideration of the "rules" and a search for more contemporary solutions to protection of individual privacy *and* promotion of data collection and evaluation efforts.

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

Early in its deliberations, the Work Group was able to identify a number of related activities ongoing in the public sector. These included:

- The National Academy of Sciences' Panel on Confidentiality and Data Access
- Office of Management and Budget (OMB) activities related to data sharing and confidentiality
- The National Academy of Sciences' Committee on Improving the Patient Record
- The DHHS Task Force on the Privacy of Private Sector Health Records
- The Work Group on Electronic Data Interchange (WEDI)

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

In July 1991 Work Group members and staff attended a session of the Public Health Conference on Records and Statistics devoted to public use data tapes and data confidentiality. In October 1991 Dr. Cannon, Work Group Chair, addressed the DHHS Task Force on Privacy of Private Sector Health Records. At that time she described the planned activities of the Work Group and responded to questions from the Task Force.

The second and third 1991 working sessions discussed and finalized plans for a public meeting to be held in January 1992. Invited representatives of public and private agencies responded to a series of questions on access and privacy, data security, data release, and the use of unique identifiers as they apply to the particular agency/organization.

The issues focused on the following:

- Summarization of activities in the area of data collection, data storage, and release
- Description of confidentiality and security provisions
- Current or planned use of unique personal identifiers
- Issues of informed consent
- Written or informal policies on data sharing
- The evolution of policies in these areas

The open meeting to address these issues was held on January 15, 1992, in Washington, DC. This meeting was designed as a fact-finding mission to obtain input from the public and private sectors on changes in the areas of data disclosure, data security, and data linkage. There was broad representation, including presentations from staff at OMB; Department of Health and Human Services (U.S. Public Health Service,

Assistant Secretary for Planning and Evaluation (ASPE), Social Security Administration (SSA), and NCHS); American Medical Association (AMA); American Health Information Management Association (AHIMA); and CNA Insurance. The National Academy of Sciences (NAS) provided written information. A listing of presenters is shown in attachment B.

The meeting was very enlightening to the Work Group. The group received a background of the evolution of privacy activities from John Fanning of the Public Health Service. Hermann Habermann, OMB, provided a description of current activities in the area of data access and confidentiality. One activity under investigation concerns the sharing of confidential data among selected federal agencies. Another is the use of a licensing technique that would allow the sharing of sensitive federally collected data with researchers in the private sector. Both projects are still in the investigative stage.

Lois Alexander, SSA, provided the viewpoint of SSA especially with regard to the linkage of files using the social security number. The Social Security Administration has been, and remains, opposed to the formal use of the SSN as a unique identifier for purposes other than the administration of the social security program. John Patterson, NCHS, updated the Work Group on proposed changes in the release policy for vital statistics data.

Dr. Joan Turek-Brezina, ASPE, heads the DHHS Task Force on the Privacy of Private Sector Health Records. She documented the concern for health and medical information that is collected, held, and shared by the private sector often without the knowledge or consent of the individual. The Task Force is holding meetings to hear from a large number of government and private organizations and individuals. Dr. Harvey Schwartz, AHCPR, staff to the Work Group, is a member of the task force; Mary Moien, key staff, has also been invited to attend. Both will keep the Work Group informed of germane topics and discussions.

In the private sector, Dr. Norbert Budde, AMA, and Mary Joan Wogan, AHIMA (formerly the American Medical Record Association), described the procedures used by and promulgated by those organizations regarding data confidentiality. Ruth Baldwin, CNA Insurance, described the issues surrounding insurance companies and their need for, use of, and sharing of medical data.

Most of the participants were able to be present for the entire day, resulting in a wide-ranging discussion of most of the presentations. Formal minutes of the meeting were produced. Participants were requested to provide written statements and/or handouts. A listing of these is included as attachment C.

## Findings

### 1. Demands for Improved Administrative Access to Health Care Data

Recently, Secretary Sullivan proposed a bill, the Medical and Health Insurance Information Reform Act of 1992. The provisions clearly indicate that the Federal Government anticipates increased use of electronic data transfer of sensitive medical information.

In addition, the Work Group on Electronic Data Interchange (WEDI) Report was finalized in July 1992. Minimum standards for an electronic health care "smart card" were described. These standards would significantly impact the "ease" with which health information is electronically mailed to various host data bases and medical record "gatekeepers."

### 2. Data Access for Research and Confidentiality

The benefit and justifiability of research depend on the whole nature of the research process and on the values of the persons who judge the research. However, the potential for risk and benefit should be assessed in advance, and continuously evaluated throughout the research process. Currently, these risks and benefits are included in many research agenda.

