

**ANALYSIS OF DEPARTMENTAL NEEDS FOR HEALTH CARE
UTILIZATION AND EXPENDITURE DATA IN THE 1990s:
RECOMMENDATIONS FOR ADDRESSING DATA GAPS**

Prepared For:

*The Data Planning and Analysis Working Group
at the
Department of Health and Human Services*

By:

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A Health & Sciences International Company

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EXECUTIVE SUMMARY

A. OVERVIEW

During the 1990's, comprehensive information on health care utilization and expenditures will become increasingly important as the Department of Health and Human Services (DHHS) addresses a growing number of health care policy issues. Issues facing DHHS include assuring access to health care for all Americans, developing options to pay for care, controlling health care costs, and monitoring the health of the American people.

Growing interest in these and other issues will require that data are available related to health care utilization and expenditures. At the same time, however, it is clear that resources for data collection activities across DHHS are limited. Therefore, it is important to determine what type of data will be required and how data collection efforts can most efficiently meet the needs of decision makers. ✓

To address these issues, the HHS Data Planning and Analysis Working Group (Working Group) was established to analyze the need for data and the develop a plan for meeting data needs. To assist with this effort, Lewin/ICF was asked to conduct a series of interviews to determine the need for data and evaluate the ability of current survey instruments in meeting data needs. Using this information, Lewin/ICF developed an inventory describing the need for new data, additions to existing survey instruments and administrative data bases, and potential data duplications. From this we developed recommendations regarding surveys and administrative data bases which would address the gaps identified. ✓

B. METHODOLOGY

Lewin/ICF conducted 85 interviews across the Department based on recommendations of the Working Group (see Appendix A). Generally those interviewed are users of data or users of information developed from analysis of data. Those interviewed were asked to identify what they believed would be the most critical issues facing DHHS over

the next decade, what data sets they currently used to address these issues, areas of data duplication or unnecessary data collection, and where they believed gaps in data collection exist. In addition to the interviews, we reviewed many Departmental reports and studies to gain a perspective of ongoing policy issues and initiatives and associated data needs facing DHHS (see Appendix C).

This methodology was useful in identifying the major areas where data gaps exist. It was not, however, as helpful in identifying specific questions and survey instruments to be used to collect the information. Therefore, this report focuses on broad issue areas for which data are required, identifies how current and planned data collection efforts meet these requirements, and suggests ways in which data could be collected where gaps exist.

C. DATA GAPS IN HEALTH CARE UTILIZATION AND EXPENDITURE DATA

The interviews and review of reports suggested three broad areas in which DHHS policy is focused: (1) analysis of DHHS programs, (2) analysis of target population groups, and (3) analysis of other policy areas. Each of these is discussed briefly below.

1 . Administrative Programs

a. Medicare

In order to make decisions related to operation of the Medicare program, HCFA requires data on the health care utilization and expenditure trends of the covered population and on the effectiveness of the services provided to this population. Specifically, data are required which can characterize the use of services by individuals according to demographic factors (e.g., race, ethnicity, sex and age), socioeconomic factors (e.g., assets, income, employment status and history), health status, risk factors, and medical history. Data required include use of services over time, out-of-pocket as well as total expenditures, and information which can be used to analyze the effectiveness of services provided to Medicare beneficiaries. ✓

Further, the Medicare program has long encouraged beneficiaries to enroll in managed care plans, believing that these plans can provide more comprehensive care at a lower cost. Data are required, however, that would allow comparison of individuals who enroll in the plans to those who do not, as well as analysis of their utilization patterns and the associated cost. ✓

HCFA is also in the process of reforming the methods used to make payment to health care providers including hospitals, physicians, and long-term care providers for services provided to Medicare beneficiaries. Data are required which can be used to design appropriate payment systems and to measure their impact on both the providers and beneficiaries.

Several currently available data sets help meet the need for data in these areas. First, the administrative data bases maintained by HCFA (including the Medicare cost report data and Part A and Part B claims data sets) provide general information on the use of services by the Medicare-eligible population. These data bases will be further improved with the National Claims History Database (NCH) and the Common Working File (CWF), both currently being developed. Administrative data bases provide only a limited amount of demographic information and do not allow for analysis of an "episode of care" or use of services over time. They also do not provide information on the effectiveness of particular procedures or on the use of non-covered services. Current data bases do provide information for some providers (particularly hospitals) useful for the design of payment systems as well as data required to measure their impact. However, for other providers, no data are available on the cost of providing services (necessary to design new systems) or on the financial status of providers (necessary to measure the impact of various reforms on providers).

Administrative data bases are also maintained related to managed care plans. Data include financial information provided by the plans and information on inquiries and

complaints made by enrolled Medicare beneficiaries. Neither of these allow for comparison of the use of services or of the cost of care for managed care enrollees to those of FFS enrollees.

Other data bases in the planning or early implementation stage include:

- The **Uniform Clinical Data Set (UCDS)**--a longitudinal study of medical records from a random sample of 10 percent of Medicare beneficiaries receiving hospital care which will provide detailed information extracted from medical records. This data set will allow for analysis of the effectiveness of particular procedures as well as provide information on the quality of care provided by various physicians and hospitals.
- The Medicare **Beneficiary Health Status Registry (the Registry)**, as planned, will collect information on risk factors, functional status, socio-demographic variables, current and past medical history, and quality of life for Medicare beneficiaries at 2 to 5 year intervals. Both the UCDS and the Registry are being supported by AHCPR and implemented by HCFA.
- The **Current Beneficiary Survey (CBS)** will provide longitudinal and cross-sectional data on over 12,000 Medicare beneficiaries' use of services and costs over time. The survey collects information on use of both covered and non-covered services, formal and informal support, associated costs, and on demographic variables and health status. The survey also collects information on current work status. As currently designed, the CBS oversamples the institutionalized and the disabled population, but does not include a large enough sample size to provide information on those enrolled in managed care plans. National implementation of Round 1 began September 1991 with a new round starting every four months thereafter.

The identified gaps in data collection related to the Medicare program will be filled by the data collection efforts currently being planned, with one major exception. Even if all of the planned data collection efforts are undertaken, little data will be available on the managed care portion of the program. Many of those we interviewed identified this as one the most significant data gaps.

b. **Medicaid**

The Medicaid program provides health care to the eligible poor and disabled as well as the indigent elderly. Major Medicaid research issues relate to the use of services by various segments of the Medicaid population, sources of care for the eligible population, use

of uncovered services, out-of-pocket expenditures, and the interaction of Medicaid coverage with Medicare, private insurance, and lack of insurance. Analysis of the impact of program changes are also required, as is the development of data for providing more accurate forecasts of the costs of the program, which have been rising more rapidly than expected over the past few years.

States are required to submit data to HCFA either through participation in the Medicaid Statistical Information System (MSIS) or on HCFA 2082 reports. Four states participate voluntarily in the Tape-to-Tape National Unit Record Medicaid Database which provides person-based data for 30 to 40 percent of all Medicaid claims from 1980 to the present.

Several significant data gaps exist with respect to the Medicaid program. These include data on:

- **program characteristics** -- There is no centrally available data set which provides information on characteristics of state Medicaid programs, Both coverage and eligibility data are required to determine the impact of program expansion.'
- **consistent utilization and expenditure data** -- Data are collected from each of the states, but some uniformity, as well as additional information, is required in order to develop meaningful policy analysis.
- **characteristics of eligible and potentially eligible population groups** -- Many individuals are eligible, but do not use Medicaid services, while other groups are not currently eligible but would be eligible under certain proposals to expand the Medicaid program. Additional information is required on the health care utilization and expenditure patterns of both of these groups.

Gaps in information on the Medicaid program are substantial and will require either additional data collection from the states or large national surveys. Interviewees, however,

'The Medicaid Bureau Budget Estimating Initiative (BEI) at HCFA is currently developing an automated data collection system in response to these specific Medicaid data needs. The data system will provide state-by-state profiles of Medicaid Program characteristics as well as allow for cross-state analyses of Program data. The data system will also indicate changes in Medicaid Program characteristics by state and nationally, and provide national totals for Medicaid Program features.

deal with the Medicaid eligible and potentially eligible population. Therefore, additional data collection efforts in this area are critical.

2. Population Sub-Grows

Throughout DHHS, researchers are concerned with the needs of particular population groups either because they have special health care needs, or it is believed that they have a problem obtaining necessary care. Groups of particular concern include:

- the uninsured and underinsured population
- individuals with substance abuse and mental disorders
- the rural population
- pregnant women and infants
- children
- minorities
- persons with disabilities
- the aged
- the long-term care population
- Alzheimer's patients
- the HIV-infected population

Information required on these population sub-groups includes data on their special health care needs, health care utilization, sources of financing, and expenditure patterns. Data are also required that describe access to care, site of care, patterns of care, and providers of care for the population groups listed above. Each group has a unique issue which presents problems for data collection, but for each, interviewees agreed that more data were required so that DHHS could develop and evaluate programs and policies directed to the health care of individuals within them.

For some of these groups, data collection efforts have already begun. For example, for the groups with substance abuse and mental health disorders, both the National Institute for Drug Abuse (NIDA) and the National Institute for Alcoholism and Alcohol Abuse (NIAAA) have initiated data collection efforts and are considering new ones to collect information on

A the types of services provided and utilization of available programs. Nevertheless, data are not available on the effectiveness of these programs,

For some of the groups, data collection must be preceded by the development of uniform definitions and coding standards. For example, data collection related to the disabled population requires the development of standard definitions related to level of disability before meaningful data can be developed. Development of information on minority groups must also be preceded by uniform definitions of race and ethnicity. Similarly the population with Alzheimer's disease cannot be effectively studied until consistent coding and diagnosis is developed to identify those with the disease on medical records. Research in the area of survey development for minority groups will be sponsored by NCHS as a result of the Disadvantaged Minority Health Improvement Act of 1990.

In general, data gaps remain related to:

- the health care needs of the various population groups,
- current sources of care for these groups,
- demographic and socioeconomic data, including data related to the ability of these groups to finance care, and
- use of public programs in order to obtain necessary health care.

Where a group with a particular clinical condition is considered, data on the types of care required, the effectiveness of the care, and the availability of care are also required.

Problems associated with data collection related to each of these population groups depend upon the size of the group, the availability of common definitions describing the group, and the availability of health status indicators that address their particular condition. For example, it is easier to develop a survey instrument for the various subgroups of the elderly, defined by age, than it is to collect data related to those with disabilities, where common definitions have not yet been developed.

The size of the particular population sub-group also has an impact on the data collection approach used and the resources required to collect the information. Some groups are so small that a separate survey would be required, and in fact, the sampling frame may be difficult to determine. For these groups, smaller sub-national research studies are required to gather enough information to enable researchers to address data needs. For other groups, national sample surveys can be used to identify these groups and obtain nationally representative samples,

3. Other Research Areas

There are a number of other areas where interviewees identified significant data gaps. One such area is on the interaction of federal and state programs. Matching of administrative data bases is required to conduct analyses but such matching is hampered by confidentiality rules.

The second area which was discussed frequently by those we interviewed relates to data required for medical effectiveness analysis. The data required to study effectiveness among the Medicare population was discussed above, but data on effectiveness is also required for population groups other than the elderly. Analysis of medical effectiveness requires large amounts of data on an individual over a period of time. Small research studies are most appropriate for this type of analysis, and AHCPH has funded several through the Patient Outcome Research Team Studies (PORTS) where specific conditions are being studied in detail.

Other areas where data gaps were identified include data on state and local expenditures for health care and information on the use and cost of prescription drugs. ✓

D. **RECOMMENDATIONS FOR DATA COLLECTION STRATEGIES**

In generating recommendations for DHHS data collection strategies, data collection activities were selected which accomplish the following:

- fill data gaps that were most frequently identified in reports and interviews across organizational entities,
- provide the data necessary to analyze policy issues outlined in "Healthy People 2000" and the Secretary's Program Direction Plan,
- provide data that could be used to fill the most gaps, and
- ensure that data useful for general public health monitoring are available.

In developing our recommendations, we: (1) identified activities which would fill the identified data gaps; (2) considered whether the data collection activity was feasible; and, (3) applied the criteria listed above to determine the priority for data collection, As requested by the Working Group, our recommendations are based upon technical considerations rather than cost.

Recommendations assume that the data collection activities already underway are continued, including the continuation and expansion of the UCDS, development of the Registry, implementation of the CBS, and the refinement of the Medicare Part A and B data bases. In addition, it is assumed that the National Health Interview Survey (NHIS) and the National Health Care Survey (NHCS) as well as other data bases from the National Center for Health Statistics (NCHS) continue to be regularly funded. Those interviewed by Lewin/ICF stressed the importance of routine data collection efforts critical for monitoring the health of the nation.

Although we were asked to identify duplication in data collection activities, no one interviewed identified unnecessary data duplication, and they uniformly reported that while additional data collection activities are required, there are none that should be eliminated.

1. Medicaid/Low Income Data

Issues related to the Medicaid eligible population and the low-income population potentially eligible for the Medicaid program are considered widely across DHHS. In addition, many of those interviewed identified this as one of the critical gaps in data within the

Department. Options to fill this data gap include collecting claims data from each state, routinely conducting a survey of the low-income population, and oversampling the low-income population in existing surveys. From among these options, **Lewin/ICF** recommends that DHHS provide the funds necessary to develop a uniform data base which would be provided by all the states, beneficiary specific, and similar to that collected by the Medicare program.

This option was chosen because we believe that these data would be a rich source of information for analysis, much as the Medicare files have been over the past few years. There are several obvious problems with this approach. First, no uniformity currently exists in eligibility and coverage across states, or in definitions of the eligible population. While it would require a large effort to identify a minimum required data set and ensure that states are consistent in reporting, data would be extremely valuable.

Even if such a data collection plan were implemented, it would provide information only on those Medicaid eligibles using services. Therefore, in order to analyze the impact of programs expansion, additional data collection efforts would be required to collect information from the potentially eligible population. Therefore, we also recommend that the low-income population be surveyed, perhaps by oversampling the low-income on a national expenditure survey.

2. Medicare **Managed Care**

There is a substantial gap in the data available for Medicare beneficiaries enrolled in managed care plans. Furthermore, there are some problems with data collection in this area. Managed care plans may not be capable of providing information on the use of services by particular beneficiaries or able to calculate the cost of services by beneficiary since they do **not bill for specific services. In addition, it is difficult to compare the use of services by**

managed care and fee-for-service (FFS) beneficiaries since managed care enrollees may use services not covered for the FFS population.

Many of the needs for data in the area of managed care could be met by an expansion of the CBS to include a larger number of managed care enrollees. The survey would provide significant information related to this population and would allow for comparison across managed care and FFS enrollees since information is collected on out-of-plan use, risk behaviors, and quality of life. The alternative, to collect claims information for the managed care population, would not allow for comparison across groups and would require a significant effort on the part of managed care plans since most would have to modify management information systems to collect the data that would be required. Therefore, we recommend that the CBS be expanded to include a larger number of managed care enrollees in order to provide the information necessary for analysis in this area.

3. **Health Expenditure Information**

Those interviewed frequently mentioned the need to routinely collect health expenditure information. These data need not be available on an annual basis, but should be available every three to five years. Options for collecting this information include expansion of the NHIS or more routine data collection by a modified NMES.

We recommend more frequent data collection by an independent expenditure survey rather than adding health care expenditure questions to the NHIS. One of the primary advantages of the NHIS is that the data are consistently collected and made available on a timely basis. Addition of expenditure data would impede the timely availability of NHIS data. Instead, the recent NMES should be modified to a "core survey" that will provide national estimates. While the data would not be as comprehensive as the surveys performed in the past, the information would be available more routinely and on a more timely basis.

4. **Mentally Retarded/Developmentally Disabled**

Many individuals interviewed by Lewin/ICF expressed interest in data on this population since this group consumes substantial amounts of medical care. Data on this population are difficult to obtain because they cannot easily be identified on national surveys. In order to obtain information on health care expenditures, data must be obtained from next-of-kin and may require extensive interviewing of health care providers.

Options to collect data on this population include development of a **separate** survey of this population or oversampling of this population on national surveys (oversampling would require the addition of questions necessary to identify this group).

We recommend that DHHS conduct a separate study of this population. We also recommend that diagnostic tools and uniform standardized definitions be developed to evaluate the MR/DD population. At this time, national surveys of this group do not appear to be feasible.

5. **Minority Populations**

Data on various minority groups are required to develop information on their special health needs, utilization patterns, access to care, and ability to finance care. These data are required to monitor health status and use as well as to develop programs specific to their needs.

Options for collecting data on minority groups include oversampling ethnic minority groups on national sample surveys or conducting special studies for particular groups. Lewin/ICF recommends a combination of these two approaches. First, where possible, standard definitions of race and ethnicity should be developed and used to collect information on national sample surveys. Because some groups are not large enough to be meaningfully captured on such surveys, special studies are also required for particular population groups.

6. Other Recommendations

Several of those interviewed discussed the need to develop consistent identifiers across surveys which would allow matching across data bases. This includes matching of administrative data bases with national sample surveys. Some matching across data bases has already been undertaken, for example, matching of HCFA data bases with those of the Social Security Administration. Additional opportunities for matching should be explored by the Working Group, perhaps by supporting the development of a common identifier system which would be required of all surveys.

Many of those interviewed also suggested that **data** from block grants would be useful in analyzing many of the issues which will arise over the next few years. These data would have to include information on both the providers of service and the characteristics of recipients. Many of those interviewed believed that not enough information is collected from the states related to the use of these funds and their impact on health.

Other suggestions made by those interviewed related to data collection within DHHS. First, many believed that better mechanisms should be established to share data across agencies within DHHS. While useful data may be available, in many cases it is not shared either because of an unwillingness to provide the data or because existence of the data was not widely known. It is clear that in many cases, no funds are provided to develop "public-use" tapes which can be made available to other researchers.

Second, those interviewed stressed the importance of timely availability of data. Many believed that the data were not analyzed or made available to others within the agency in a timely fashion, limiting their usefulness to policy makers. Because of this, many suggested a need to separate data collection from research activities.

Third, many suggested a need across the Department to consider the use of small studies to collect data on particular population groups. Research interests within DHHS are

becoming more specialized and focused on particular groups. Therefore, smaller studies of particular populations should be considered in addition to large national sample surveys.

Finally, those interviewed uniformly agreed that much more information on health care utilization and expenditures is required. They encouraged the Working Group to support additional investment in data collection activities across the Department.

CHAPTER ONE

INTRODUCTION

A. BACKGROUND

During the 1990s, comprehensive information on health care utilization and expenditures will become increasingly important as the Department of Health and Human Services (DHHS) addresses a growing number of health care policy issues. Examples of the many issues facing DHHS related to health care utilization and spending include:

- assuring access to quality care for all Americans, particularly low-income persons and minorities,
- developing new options for financing health care for the uninsured,
- meeting the increased demand for health care services by the aging American population, those with disabilities, and those with long-term illnesses such as AIDS and Alzheimer's disease,
- controlling rising health care costs,
- emphasizing health promotion and disease prevention, and
- ensuring that the health care provided to Americans is effective and of high quality.

The growing requirement for analysis of these issues will require that substantial amounts of data be available related to health care utilization and expenditures. Because of this, there is a need to examine whether data gaps or duplications exist in order to plan for health care utilization and expenditure data collection efforts across the Department.

To address these concerns, the HHS Data Planning and Analysis Working Group was established to analyze Departmental data requirements and to develop a plan to minimize barriers to full utilization of such data. The Group is responsible for identifying needs for data within DHHS, evaluating current systems for meeting these needs, and preparing recommendations for ensuring effective and efficient performance of DHHS data systems. The Group shall prepare a strategic plan identifying current and future data requirements,

evaluate whether and how well current data systems meet these requirements (including examination of existing data sharing and access policies), and make recommendations for changes that ensure Departmental data systems are of maximum Department-wide utility. Priorities shall be established for meeting Departmental needs which are consistent with current resource availability.

To assist with this effort, **Lewin/ICF** was asked to conduct a series of interviews with individuals across the Department, review related literature identifying the needs for these types of data, and evaluate survey instruments and administrative data bases in order to identify data needs, data gaps, and duplication. From this evaluation, **Lewin/ICF** was to identify potential solutions and develop recommendations regarding surveys and administrative data bases to address data gaps and duplication. This report presents the findings of this review.