In the area of data access and confidentiality, there is currently a plethora of activity, most at the federal level, but some activity at the private and State government level. Some of the federal activities, moreover, include representation and input from those in private research positions.

The "confidentiality" recommendations made in the WEDI report included preemptive federal legislation to establish national protections and delineate some of the perceived fragmentation at the State level. Other recommendations included:

- Establishing uniform requirements for preservation of confidentiality and privacy rights in electronic health care claims processing and payment;
- Delineating protocols for secure electronic storage and transmission of health care data; and
- Providing for enforcement by government officials and private, aggrieved parties.
- In addition, a longer-term goal should be the standardization of all legal requirements for record-keeping procedures. WEDI encourages the Sullivan Task Force on Patient Information to examine more fully the confidentiality issues associated with computerized patient records.

### 3. Unique Identifiers

In 1989 the NCVHS had transmitted to the Assistant Secretary for Health an endorsement of the use of the social security number as the only feasible unique identifier for certain health surveys. To date, the Work Group has found no unique identifier that approaches the coverage of the SSN. However, the SSA remains opposed to these types of uses. Moreover, in February 1992, the Senate Subcommittee on Social Security and Family Policy met to hear testimony on an

investigation into alleged widespread theft and sale of SSA records. This highlighting of problems of misuse of SSN will almost certainly add to the difficulty of obtaining the use of SSN as the unique identifier.

The work group and staff monitored a number of other activities as well in the area of unique identifiers. In November 1991 during a presentation to the full Committee on the Institute of Medicine Report on the Computer-Based Patient Record, Dr. Richard Dick and Elaine Steen informed the Committee that the identification of a unique identifier was outside the scope of that project. They indicated, however, that the unique identifier was crucial to the development of the record. Dr. Harvey Schwartz informed the Work Group of a presentation to the DHHS Task Force in spring 1992 by Margaret Amatayakul, Interim Executive Director of the newly formed Computer-Based Patient Record Institute and also on the staff of AHIMA. Ms. Amatayakul stated that the Computer-Based Patient Record Institute is now investigating potential unique identifiers.

The interest definitely exists of establishing a unique identifier or of expanding the use of the SSN as unique identifier from the private sector to the federal sector.

## **Discussion**

Before making its recommendations to the National Committee, the Work Group would like to frame the issue of data confidentiality for Committee members. The initial charge for the group derived from the conflicting goals of serving the data needs of health and health care researchers and simultaneously preserving the confidentiality of sensitive information. The Work Group has detailed the wide range of public policy activities already underway on this topic. To change national policy regarding health data access and linkages, these groups must complete their work in the areas of technical guidelines (new parameters for sharing of data); security standards and penalty structures related to inadvertent and deliberate disclosure of sensitive information; and language for model legislation to mandate the needed changes. The Work Group anticipates the release in 1993 of recommendations in these areas by the groups cited earlier in this report.<sup>9</sup>

The Work Group offers a set of recommendations for the National Committee's consideration in the final section of this report. These have evolved from our understanding of the problems associated with disclosure (with and without unique personal identifiers) of sensitive health information. In its simplest form, it is an issue of ethics. Given the mandate of the National Committee on Vital and Health Statistics, the Work Group proposes that the Committee consider the following discussion from that vantage point.

### *Data Access & Ethics: Fundamental Principles*

The methods and ethics of research may be conceptually distinct topics but in practice they are inseparable. Poor quality data may be obtained when the researcher is insensitive to the needs and interests of individuals. This discussion

addresses a basic ethical issue—considering risks, benefits, and associated conflicts in outcomes and other research that encompass the sharing of either computerized or paper records containing either directly or indirectly identifiable patient and/or physician data.

When designing research that entails gathering identifiable data (that is, data that includes a name, address, or other forms of unique identification), there are two distinct risks to the privacy of individuals who provide information about themselves to researchers. The risk of unauthorized use of sensitive data involves the possibility that identifiable information collected for research purposes might be obtained by unauthorized persons and used against an individual. Here the problem for the researcher is how to provide physical protection of the data, either by reducing the number of persons with access to identifiable records, or by devising strategies to destroy the link between identifiers and other data.

The other risk is that of official misuse of sensitive data for law enforcement or other official purposes. The problem here is how to provide legal protection for individuals so that they can be assured that the information they provide about themselves cannot and will not be used for other purposes.

Advances in technology complicate the challenges of physical and legal protection. For instance, a report released in 1991 by the General Accounting Office analyzing hospitals' use of automated medical records states:

“Security issues arise when automated patient data are collected within and transmitted outside individual health care facilities. Increasing interest in outcomes research will require collecting data from hundreds of health care organizations, which could present unforeseen risks to the privacy and integrity of the information.”