B. METHODOLOGY

Lewin/ICF conducted interviews with 85 individuals across DHHS from the following administrative and program areas:

- Health Care Financing Administration,
- Office of the Assistant Secretary for Planning and Evaluation,
- Office of the Undersecretary,
- Public Health Service,
 - Office of the Assistant Secretary for Health
 - Office of Minority Health
 - Health Resources and Services Administration
 - National Institutes of Health
 - National Institute on Aging
 - Alcohol, Drug Abuse, and Mental Health Administration
 - National Institute on Alcohol Abuse and Alcoholism
 - National Institute on Drug Abuse
 - National Institute of Mental Health
 - Indian Health Service
 - National Center for Health Statistics
 - Agency for Health Care Policy and Research
- Office of the Assistant Secretary for Management and Budget,
- Office of Human Development Services,
- Social Security Administration, and
- Administration for Children and Families.

Departmental personnel interviewed by Lewin/ICF were selected by members of the HHS Data Planning and Analysis Working Group and represent users as well as producers of health care utilization and expenditure data. Individuals were selected because of their ability to identify current and future policy issues requiring health care utilization and expenditure data for analysis as well as identify data gaps and duplications. The individuals interviewed by Lewin/ICF include policy and program analysts, economists, actuaries, and survey statisticians. A complete list of those interviewed is included as Appendix A, and the interview guide is included as Appendix B.

Interviewees were asked to identify what they believed to be the most critical issues facing DHHS in the 1990s. They were also asked to identify data sets currently used for analysis of these issues as well as any existing data gaps. Most of our recommendations for change are based upon these interviews; others were based upon a review of past-DHHS reports and materials. A list of reports reviewed is included as Appendix C and include the Public Health Service's "Healthy People 2000," the Secretary's "HHS Program Directions Plan," and the National Academy of Sciences' report "The Aging Population in the Twenty-First Century," which were used to gain a perspective of ongoing policy issues, Departmental initiatives, and the associated data needs and gaps facing DHHS.

The Lewin/ICF review of data bases included both administrative and national survey data bases. Administrative data bases are those associated with DHHS programs, such as Medicare and Medicaid, Administrative data bases can provide a wealth of information related to the health care utilization and expenditure patterns of specific program populations. National survey data bases have traditionally been used to analyze health policy issues and are useful in analysis of utilization and expenditure characteristics of the entire population as **well as making comparisons among particular population groups. Recommendations related to filling data gaps** may suggest changes to either or both of these types of data.

Overall, individuals interviewed stated that they believe DHHS should invest more heavily in data collection and that there is no unnecessary duplication in current data collection efforts. Interviewees believe that most data collected are used by researchers to address current policy issues or to monitor health patterns of the U.S. population. None of those interviewed suggested elimination of all or parts of any survey. The sentiment of many interviewees was that accurate and timely data are needed to support sound policy development and that the amount of funds spent on data are minor compared to the significant amount of funds that are spent on health care programs which require data to support policy analysis of those programs.

C. ORGANIZATION OF THE REPORT

The following chapter (Chapter 2) provides a summary of the major research issues and subsequent data needs facing the Department in the 1990s as described by those interviewed. A description of available data and data initiatives providing opportunities for analysis of each research area is provided. Data gaps are noted for issues where adequate data for analysis are neither currently available nor under development.

The final chapter (Chapter 3) presents options for the HHS Data Planning and Analysis Working Group to consider in addressing data gaps identified in Chapter 2. Criteria for prioritizing data gaps are discussed in the beginning of the chapter. *Lewin/ICF* recommendations are presented for each data gap based on an assessment of the options presented. The report concludes with recommendations for improving data collection, dissemination, and sharing across DHHS .

CHAPTER TWO

DATA GAPS IN HEALTH CARE UTILIZATION AND EXPENDITURE DATA

Interviews identified three broad areas in which future DHHS policy analyses will be focused. These include analyses of:

- **DHHS programs** -- DHHS operates or supports numerous programs that directly or indirectly provide health care services. Crucial questions regarding these programs relate to the cost and impact of program expansion or contraction and the effectiveness of these programs in meeting the needs of the populations of concern.
- **target population groups** -- Across the Department, analysts are interested in the health care utilization and expenditure patterns of the total U.S. population and various subgroups. Policy makers are interested in identifying where these groups receive care, gaps in the care available to these populations, and sources of financing. In addition, policy makers require general monitorino and assessment of public health for the entire population and subgroups thereof.
- **other policy areas** -- Several other policy areas not included above were also identified as important areas for future research. These include issues related to the interaction of state and federal programs, medical effectiveness, prescription drug use and cost, and health care expenditures and programs operated by state and local governments.

Each of these areas is discussed in the following sections.

A. ADMINISTRATIVE PROGRAMS

Reports and interviews identified several research areas specific to DHHS programs, including:

- Medicare
- Medicare Prepaid Health/Managed Care
- Medicare Payment System Reform
- Medicaid

This section discusses the major research questions for each area. Data necessary for analysis, related data initiatives currently under development, and remaining data gaps are discussed.

1. Medicare Issues

The Health Care Financing Administration's (HCFA) Medicare program had total expenditures of \$108.7 billion in 1990.² The Medicare program provides health care services to the elderly and to selected persons with disabilities (e.g., persons less than age 65 after they have been on Social Security Disability Insurance (SSDI) for two years). Decisions related to program implementation, coverage, and expenditures must frequently be made, and these changes directly affect beneficiary utilization and expenditure patterns as well as program costs. Furthermore, these decisions can have a far-reaching impact on the health care system because changes made to the Medicare insurance system are often followed by similar modifications to private insurance coverage. Furthermore, changes to the Medicare program may have a direct impact on coverage, and therefore premiums, of Medigap policies purchased by many of the elderly.

Interviews identified two major areas where data are required. The first relates to trends in health care use and expenditures. Those implementing the Medicare program need to understand what types of health-related services are required by the covered population (including both the elderly and those with disabilities), where these services are obtained, how these services are financed, and how the need for services changes as the population ages. The second broad area relates to analysis of the effectiveness of services provided to Medicare beneficiaries. These areas are discussed below. In the following sections, Medicare issues related to prepaid health care and payment system reform are presented.

²1990 Annual Report of the Board of Trustees of the Federal Hospital Insurance Trust Fund and 1991 Annual Report of the Board of Trustees of the Federal Supplementary Medical Insurance Trust Fund, HCFA Office of the Actuary, 1991.

a. **Health Care Utilization and Expenditure Trends**

Policy makers require data describing health care utilization and expenditure trends among the Medicare population. To identify these trends, beneficiary-specific data are needed that characterize the Medicare population according to:

- demographic variables (particularly race and ethnicity),
- assets and income,
- health and functional status, including those with end stage renal disease (ESRD),
- medical history,
- employment status/work history (including those with Employer Group Health Plans - EGHP),
- level of family support,
- geographical distribution of specific groups of Medicare beneficiaries (e.g., the working aged) as well as Medicare providers,
- risk factors/health behaviors,
- utilization behavior of particular groups of Medicare beneficiaries,
- reimbursement and expenditure patterns, and
- out-of-pocket expenses.

These data are required both on a cross-sectional basis (e.g., for the entire Medicare population and subgroups thereof) and across time. Data on expenditures for covered services (both program and out-of-pocket) are needed annually; data related to those factors likely to influence spending and use are needed less frequently (but at least every five years).

HCFA is currently developing and implementing several data initiatives that will assist in meeting these data demands including the expansion of administrative data bases and the development of new **surveys**.³ Administrative data bases designed to provide data on the

³Descriptions of each of the data bases are provided in Appendices D and E. Appendix E includes additional detailed information on sample size, survey supplements and the type of information collected for the major health care surveys conducted at DHHS.

Medicare population include the Common Working File (CWF) and the National Claims History Database (NCH).

The CWF is a decentralized Medicare claims validation and benefit authorization process. CWF data are used to support a large scale distributed transaction processing system which controls the payment of Medicare claims. Transaction validated as correct by the CWF, including denied claims, are organized into a series of databases which comprise the NCH. These data bases will merge Part A and Part B claims and allow researchers to analyze geographic variations in service utilization and beneficiary and provider-specific profiles. The NCH will include 100 percent of Medicare claims information, including specific physician claims data (previously "rolled up" into a single-line item). NCH information will be collected upon payment authorization and is therefore likely to be available more quickly than currently. Full access to the various data bases that comprise the NCH is expected after October 1991, when training sessions for HCFA personnel begin.

HCFA has recently implemented the Current Beneficiary Survey (CBS), which will provide longitudinal and cross-sectional data, as well as information on Medicare beneficiaries' patterns of health care use and costs over time (for those services covered by Medicare and out-of-plan use), their sources of coverage and payment, their assets and income, demographic characteristics, and health status. This survey will allow longitudinal analysis of some issues such as patterns of home care and institutionalization, spend-down of asset, and the long-term impact of the Medicare program. The CBS will collect information from the sample population on current work status and enrollment in employer-based health insurance plans, but will not obtain a work history. It will also collect information on household composition and sources of formal and informal care provided to the beneficiary in the home.

The CBS will sample 12,000 Medicare beneficiaries, oversampling groups with high health service utilization rates, such as those with disabilities,, those in nursing homes, and those greater than 85 years old. The purposes of the CBS are to:

- interview the same individuals over several years to observe, monitor, and record changes in use associated with changes in coverage,
- provide timely information on Medicare beneficiary use, cost of covered and uncovered services, and out-of-pocket expenses,
- measure and monitor access to care for different subgroups and changes over time,
- describe beneficiary characteristics associated with health care expenditures,
- monitor and evaluate the effect of current legislation on new program features,
- provide feedback for program administration,
- analyze policy initiatives,
- respond to legislative proposals with appropriate and timely information,
- produce cost projections of current program and proposed program changes, and
- provide estimates of national health care expenditures of the aged and disabled by group.

Interviewing for the first round of the survey began in September 1991, and the second round will begin in January 1992.

b. **Medical Effectiveness Issues**

There are two reasons for collecting medical effectiveness data on Medicare beneficiaries. First, data collected on the effectiveness of medical interventions will be used to make decisions regarding program coverage. These data will be useful to evaluate currently covered procedures to determine whether covered procedures are effective for the Medicare population and to determine the effectiveness of new procedures and technology. Second, data will be used to provide, through the Peer Review Organization (PRO) system,

information to providers on the medical effectiveness of particular procedures to allow them to compare the outcome of their medical interventions with those of their peers. Eventually it is expected that expert systems will replace the current practice of case-by-case PRO review and provide prospective information to physicians related to the risks associated with following a specific treatment course given a patient's overall medical condition,

Data are required which relate the medical effectiveness of services provided to the Medicare population to trends and patterns of health care service utilization by geographic region, population group, physician, and hospital and to determine variations in treatment outcomes. To evaluate medical effectiveness issues, longitudinal, detailed Medicare claims data are needed describing the types of treatments received, morbidity, mortality, readmission, level of disability, and use of health care services (including hospitals, nursing homes, and home health agencies). In order to achieve the objectives of this analysis, these data must be person-based.

HCFA is currently promoting this type of data analysis through its support of the Agency for Health Care Policy and Research (AHCPR) Patient Outcome Research Teams (PORTS) which are collecting person-based data on particular procedures. In the future, the development and implementation of the Medicare Beneficiary Health Status Registry (the Registry), the Uniform Clinical Data Set (UCDS), and the CBS are expected to provide a substantial source of data for researching medical effectiveness issues. If implemented, the Registry is likely to collect information on risk factors, functional status, socio-demographic variables, current and past medical history, and quality of life for Medicare beneficiaries as they age.⁴ The Registry has a planned sample of 2.5 percent of newly enrolled beneficiaries (approximately 40,000 beneficiaries per year) and will re-interview this same group at 2 to 5 year intervals (more frequently as they age). The sample will be a subset of the 5 percent

⁴HCFA is currently conducting a feasibility study for the Registry.

Medicare sample and therefore it will be possible to link Registry data to the NCH and the UCDS. The purposes of the Registry include the following:

- measure the relationship of Medicare reimbursed services to the health status of Medicare beneficiaries,
- describe, analyze, and understand health and disease (including quality of life, well-being, functional status and the prevalence, incidence, and progression of disease and decline in health), longitudinally in successive cohorts of Medicare beneficiaries,
- assess and evaluate the effectiveness and impact of specific medical and surgical interventions on the health status, functional status, and quality of life of Medicare beneficiaries,
- monitor access to care in special populations,
- describe, analyze, and understand the use and cost of Medicare reimbursed services, lifetime Medicare costs, and utilization patterns as they relate to health status,
- provide an efficient sampling frame for studies of special subgroups (e.g., racial groups, high-level users, and specific disease conditions) on whom **extensive** baseline data have been collected,
- provide information to monitor existing DHHS Healthy People 2000 objectives among the elderly, and
- assist in developing equitable payment adjustments for **HMOs, PPOs**, and providers in rural areas.

Through repeated survey contacts with individual Medicare beneficiaries, it is hoped that the progression of health and disease can be monitored, the relationship between the Medicare program and the health status of its beneficiaries can be examined, and the medical effectiveness of specific health interventions in influencing health status can be measured.

AHCPR is supporting the development of the Registry data base and assisting HCFA in its design. Data gathered by the Registry will be used by the Medical Treatment Effectiveness Program (MEDTEP) in AHCPR to support medical effectiveness research.

The UCDS, which is being implemented by HCFA with the support of AHCPR, is a longitudinal study of medical records data collected by **PROs** from a random sample of 10

percent of Medicare beneficiaries receiving hospital-based care. It is designed to provide data related to medical effectiveness. The UCDS collects a standard set of data about each episode of hospitalization, subjects the data to an expert system, and provides the physician reviewer a case summary that reflects the specific areas that need further investigation. The goal is to select cases for physician review in each state by an identical standard, thus estimating the differences in PRO review attributable to individual **judgment**.⁵

The CBS will also provide data related to medical effectiveness, although it will not be useful for rare events because of the small sample size. It will allow, however, for longitudinal analysis of the use of health care services following more common interventions.

c. **Data Limitations**

As discussed above, the data initiatives under development at HCFA will provide much of the data required for analysis of utilization and expenditure trends of the Medicare population as well as medical effectiveness issues. Those interviewed at DHHS, however, suggested that gaps will remain even if all of these planned data collection activities are undertaken. Specifically, more detailed claims data are needed to undertake detailed analysis of medical effectiveness issues, particularly those treatments aimed at relatively rare medical events. Furthermore, more descriptive items, such as health status, socio-demographic variables, morbidity, mortality, level of disability, post-discharge outcomes, and utilization of outpatient services, would provide an extensive data source to evaluate medical effectiveness issues and variables that influence the use of services. Some of these could be collected as part of claims data with relatively little additional effort because they would be available on the patient medical record for any period of service. Other variables would require a substantial effort to collect and could result in additional expense. These types of variables (**socio-**demographic characteristics, use of services other than the current claim **service** and health

⁵For additional information on the UCDS see Appendix D.

status, for example) would have to be collected separately from claims data. These data items might best be collected as part of the UCDS effort rather than from claims data. Sample size, however, would have to be sufficient to analyze population subgroups and the Medicare population by age group (at least in ten-year subgroups). Furthermore, any analysis of the utilization and expenditure characteristics of the Medicare population using claims data would miss those individuals not yet qualified for the program, namely those waiting for eligibility as a result of disability (because of the two-year Medicare eligibility waiting period for those individuals receiving SSDI).

Table 1 on the following five pages summarizes data needs, data availability, and data limitations/gaps related to the Medicare program. Additional data gaps related to the Medicare program include data for analysis of prepaid health/coordinated care programs and provider reimbursement issues. Because of different data needs and significant data gaps related to these research areas, sections 2 and 3 provide information specific to prepaid health issues and provider reimbursement issues, respectively.

2. Medicare Prepaid Health Issues

Managed care has been an interest of DHHS for many years, and efforts to enroll the Medicare population in prepaid plans have recently been expanded. Medicare beneficiaries enrolled in prepaid health care plans frequently receive a more comprehensive benefit package than those enrolled in the traditional fee-for-service plan. Plans are paid based upon a percentage of the average cost of caring for other Medicare beneficiaries in the same geographical area. While efforts promoting managed care have continued, much more needs to be known about the characteristics of these programs and the impact of managed care on beneficiary health status. In addition, in order to promote expansion in enrollment, additional information is required on those beneficiaries who enroll in the plans as compared to those who do not.

TABLE 1
DATA RELATED TO THE MEDICARE PROGRAM

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p><i>• Data are needed which characterize the Medicare population according to the following:</i></p> <p>(1) demographic variables (particularly race and ethnicity),</p> <p>(2) assets and income,</p> <p>(3) health and functional status, including those with end-stage renal disease,</p>	<p>(1)</p> <ul style="list-style-type: none"> • NCH (1) • The Registry (2) • UCDS (3) • CBS (4) • EDB (7) • ESRD-PMMIS (14) • CPS (11) • SIPP <p>-</p> <p>wages and salary only</p> <p>CPS</p> <p>SIPP</p> <p>-</p> <p>-</p>	<p>(I-I 9)</p> <ul style="list-style-type: none"> • HCFA administrative databases and Medicare surveys do not collect data on individuals less than 65 years old receiving Social Security Disability insurance (SSDI) during the two year waiting period for Medicare eligibility. <p>(1)</p> <ul style="list-style-type: none"> • Except for select files in the ESRD-PMMIS, HCFA administrative data bases contain limited indicators for ethnicity. Those that contain ethnic indicators only include Hispanic and non-Hispanic probes. Meanwhile, race indicators only include probes for White, Black, Unknown, or Other. Medicare claims data do not include any indicators for ethnicity. Although the CPS, SIPP, and NBS provide more detailed race and ethnicity indicators than HCFA administrative databases, the sample sizes are too small to provide statistically reliable analysis of Medicare beneficiaries by race or age groups. In addition, the health care information contained is limited. <p>(2)</p> <ul style="list-style-type: none"> • HCFA administrative databases do not indicate beneficiary income unless matched to SSA files. Currently they are not matched due to confidentiality. Although CPS, SIPP, and the NBS provide detailed information on assets and income, their sample size is too small to provide statistically reliable data on Medicare beneficiaries. Previously, no longitudinal data were routinely collected on Medicare beneficiaries' assets and income, but the CBS will collect this information in the future. <p>(3)</p> <ul style="list-style-type: none"> • No longitudinal data on the health and functional status of Medicare beneficiaries are currently available, but the Registry and the CBS will collect this information in the future.

TABLE 1
DATA RELATED TO THE MEDICARE PROGRAM
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
(4) medical history,	<p style="text-align: right;">(4)</p> <ul style="list-style-type: none"> . The Registry (2) 	<p style="text-align: right;">(4)</p> <ul style="list-style-type: none"> • There are currently no data available on Medicare beneficiaries' medical history, although a primary focus of the Registry will be collection of this information. It is anticipated that the Registry will be field tested in the Fall of 1991 and implemented the beginning of FY 1994.
(5) employment status/work history, (including those with Employer Group Health Plans - EGHP),	<p style="text-align: right;">(5)</p> <ul style="list-style-type: none"> . NCH (1) . EDB (7) . CBS (4) . CPS (11) . SIPP (12) . NBS (13) . CMHS - 5% (16) . NMES (17) 	<p style="text-align: right;">(5)</p> <ul style="list-style-type: none"> • The CPS and NBS (which provide information on employment status and private insurance), and SIPP (which also provides information on work history) fail to survey the institutionalized population and have too small a sample size to provide statistically reliable data on the Medicare population. HCFA administrative databases do not include information on employment status or accurate information on those Medicare beneficiaries enrolled in EGHPs. The CBS will collect information on current work status and enrollment in employer-based health insurance beginning Fall of 1991.
(6) level of family support,	<p style="text-align: right;">(6)</p> <ul style="list-style-type: none"> . The Registry (2) . CBS (4) . CPS (11) . SIPP (12) . NMES (17) . NLTCS (25) . LSA (49) 	<p style="text-align: right;">(6)</p> <ul style="list-style-type: none"> • Currently, no longitudinal data are collected on the long-term affect family support has on institutionalization, although the CBS will be collecting this information beginning Fall of 1991.
(7) geographical distribution of specific Medicare beneficiaries (i.e., the working aged) as well as Medicare beneficiary providers,	<p style="text-align: right;">(7)</p> <ul style="list-style-type: none"> . NCH (1) . CBS (4) . UPIN Directory (5) - physicians only . POS file (6) - institutional providers only . EDB (7) . NBS (13) . NMES (17) . NLTCS (25) . NHCS (47) 	<p style="text-align: right;">(7)</p> <ul style="list-style-type: none"> • There are data missing on Medicare beneficiaries receiving services in decentralized settings such as ambulatory surgical centers, board and care homes, and hospices, although these alternative sites of care will be added to the NHCS in the future. The NCH, which will merge Part A and Part B claims data, will allow analysis of geographic variations in service utilization, and beneficiary- and provider-specific profiling.