Another illustration of the importance of security is a recent report of the American Medical Association's Board of Trustees that urged that stringent security procedures be developed to preserve patient and physician confidentiality.

“With the expansion of outcomes research and its frequent reliance on computer analysis . . . patient and physician confidentiality must be maintained. . . the findings of outcomes research must be handled strictly within a peer review context to assure that the results are interpreted correctly and used properly.”

While the issue of who should have responsibility for reviewing outcomes research is not a point dealt with by the Work Group, the issue of security is relevant.

Regardless of the level of automation, another complication arises with research relying on data collection in sites with vulnerable populations. People with acquired immunodeficiency syndrome (AIDS) need to have a trusting relationship with the staff that work at clinics. Clinics will not permit research that might reduce the level of trust between patients and clinic staff or create bad public relations. Moreover, all patients have certain needs to establish personal boundaries and have claims to autonomy that may also be claims to privacy. For example, people with AIDS have their privacy and autonomy violated when research data disclosed to employers becomes a basis for firing employees.

Fundamental to ethical research is an agreement among subjects, information gatekeeper, and researcher about how the data generated by the research will be controlled. Thus, there is a possible conflict between the principle of openness, or scientific freedom, and the need of applied researchers to accommodate the interests of the gatekeepers (be they health care providers or data managers).

Another possible conflict between openness and confidentiality arises when scientific data are shared. The legal rights of property ownership do not necessarily pertain to data that form the basis of publication, as these data are the basis of the researcher's claim to the validity of findings. In other words, the protection of the original sensitive information may be at risk when analytical data are presented in publications.

Minimal harm, valuable knowledge, a peer reviewed publication, and enlightened public policy are among desired research outcomes. Benefit to science and society, however, is the most difficult good research outcome to deliver in the short run. Much research does not immediately lead to recognizable improvements in the condition of humankind. Many theses and dissertations are not published. The more likely and more immediate benefits are those to subjects and in the case of some community-based research to their communities. The intermediate benefits to the researcher, the research institution, and the funder are ones that a good research program can produce in some measure. It is upon achieving these immediate and intermediate goals and benefits that any ultimate scientific and social benefits are likely to be based.

Promises to potential subjects or gatekeepers of real-world benefits to society may be false promises. Promises of benefits to subjects or to a community may be feasible promises. It is important to take those steps that make real benefits a distinct possibility. In research planning one can begin by considering the kinds of benefits that are possible and asking which of these are feasible and which can be responsibly promised and accomplished.

## **Conclusion and Recommendations**

What are termed the "long-term benefits to society" of improved health data information and measures are the real focus of the Work Group's efforts. Systematic and comprehensive data access, through mandated linkages and the universal

adoption of unique personal identifiers, would greatly enhance the ability of policymakers to analyze options available to them and make informed decisions. The members of the Work Group see the need for the National Committee to take a two-staged approach to recommending changes in this area.

First, the National Committee may seek to continue monitoring the activities of groups currently working on data confidentiality and carefully review the technical and policy recommendations coming from this work. Next, with the results of that process available, the National Committee may consider a set of specific recommendations to the Secretary. These could directly address the need for mandates regarding use of a unique personal identifier and, with respect to government entities, sharing critical health data more efficiently.

In the short term, the Work Group on Confidentiality recommends the following to the National Committee:

- The continuation of the Work Group as a monitor of the current national activities and studies related to data sharing and confidentiality issues.

The Work Group has thrown a wide net in its effort to determine the scope of activities already underway in the area of data privacy and confidentiality. As has been noted above and in every interim report presented, a variety of serious and productive descriptive or evaluation efforts have been undertaken and should result in a series of recommendations to federal organizations and to Congress in the next 24 months. Since it has never been the Work Group's intention to duplicate the work of these previously established committees and study panels, it is our recommendation that the National Committee continue to monitor their activities and plan to respond to results of their work at the time they become available.

- Continued support by the National Committee for the adoption of a unique personal identifier to enhance opportunities for interagency and research-related data linkages.

In addition, the Work Group recommends that the National Committee continue to strongly support the adoption of a uniform unique identifier to enhance efficient data linkage. As National Committee members know, such enhanced data access would contribute dramatically to interagency information analyses. In addition, basic health care research and health services research conducted in academic and private sector settings would be aided. Increased knowledge of health status at the community or "small-area" level would also be a benefit of increased linkage, but such "person-level" data linkages would demand very strong confidentiality protections. Therefore, the Work Group recommends that the National Committee also include in its ongoing support for greater linkage a willingness to see rules, guidelines, methodologies, specific security standards, and enforcement penalties developed.

- The ongoing commitment of the National Committee to represent the need for a solution to the problem of data requirements in support of critical research

that will inform public policy and the national health care agenda *and* meet the confidentiality requirements of the individual health care consumer.

The least attractive outcome to the debate over increased data sharing/linkage compared with preservation of confidentiality may be that of *no action*. Escalating technology and health care costs as well as the need to improve access to health care and to improve the quality of patient care itself are creating new pressures for administrative efficiencies in health data accumulation, storage, and linkage. The National Committee on Vital and Health Statistics will face opportunities to call for explicit policies that protect confidentiality while enhancing health care data sharing goals.

## **Attachment A Work Group on Confidentiality**

### *Chair*

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

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

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

George H. Van Amburg (1993)  
State Registrar and Chief  
Office of the State Registrar and  
Center for Health Statistics  
Michigan Department of  
Public Health  
4323 North Logan Street, Box 30195  
Lansing, MI 48909

### *Staff*

Mary A. Moien  
National Center for Health  
Statistics (NCHS)  
Presidential Building  
6525 Belcrest Road  
Hyattsville, MD 20782

Glenn Martin  
Health Care Financing  
Administration (HCFA)  
Security Office Park  
7000 Security Blvd.  
Baltimore, MD 21207

Harvey Schwartz, Ph.D.  
Agency for Health Care  
Policy and Research (AHCPR)  
2101 East Jefferson Street  
Suite 604  
Rockville, MD 20853

**Attachment B**  
**NCVHS Work Group on Confidentiality**  
**January 15, 1992**

*Invited Participants*

Ms. Lois Alexander  
Assistant to the Counselor  
to the Commissioner of the  
Social Security Administration  
639-H Hubert Humphrey Building  
200 Independence Ave., SW.  
Washington, DC 20201

Ms. Ruth Baldwin  
CNA Insurance Company  
CNA Plaza  
Wabash & Van Buren Streets  
Chicago, IL 60685

Joan Turek-Brezina, Ph.D.  
Director  
Division of Technical and  
Computer Support  
Assistant Secretary for Planning  
and Evaluation  
Hubert Humphrey Building  
Room 438-F  
Washington, DC 20201

Norbert Budde, Ph.D.  
American Medical Association  
Director  
Division of Survey Data  
and Resources  
515 North State Street  
Chicago, IL 60610

Ms. Virginia de Wolf\*  
Study Director  
Panel on Confidentiality and  
Data Access  
National Research Council  
2101 Constitution Ave., NW.  
Washington, DC 20418

Mr. John P. Fanning  
Senior Health Policy Advisor  
Office of Health Planning  
and Evaluation  
740-G Hubert Humphrey Building  
U.S. Department of Health and  
Human Services  
Washington, DC 20201

Mr. Hermann Habermann  
Chief Statistician  
Office of Information and  
Regulatory Affairs  
Financial Management Office  
725 17th Street, NW.  
Room 3228  
Washington, DC 20503

Mr. John Patterson  
Director  
Division of Vital Statistics  
Office of Vital and Health  
Statistics System  
National Center for Health  
Statistics  
6525 Belcrest Road  
Presidential Building, Room 840  
Hyattsville, MD 20782

Mary Joan Wogan, R.R.A.  
Director, Washington Office  
American Health Information  
Management Association  
1919 Pennsylvania Ave., NW.  
Suite 300  
Washington, DC 20006

\*Ms. de Wolf was unable to attend  
and submitted written document only.

## Attachment C

### NCVHS Work Group on Confidentiality January 15, 1992

#### Written Presentations/Handouts

##### *American Medical Association*

Statement to the National Committee on Vital & Health Statistics Work Group on Confidentiality Re: Data Confidentiality and Disclosure. Presented by: Norbert Budde, Ph.D.

##### *National Academy of Sciences*

Panel on Confidentiality and Data Access: A Status Report by: George T. Duncan, Thomas B. Jabine, and Virginia A. de Wolf. (Draft)

##### *American Health Information Management Association*

Testimony Before the National Committee on Vital and Health Statistics Addressing the Issue of Data Confidentiality and Disclosure. Presented by Mary Joan Wogan, R.R.A.

##### *Social Security Administration*

Statement by Gwendolyn S. King, Commissioner of Social Security Before the Committee on Ways and Means, on Social Security Number and Card, February 27, 1991.

##### *American Health Information Management Association*

Guidelines for Handling Health Data on Individuals Tested or Treated for the HIV virus. Confidentiality of Patient Health Information. (Both of the above were prepared when AHIMA was the American Medical Record Association.)

##### *DHHS Task Force on the Privacy of Private Sector Health Records*

Draft Mission Statement.