TABLE 1
DATA RELATED TO THE MEDICARE PROGRAM
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
(8) risk factors/health behaviors,	(8) <ul style="list-style-type: none"> . The Registry (2) . CBS (4) - (tobacco use only) 	(8) <ul style="list-style-type: none"> . There are currently no data collected on risk factors/health behaviors among Medicare beneficiaries, although a primary focus of the Registry will be collection of this information.
(9) service utilization (including uncovered services),	(9) <ul style="list-style-type: none"> . NCH (1) . CBS (4) . CMHS-5% (16) . EDB (7) - to be linked to the utilization database for development of enrollment/utilization samples . NMES (17) . POS file (6) - the POS file is matched to bill records and stay records to enable tabulation of utilization by provider type . NLTCS (25) . LSA (49) - hospitals and nursing homes only 	(9-1 1) <ul style="list-style-type: none"> . HCFA administrative databases only include information on covered services. In addition, no longitudinal beneficiary-specific data are routinely collected which describe and match utilization to reimbursement and expenditure patterns, but the CBS will provide this information for covered and uncovered services. Round 1 will collect utilization but not expenditure data, while round 2 will include both kinds of data. It is anticipated that edited tapes from round 1 will be available October 1, 1992.
(10) reimbursement and expenditure patterns, and	(10) <ul style="list-style-type: none"> . NCH (1) . CBS (4) . UPIN Directory (5) . ESRD-PMMIS (14) . HCRIS & Section 223 Cost Limit File for SNFs and HHAs (15) . NMES (17) . CMHS-5% (16) . NLTCS (25) 	
(11) out-of-pocket expenses	(11) <ul style="list-style-type: none"> . CBS (4) . NMES (17) . NLTCS (25) - for prescription drugs, therapists, and mental health professionals only 	

TABLE 1
DATA RELATED TO THE MEDICARE PROGRAM
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<ul style="list-style-type: none"> • To assess the medical effectiveness of care received by the Medicare population, data describing the following are needed: (12) types of treatment received, (13) patterns of care (longitudinal utilization of services), (14) morbidity, 	<p style="text-align: center;">(12)</p> <ul style="list-style-type: none"> • NCH (1) - although specific treatments received are not indicated, type of service used is; a maximum of three ICD-9-CM, volume III procedure codes may be indicated • The Registry (2) - includes indicators for use of preventative services, and specific surgical procedures, in addition to beneficiary's age at time of the procedure • UCDS (3) • CBS (4) • ESRD-PMMIS (14) - files may include an indicator for type of dialysis received and a surgical procedure code • NMES (17) • NLTCS (25) - surgical codes are obtained from Medicare billing data <p style="text-align: center;">(13)</p> <ul style="list-style-type: none"> • The Registry (2) • CMHS - 5% (16) • CBS (4) <p style="text-align: center;">(14)</p> <ul style="list-style-type: none"> • NCH (1) - a maximum of five ICD-9-CM diagnoses and a DRG code may be indicated • The Registry (2) - past and current medical conditions • UCDS (3) • CBS (4) • EDB (7) • ESRD-PMMIS (14) - indicated by ICD-9-CM and DRG codes • NMES (17) • LSA (49) 	<p style="text-align: center;">(12-I 9)</p> <ul style="list-style-type: none"> • Those interviewed suggested that more detailed claims data would provide an extensive data source to evaluate medical effectiveness issues and variables that influence the use of services, particularly for treatments aimed at rare medical events. Specific items for which additional descriptive information was requested include readmission, morbidity, mortality, and level of disability. Other descriptive items requested such as socio-demographic characteristics, use of services other than those represented on the current claim, and health status would have to be collected separately using a sample survey or in conjunction with the UCDS. HCFA plans to link the Registry with administrative databases (i.e., the NCH, the CMHS - 5%, and the Hospital Out-patient bill file) as well as the UCDS and the CBS providing an extensive data base to evaluate medical effectiveness issues.

TABLE 1
DATA RELATED TO THE MEDICARE PROGRAM
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
(15) mortality,	(15) <ul style="list-style-type: none"> . NCH (1) . CBS (4) . EDB (7) . ESRD-PMMIS (14) - includes primary and secondary causes of death . NVSS (48) . LSA (49) 	(15) <ul style="list-style-type: none"> • Interview records from the LSA have been matched to the National Death Index and Medicare records to enable a study of survival and death related to social, demographic, family support, and health conditions. Additional matching of listed data bases to the Death Index with uniform reporting on Death Certificates would facilitate additional research in this area. The CBS will collect data on mortality by interviewing next-of-kin and linking information to Medicare eligibility files and the National Death Index.
(16) readmission,	(16) <ul style="list-style-type: none"> . CBS (4) . NMES (17) 	
(17) level of disability,	(17) <ul style="list-style-type: none"> . The Registry (2) . UCDS (3) . CBS (4) . NMES (17) . CBS (4) . NLTCS (25) 	(17) <ul style="list-style-type: none"> • No consistent standardized definition to indicate level of disability has been developed. In addition, there is a lack of diagnostic tools to evaluate those with disabilities in the survey setting.
(18) use of ambulatory services, nursing homes, and home health agencies	(18) <ul style="list-style-type: none"> . NCH (1) . CBS (4) . POS file (6) . CMHS-5% (16) . NMES (17) . NLTCS (25) . NNHS (26) . NHCS (47) 	

a. Analysis Issues

Data required in the area of managed care include that necessary for analysis of the characteristics of enrollees (both health status and utilization), the types of care provided by managed care plans, and the cost effectiveness and quality of care provided by managed care plans. Data are required that can be used to compare costs, expenditures, and utilization of managed care and fee-for-service (FFS) beneficiaries.

Conceptually, however, this comparison is difficult because the range of covered services for managed care enrollees is broader than that for beneficiaries receiving care in the FFS. Therefore, it is difficult to compare utilization without collecting information on total use by managed care enrollees and FFS beneficiaries including use of both covered and non-covered services. Likewise, comparing costs is difficult because managed care plans frequently cannot assign a cost to any particular service for any particular beneficiary. Therefore, while these issues were identified as important, many conceptual issues would have to be resolved before recommendations related to data collection in this area can be developed.

A number of systems are available or being developed to capture data related to Medicare managed (coordinated) care programs. These systems include the National Data Reporting Requirement (NDRR), the Beneficiary Inquiry Tracking System (BITS), and the Plan Information Control System (PICS).

The NDRR includes the financial, enrollment, and utilization reporting requirements for federally qualified Health Maintenance Organizations (HMOs) and Competitive Medical Plans (CMPs). Each federally qualified HMO and CMP is required to submit data on a quarterly or annual basis (depending on its financial status). Certain data elements are then entered into a data base called the NDRR subsystem which is subsequently linked to PICS, a system that

provides HCFA with a central data base of plan- specific information. These data bases are used primarily for overseeing daily operations of federally qualified **HMOs** and **CMPs**.⁶

An additional data system, BITS, is used primarily by regional offices to collect data on the type and disposition of inquiries and complaints made by and on behalf of Medicare beneficiaries enrolled in **HMOs/CMPs**. BITS provides aggregated data to assist in the identification of potential problems within specific health care plans. BITS provides HCFA with a national data base for conducting comparative studies on the various types of prepaid health/coordinated care plans.

As previously mentioned, the CBS will provide both longitudinal and cross-sectional data sets on the Medicare population, including those enrolled in prepaid health/coordinated care plans. The CBS could provide general data for comparing expenditures and utilization between managed care and fee-for-service beneficiaries, although the sample size may be too small (approximately 12,000) to provide statistically significant data on those enrolled in prepaid health plans (approximately 5.46 percent of Medicare beneficiaries in July 1989).⁷ If the CBS, however, does provide a statistically valid sample of managed care enrollees (or is expanded to do so), the methodology to be used would allow for comparison of utilization of services. The CBS, however, cannot provide information on the cost of services for patients in prepaid health plans, because these plans do not submit bills.

The Registry will also collect longitudinal data on those Medicare beneficiaries enrolled in prepaid health plans. The Registry will collect data on Medicare beneficiaries' health status at two- to five-year intervals and allow analysis of treatment interventions provided to Medicare beneficiaries. However, because the Registry depends on claims data for utilization information, and claims data are not available for managed care enrollees, it will not provide

⁶See Appendix D for additional information on the NDRR as well as other managed care databases discussed in this report.

⁷From the Office of Prepaid Health, Health Care Financing Administration.

data necessary to compare utilization. This data base could provide a potential source of data for comparing the health status of those enrolled in prepaid health plans to those receiving care in fee-for-service sector; however, because of the long interval between surveys, it may be difficult to monitor movement in and-out of managed care plans.

b. Data Limitations

As discussed above, data on managed care are limited to administrative data bases, and these provide little information useful for research. Because managed care plans do not submit claims data, beneficiary-specific data on utilization of services are not available. Data are required related to the use of managed care services by the Medicare population, as well as demographic, socioeconomic, and health status variables describing beneficiaries enrolled in prepaid health plans as compared to those enrolled in fee-for-service plans. In order to meet these data needs, plans would have to be required to provide claims data. In addition, a national sample survey (such as the CBS), which will collect information on use of both covered and non-covered services for managed care enrollees and those in the FFS system, would be required to enable researchers to compare the utilization of covered and non-covered populations. Because of the difficulty in estimating costs for care in a managed care program, none of these data efforts would allow for a direct comparison of costs.

Many of those interviewed viewed the gaps in managed care data as one of the most serious facing DHHS. Furthermore, those interviewed believed that high quality data in the managed care area could be used to analyze a number of other health policy issues, particularly related to the use of non-covered services.

Table 2 on the following page summarizes data needs, data availability and data limitations/gaps specific to Medicare Managed Care Plans.

TABLE 2
DATA RELATED TO MEDICARE PRE-PAID HEALTH/MANAGED CARE

Data Needs	Data Availability (see Appendix D for explanation of databases)		Data Limitations/Gaps
<p>• Data related to the Medicare population enrolled in Managed Care Plans are needed which provide the following information:</p> <p>(1) quality of care provided by Managed Care, and</p> <p>(2) comparisons of costs, expenditures, and long-term utilization trends among Managed Care and Fee-for-Service (FFS) beneficiaries adjusted for demographic, socioeconomic, and health status variables such as:</p> <ul style="list-style-type: none"> -age, -sex, -welfare (enrollment for state buy-ins, and non-buy-ins) -geographical area, and -institutional status 	<p style="text-align: center;"><u>Fee-for-Service</u></p> <p style="text-align: center;">(1)</p> <ul style="list-style-type: none"> • The Registry (2) • UCDS (3) <p style="text-align: center;">(2)</p> <ul style="list-style-type: none"> • NCH (1) • The Registry (2) • UCDS (3) • CBS (4) • EDB (7) • CMHS - 5% (16) 	<p style="text-align: center;"><u>Managed Care</u></p> <p style="text-align: center;">(1)</p> <p style="text-align: center;">(2)</p> <ul style="list-style-type: none"> • EDB (7) • Group Health Plan Master File (18) • Cost Reports (for cost HMOs) (19) • ACR (for risk HMOs) (20) • NDRR (21) • Disenrollment Survey (22) • BITS (23) • PICS (24) 	<p style="text-align: center;">(1)</p> <ul style="list-style-type: none"> • Currently there are no data sets available to analyze quality of care provided by Managed Care Plans. The Registry, which has a sample size of approximately 47,000, and the UCDS could provide information on quality of care provided by Managed Care Plans by oversampling Medicare beneficiaries enrolled in Managed Care Plans. <p style="text-align: center;">(2)</p> <ul style="list-style-type: none"> • There is no standard clinical data set that can readily access, manipulate, and track data regarding Medicare Managed Care programs. Data which are listed under Managed Care would provide some of the information needed to analyze utilization and expenditure trends of Managed Care Plans, but are used primarily for operational purposes. To compare costs, expenditures, and utilization among Managed Care and FFS beneficiaries, databases listed would have to be redesigned and matched to allow a comparative analysis of costs, expenditures, and utilization among Managed Care and FFS beneficiaries. For example, HCFA plans to link data gathered from the Registry with administrative data bases (i.e., the NCH, the CMHS -5%, and the Hospital Out-patient Bill record file) as well as the UCDS and the CBS to incorporate data on cost and utilization of care provided to FFS Medicare beneficiaries. Although these data bases include Medicare beneficiaries enrolled in Managed Care Plans, the overall number of individuals is too small to provide an adequate sample size. In addition, Managed Care Plans do not collect the same kinds of data as FFS. For instance, Managed Care Plans do not collect claims data; therefore, beneficiary-specific data are not available. Finally, cost data submitted by Managed Care Plans and FFS do not provide information on costs for treatment or service.

3. **Medicare Payment System Reform**

During the 1980s major changes were made related to hospital payment for services provided to the Medicare population. The largest change was made in fiscal year 1984 with the implementation of the Prospective Payment System (PPS). Subsequent modifications have been made to the program that might be expected to have an impact on access to care for the covered population. For example, HCFA recently proposed changes in the methods used to reimburse hospitals for capital costs. In addition, major changes related to physician payment are being implemented.

Currently available data, however, do not allow for a comprehensive analysis of the potential impact of these proposals. This has made design and evaluation of these reforms difficult. For example, the impact of the Medicare PPS system is difficult to analyze as the system struggles to meet competing goals: cost containment and access to care. Data on the cost of services are available (although the methods used by hospitals to identify costs on the cost report has been questioned). Data on the impact of PPS on access to care, however, are not as readily available. In all areas, therefore, data are required which enable researchers to identify the impact of payment reform on costs, payments, utilization of services, and beneficiary access to care. Data collected must also include measures that enable researchers to determine the impact of reform on payments to providers and their willingness to accept Medicare beneficiaries.

a. **Analysis Issues**

Analysis of payment reform is required for hospitals, physicians, nursing homes, home health agencies, and other health care providers. Data are required related to both operating and capital costs for these providers. As discussed above, most aspects of hospital payment reform have already been implemented; however, changes in capital payment have only recently been proposed. Although administrative data bases for hospitals provide much of

the required information, data continue to be required to analyze the impact of this proposed reform on the financial performance of providers (including hospitals and other providers affected by the change in incentives created by PPS) and on beneficiary access to care. In addition, data are needed to shape capital payment reform and measure its potential impact.

Physician payment reform is currently being implemented. Issues raised in this area relate to the resources required to provide physician services, as well as utilization of and payment for these services. Difficulties in analyzing physician payment reform options stem primarily from deficiencies in Medicare Part B (BMAD) data. Procedure codes on physician claims data indicate the types of services provided, while physician identifiers are used to specify particular providers. Numerous problems exist in using these claims data for research. First, physicians are not always uniquely identified on current records, and many physicians (for example, those in group practices) may use the same identifier. The Uniform Physician Identification (**UPIN**) Directory will help resolve this problem by establishing a unique identifier for each physician who provides services for which payment is made under Medicare.* Second, carriers continue to use local procedure codes instead of the national codes (CPT-4 and HCPCS codes), and where national codes are used, they are often used inconsistently. Third, specialty does not always match with common specialty definitions, and specialty reporting may vary by carrier. Finally, because of the large volume of data, timely processing is difficult.

Two data initiatives mentioned previously, the NCH and the CBS, will provide new sources of data for analysis of physician payments. The NCH will allow for more timely analysis of Medicare Part B data by incorporating the claims data submitted through the CWF. The Bureau of Data Management and Strategy (BDMS) at HCFA will produce Part B data files that will be available more quickly than in the past. The four BMAD files submitted

⁸For additional information on the **UPIN** Directory, see Appendix D.

annually by carriers (which include summary procedure information, provider profile files, claims from end-stage renal disease beneficiaries, and detailed claims data from a **five-** percent sample of all other beneficiaries) will be "phased out" after the 1990 routine BMAD files have been submitted. The NCH will improve access to data for policy analysis with summary data bases that are more detailed, updated more frequently, and made available through a user-friendly menu system within HCFA. Also, the CBS will provide information on inappropriate utilization of services and the effects that the fee schedule has on access to care for beneficiaries.

b. Data Limitations

Despite proposed improvements in Part B data bases, data gaps in physician information remain. In addition, there are no reliable data on the cost of providing nursing home services, and home health services. Physician claims do not include cost information (only charge data); and such information would be difficult for physicians to **estimate**.⁹ While cost report data includes some information on nursing home and home health agency costs, these data are not associated with a particular patient and/or diagnosis. Therefore, it is difficult to estimate patient or diagnosis-specific costs. Improvements in this information require the development of common definitions of types of costs and additional efforts to collect these data for particular patients and/or disease categories.

During-the **1980s**, HCFA made particular efforts to improve the quality of hospital data bases to allow researchers to use these data more effectively. Filling some of the data gaps related to other providers would require the same effort. This is difficult, however, because of the volume and tremendous variety of services obtained from non-hospital providers,

⁹Despite this limitation, there are data available on the relative value of physician services. This information is contained in two reports entitled, "A National Study of Resource-Based Relative Value Scales for Physician Services," (September 1989) and 'A National Study of Resource-Based Relative Value Scales for Physician Services Phase II," (November 1990). These reports were produced by a research team at the Harvard University School of Public Health led by William Hsiao, Ph.D., under a cooperative agreement with HCFA.

Data on utilization of non-physician/non-hospital services are also required, particularly for outpatient services, skilled nursing facilities (**SNFs**), home health agencies (**HHAs**), and PPS-exempt hospital services (psychiatric, rehabilitative, and cancer facilities). More detailed information is required on the patterns of care provided by these facilities, utilization rates of services provided, and the case mix of their patient population. Currently, cost report data from **SNFs** and **HHAs** are not readily accessible, nor are they available in aggregate form. Direct access to this information by merger of the cost report files for **SNFs** and **HHAs** would allow for more efficient data analysis. BDMS has started to collect these cost reports centrally and will soon have one year of data available for analysis.

In many cases, use of these services is not covered by Medicare, so filling this gap will require survey data, not just improvements in administrative data bases. Utilization information will need to be supplemented by data on the demographic and socioeconomic characteristics of those using these services. Finally, it will be necessary to link utilization of all covered and non-covered services to determine beneficiary use over each episode of illness and over time. For some PPS-exempt and uncovered services, the CBS will collect this information.¹⁰

Significant gaps related to capital expenditures for all providers also exist. Data required include information on acquisition of new capital, financing mechanisms, and schedules for retirement of new assets. Table 3 on the following two pages summarizes data needs, data availability, and data limitations/gaps related to Medicare Payment System Reform.

¹⁰The CBS will gather information on home health visits by health professionals (i.e., nurses, social workers, therapists, and hospice workers) as well as the place or organization the health professional is affiliated with. Respondents are also asked the name of all long-term care facilities they have been a patient at since a specified reference date. Finally, the CBS asks where a medical visit took place (indicators include neighborhood/family health center, freestanding surgical center, rural health clinic, company clinic, laboratory, walk-in urgent center, at home, hospital outpatient, and other).

TABLE 3
 DATA RELATED TO MEDICARE **PAYMENT** SYSTEM REFORM
 (Physicians, SNFs, HHAs, Out-patient services, and PPS-exempt hospitals and services)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• <i>The following data are needed for analyzing Medicare payment system reform:</i></p> <p>(1) availability of new services, their associated costs, and effect on Medicare costs,</p> <p>(2) the cost-effectiveness of new services,</p> <p>(3) whether increased Medicare costs are related to an increase in volume or price,</p> <p>(4) the impact of physician payment reform on physicians' income levels,</p> <p>(5) access to care by population sub-groups,</p>	<p style="text-align: center;">(1)</p> <p>• NCH (1) • PORTS (50) • PHOS (51)</p> <p style="text-align: center;">(2)</p> <p>• NCH (1) • The Registry (2) • UCDS (3) • EDB (7) • PORTS (50) • PHOS (51)</p> <p style="text-align: center;">(3)</p> <p>• NCH (1)</p> <p style="text-align: center;">(4)</p> <p style="text-align: center;">(5)</p> <p>• The Registry (2) • CBS (4) • NMES (17)</p>	<p style="text-align: center;">(1-3)</p> <p>• There are no data available on the cost of services provided by physicians, Physicians claims do not include cost information (only charge data). In addition, physicians are not always uniquely identified on current records as carriers often use local codes instead of national codes (CPT-4 and HCPCS codes), and specialty is self-reported by physicians. There is also a lack of data on new treatments/services for rare medical events. Meanwhile, cost reports from institutional providers are not associated with a particular patient or diagnosis code. Currently they are not readily accessible or available in aggregate form, although the Bureau of Data Management and Strategy at HCFA has started to collect this information and will soon have one year of data available for analysis.</p> <p style="text-align: center;">(4)</p> <p>• There are no databases which provide statistically reliable data on the impact of physician payment reform on physicians' income levels.</p> <p style="text-align: center;">(5)</p> <p>• There are currently no databases which routinely collect information on access to care for Medicare beneficiaries on a longitudinal basis, although two data initiatives, the Registry, and the CBS will collect this information in the future.</p>

TABLE 3
DATA RELATED TO MEDICARE PAYMENT SYSTEM REFORM
(Physicians, SNFs, HHAs, Out-patient services, and PPS-exempt hospitals and services)
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
(6) long-term versus short-term use of SNFs and other nursing homes by Medicare beneficiaries,	(6) <ul style="list-style-type: none"> • NCH (1) • The Registry (2) • CBS (4) • NMES (17) • NLTCS (25) • NNHS (26) • NHCS (47) 	(6) <ul style="list-style-type: none"> • Currently, there are no longitudinal data available to analyze long-term versus short-term use of SNFs and other nursing homes by Medicare beneficiaries, although the Registry and the CBS will collect this information in the future.
(7) the number of nursing home residents enrolled in both Medicare and Medicaid,	(7) <ul style="list-style-type: none"> • NCH (1) • CBS (4) • EDB (7) • NNHS (26) • NHCS (47) 	(7) <ul style="list-style-type: none"> • HCFA administrative databases contain limited information on those Medicare beneficiaries enrolled in Medicaid. The CBS will collect longitudinal data on Medicaid spend down among the nursing home population.
(8) number of beneficiaries receiving services in outpatient and ambulatory surgical centers by diagnosis and medical status,	(8) <ul style="list-style-type: none"> • NCH (1) • NHCS (47) 	(8) <ul style="list-style-type: none"> • Currently there are limited data related to care provided in outpatient and ambulatory surgical centers, The NCH contains diagnostic information, but not medical status. The National Health Provider inventory (NHPI) component of the NHCS will add these sites of care in the future.
(9) the case mix of patient populations,	(9) <ul style="list-style-type: none"> • NCH (1) 	(9) <ul style="list-style-type: none"> • There is no data base available containing the case mix of PPS-exempt facilities. Additional information is required on the health status of individuals receiving care from PPS-exempt facilities to facilitate the development of a case mix classification system.
(10) total capital expenditures, schedules for the retirement of assets, and the rate of new capital expenditures, and	(10) <ul style="list-style-type: none"> • HCRIS & Section 223 Cost Limit File for SNFs and HHAs (15) 	(10) <ul style="list-style-type: none"> • Cost report data from skilled nursing facilities (SNFs) and home health agencies (HHAs) are not available in aggregate form or readily accessible, although the BDMS has started to collect these cost reports centrally and will soon have one year of data available for analysis.
(11) the amount of uncompensated care/charity care PPS-exempt health care facilities provide	(11)	(11) <ul style="list-style-type: none"> • Data are not routinely collected which describe the amount of charity care provided by health care facilities.

4. **Medicaid Issues**

The Medicaid program provides access to health care for the eligible poor and disabled as well as the indigent elderly. Medicaid programs are operated by each state, but the federal government provides significant program funding. Medicaid program expenditures have increased more rapidly than forecasted. Major Medicaid research issues relate to the use of services by the various segments of the Medicaid population, sources, of care for this population, use of uncovered services, and out-of-pocket expenditures, Furthermore, analysis of the impact of program expansion, both in terms of coverage and eligibility, is required as part of federal efforts to ensure coverage of the uninsured population.

a. **Research Issues**

Analysis of these questions requires data characterizing health care utilization, reimbursement, and expenditure patterns of recipients. Data are also required on the characteristics of state programs, including the scope of coverage, enrollment and benefits provided as well as payment methods. Evaluation of the impact of program expansion requires these data in addition to information on the characteristics of current and potential Medicaid beneficiaries, and use of uncovered services by both the covered and potentially covered populations.

Limitations in the availability of data to analyze the Medicaid program at the federal level are largely due to the fact that the Medicaid program is operated at the state level. Although much of the data needed to answer research questions exists at the state level, it is not collected consistently across states nor compiled at the federal level. In addition, there are state-by-state variations in services covered and eligibility requirements. As a result, the types of data and information collected at the state level vary widely. These factors lead to a lack of aggregated data and beneficiary-specific information at the federal level.

Most states are required to submit an annual HCFA-2082 report (states that voluntarily participate in the Medicaid Statistical Information System (MSIS) project are exempt from this requirement). The HCFA-2082 file is used by HCFA to prepare national summaries on Medicaid eligibles, recipients, service utilization, and vendor payments. These data are used to obtain a description of federal obligations. The 21 states participating in the MSIS project voluntarily provide HCFA with beneficiary-specific data, which HCFA uses to generate the same information provided by other states in aggregated form. The MSIS data are used for operational purposes only, although BDMS is studying ways to merge the Tape-to-Tape data bases (described below) with the MSIS data bases and use the combined data for research purposes.

An additional Medicaid data source is the Tape-to-Tape National Unit Record Medicaid Database. This voluntary data collection effort began in 1980 and currently includes four states: California, Michigan, Tennessee, and Georgia. A fifth state, New York, was originally part of the effort, but dropped out. Person-based unit records from state paid claims, eligibility, and provider files for the four states are available from 1980 to the present. This database includes 30 to 40 percent of all Medicaid claims.”

b. Data Limitations

As described above, data on the Medicaid program are limited to incomplete and inconsistent state administrative data bases. Therefore, significant data gaps exist, including:

- **program characteristics** -- There is no centrally available data set that provides information on characteristics of state Medicaid programs. As discussed above, both coverage and **eligibility** data are required to determine the impact of program expansion.¹²

“Division of Medicaid Statistics, Office of Statistics and Data Management, Bureau of Data Management and Strategy, Health Care Financing Administration.

¹² The Medicaid Bureau Budget Estimating Initiative (BEI) at HCFA is currently developing an automated data collection system in response to these specific Medicaid data needs. The data system will provide state-by-state profiles of Medicaid Program characteristics as well as allow for cross-state analyses of Program data. The data system

- **consistent utilization and expenditure data** -- Data are collected from each of the states, but uniformity is required for meaningful policy analysis, and such uniformity currently does not exist. To address major research questions, additional data are also required.

Both of these gaps can be characterized as gaps in administrative data collection efforts.

These data gaps would be filled with expansion of program data bases.

A third gap would require a national sample survey. This gap relates to:

- **characteristics of eligible or potentially eligible population groups** -- Data are required for those groups covered under the Medicaid program as well as those who are potentially eligible. Potentially eligible groups are those groups who may be eligible under proposals to expand the program, or those who are eligible but do not participate. Information is required on covered services and potentially covered services, as well as data on the demographic and socioeconomic characteristics of eligible and potentially eligible groups.

Table 4 on the following two pages summarizes data needs, data availability, and data limitations/gaps specific to the Medicaid program.

B. POPULATION SUB-GROUPS

Throughout DHHS, individuals are concerned with the needs of specific population groups because they are believed to have special health care needs or particular problems related to access to care. Population sub-groups identified include:

- the uninsured and underinsured population
- populations with substance abuse and mental disorders
- rural populations
- pregnant women and infants
- children
- minorities
- persons with disabilities
- the aged population

will also indicate changes in Medicaid Program characteristics by state and nationally, and provide national totals for Medicaid Program features.

**TABLE 4
DATA RELATED TO THE MEDICAID PROGRAM**

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• Medicaid data are needed which describe the following:</p> <p>(1) utilization and expenditure patterns of Medicaid beneficiaries by income level,</p> <p>(2) state-by-state Medicaid reimbursement and expenditures,</p> <p>(3) scope of coverage and benefits provided by state programs,</p> <p>(4) potential increase in Medicaid costs and beneficiary enrollment from program expansions,</p>	<p align="center">(1)</p> <ul style="list-style-type: none"> • Tape-to-tape (10) - for California, Michigan, Tennessee, and Georgia only • CPS (11) • SIPP (12) • NMES (17) <p align="center">(2)</p> <ul style="list-style-type: none"> • HCFA 2082 report (8) - for states not participating in MSIS • MSIS (9) - for twenty-one states only • Tape-to-tape (10) - for California, Michigan, Tennessee, and Georgia only <p align="center">(3)</p> <p align="center">(4)</p> <ul style="list-style-type: none"> • HCFA 2082 report (8) - states not participating in MSIS • MSIS (9) - twenty-one states only • Tape-to-tape (10) - California, Michigan, Tennessee, and Georgia only • CPS (11) • SIPP (12) • NMES (17) 	<p align="center">(1)</p> <ul style="list-style-type: none"> • CPS and SIPP provide information on income level and insurance status, but fail to provide adequate information on health care utilization and expenditure patterns. Meanwhile, the tape-to-tape database provides beneficiary specific information but only includes four states. Databases would need to be matched to provide this data. <p align="center">(2)</p> <ul style="list-style-type: none"> • Data are missing on Medicaid contributions from voluntary donations and provider taxes. <p align="center">(3)</p> <ul style="list-style-type: none"> • There is no readily accessible database which contains state-by-state information on covered benefits and eligibility requirements, although the Medicaid Bureau Budgeting Estimating Initiative (BEI) at HCFA is currently developing an automated data collection system in response to these specific Medicaid data needs. The data system will provide state-by-state profiles of Medicaid program characteristics as well as allow for cross-state analyses of Program data. The data system will also indicate changes in Medicaid Program characteristics by state and nationally, and provide national totals for Medicaid Program features. <p align="center">(4)</p> <ul style="list-style-type: none"> • The databases listed would have to be matched to provide information on the effects program expansion would have on Medicaid costs and enrollment levels. Common beneficiary identification numbers would need to be developed before matching could occur. In addition, it is difficult to project aggregate changes in Medicaid utilization and expenditures due to state-by-state variations in services covered, eligibility requirements, and type of data collected and reported.

TABLE 4
DATA RELATED TO THE MEDICAID PROGRAM
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
(5) use of Medicaid services by Medicare buy-ins,	(5) <ul style="list-style-type: none"> • CBS (4) 	(5) <ul style="list-style-type: none"> • Currently, no data are routinely collected on the use of Medicaid services by Medicare buy-ins, but the CBS will collect this information when it is implemented the Fall of 1991.
(6) the dynamics of program participation (factors affecting enrollment/disenrollment in and out of the Medicaid program), and	(6) <ul style="list-style-type: none"> • HCFA 2082 report (8) - submitted by states not participating in MSIS • MSIS (9) - for twenty-one states only • Tape-to-tape (10) - for California, Michigan, Tennessee, and Georgia only • CPS (11) • SIPP (12) 	(6) <ul style="list-style-type: none"> • Although much of the data needed for research exists at the state level, state-to-state beneficiary-specific data are not collected consistently across states or compiled at the federal level (except for states participating in the MSIS and Tape-to-tape database). Although the tape-to-tape database is used for research purposes, the primary focus of the MSIS database is operational. In addition, states use different data qualifiers in gathering data. For instance, beneficiary identification numbers vary by state, and beneficiaries who re-enroll in the Medicaid program, or relocate to another state, may receive an identification number which is different from their previous number, making it virtually impossible to track beneficiaries over time and across states.
(7) access to care	(7)	(7) <ul style="list-style-type: none"> • Medicaid data submitted by states do not describe factors affecting access to care for Medicaid beneficiaries. This kind of information would most likely need to be collected in a survey.

- the long-term care population
- Alzheimer's patients
- the HIV-infected population

Information required for these population sub-groups includes data on their special health care needs, health care utilization, sources of financing, and expenditure patterns. Data are also required that describe access to care, site of care, patterns of care, and providers of care for the population groups listed above. It is important to note that these population sub-groups are frequently overlapping or one may be a subgroup of another (e.g., Alzheimer's population and long-term care population). These groups were selected because they were identified by those we interviewed as important to specific DHHS programs or research areas.

Minority groups and children are a focus of both the Secretary's Initiatives and the Public Health Service's "Healthy People 2000." Data to monitor the health care utilization and expenditures of these populations are required in order to measure achievement of these objectives. Because of the focus on these groups across DHHS, we have identified these data needs separately, although they are closely linked to the public program issues discussed earlier.

Research questions and related data needs of these groups are discussed below. A summary section (Section B-12) discusses the major data gaps in more detail.

1. **The Uninsured and Underinsured Population**

Several groups within DHHS and other government agencies are studying issues related to the uninsured and underinsured (those individuals with only intermittent or limited coverage). These groups are believed to experience difficulties obtaining health care, and while extensive research has been done relative to their numbers and characteristics,

less is **known about their health care** needs, sources of care, financing of care, and the limitations they face in obtaining care. In addition, the availability of state and local services to meet their needs is unknown.

The uninsured and underinsured include a broad range of individuals and frequently overlap with many of the population subgroups discussed below. Because of the current focus on issues related to access to care, data needs related to this population were frequently discussed in our interviews.

For research in this area, analysts require additional data describing characteristics of Medicaid eligibles who fail to enroll in the program as well as persons ineligible for Medicaid who are uninsured. Characteristics of interest include geographic location, demographic and socioeconomic factors (such as employment and education level), health status, and reason for failure to enroll.

Table 5 on the following page summarizes data needs, data availability, and data limitations/gaps related to the uninsured and underinsured population.

2. **Populations with Substance Abuse and Mental Disorders**

Research on populations with substance abuse and mental disorders focuses on sources of care, effectiveness of treatment services for substance abuse and mental health disorders (including issues related to recidivism), demographic and socioeconomic data of both those receiving and those needing but not receiving care, and the relationship between mental illness and alcohol/substance abuse. There is a particular interest in substance abuse and mental health research data describing the range of services offered (including substance abuse treatment for pregnant women), associated costs, payment sources, type of drug(s) abused by persons, short- and long-term treatment outcomes, and co-morbidities.

Data are collected on the characteristics of facilities providing services but are incomplete for certain provider groups such as the for-profit facilities and the more informal

TABLE 5
DATA FOR THE UNINSURED AND UNDERINSURED POPULATION

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• Data on <i>the uninsured and underinsured</i> should describe the following:</p> <p>(1) state and local public health care services for the indigent, uninsured, and poor,</p> <p>(2) characteristics of state and local public health care recipients (demographic and socioeconomic factors such as employment and education level, and health status),</p> <p>(3) characteristics of underserved areas,</p> <p>(4) availability of health care professionals to meet the needs of regional populations,</p> <p>(5) sources of financing for public health services,</p> <p>(6) private support of health care services for this population group (e.g., amount of charity care provided by hospitals, physicians, and non-profit groups), and</p> <p>(7) characteristics of Medicaid eligibles who fail to enroll in the program according to the following:</p> <p style="padding-left: 40px;">geographic location, demographic and socioeconomic factors such as employment and education level, health status, and reason for failure to enroll.</p>	<p>(1)</p> <p>(2)</p> <ul style="list-style-type: none"> • CPS (11) • SIPP (12) • NMES (17) <p>(3)</p> <p>(4)</p> <p>(5)</p> <p>(6)</p> <p>(7)</p> <ul style="list-style-type: none"> • NMES (17) • CPS (11) • SIPP (12) • NHIS (27) - Health Insurance Supplement 1989 and 1990 	<p>(1-6)</p> <ul style="list-style-type: none"> • Programs financed with block grant funds are not required to collect data on program or beneficiary characteristics, or have only recently been required to collect data (e.g., the Maternal and Child Health Block Grants). In addition, there are no data collection instruments that gather information on state and local support for health services or which describe private support for health care (charity care) through institutions, providers, and non-profit groups. <p>(7)</p> <ul style="list-style-type: none"> • There are no data collection instruments which routinely collect information on the health status of the low-income population, including individuals who may fail to enroll in the Medicaid program. Because there is no central data set describing eligibility requirements and services covered by state Medicaid programs, research in this area is limited. In addition, low-income individuals are difficult to reach due to their mobility. Data bases listed contain some of the information required for this analysis, but fail to identify those eligible for Medicaid who fail to enroll or participate in the program.

services provided in some communities. Data on substance abuse and mental health programs funded with block grant dollars are unavailable, as are complete data on state and local support for substance abuse and mental health services.

The National Institute on Mental Health (NIMH), the National Institute for Drug Abuse (NIDA), and the National Institute for Alcoholism and Alcohol Abuse (NIAAA) sponsor data activities in these areas. The Statistical Research Branch at NIMH collects national statistics on specialty mental health organizations and patients they serve. Major publications through which NIMH disseminates statistical findings from their data collection efforts include Mental Health, United States, Mental Health Directory, Mental Health Service System Reports, and Statistical Notes. Information presented in Mental Health, United States, 1990, the most recent edition, includes the following:

- characteristics of mentally ill persons in nursing homes and state mental hospitals,
- trends in the availability, volume, staffing, and expenditures of organized specialty mental health services in the United States,
- characteristics of persons who use specialty mental health services,
- the features of organized specialty mental health services by state,
- revenues,
- expenditures, and
- human resource availability.

The Mental Health Directory provides a central source of information on mental health organizations throughout the United States. This nationwide listing of mental health organizations and related resources serves as a guide to mental health providers in facilitating patient referrals.

NIMH also publishes data in the Mental Health Service System Reports, and Statistical Note series. These two publications also serve as a reference for the latest statistics on the

mental health service delivery system, and are published more frequently as data from surveys and research become available.

Much of the information contained in NIMH publications is derived from NIMH's organizational inventory databases and patient surveys.¹³ The Inventory of Mental Health Organizations and General Hospital Mental Health Services (IMHO/GHMHS), conducted every two years, is a periodic, complete enumeration survey of specialty mental health organizations, designed to collect information on organizational characteristics, programs offered, aggregate patient characteristics, patient movement statistics, staffing, revenues, and expenditures. The 1986 IMHO/GHMHS marked the beginning of major improvements in the NIMH Inventory by combining the Inventory of Mental Health Organizations (IMHO) with the Inventory of General Hospital Mental Health Services (IGHMHS), previously Conducted separately. This allowed for the development of a common core form with three versions, one for specialty mental health organizations, one for general hospitals with separate psychiatric services, and a brief screening form for general hospitals without separate psychiatric services. The inventories include questions on types of services provided (e.g., inpatient, outpatient, and partial care); number of inpatient beds; number of inpatient, outpatient, and partial care additions; average daily and end of year inpatient census; expenditures; staffing by type of discipline; and revenue by sources (only after 1983). In 1988, the Inventory was expanded to cover community residential organizations, and questions were added on case management services. The 1990 Inventory was sent to the field **in the beginning of 1991**. It is **anticipated that data** will be available the summer of 1992.

The State Organizational Information System and Profile System is a data initiative sponsored by NIMH to enhance the IMHO/GHMHS. The goal of this initiative is to assess the **feasibility of implementing state organizational information systems for electronic reporting to**

¹³See Appendix D for additional information on NIMH surveys.

replace selected components of the IMHO. Another goal of this initiative is to assess the feasibility of implementing a state profile system of policy-oriented quantitative and qualitative information to simplify state-by-state comparisons. Through this initiative, NIMH has facilitated state mental health agency data collection activities.

An additional ongoing inventory at NIMH includes the Inventories of State Prison and Local Jail Mental Health Services. These inventories include complete enumeration surveys designed to collect information parallel to that of the IMHO/GHMHS. Data collection includes the 1988 Inventory of State Prison Mental Health Services, and the Local Jail Mental Health Services Survey. The Local Jail Mental Health Services Survey, which is currently planned for 1992 and will inventory approximately 3,300 local and county jails, serves as a companion to the 1988 Inventory of State Prison Mental Health Services. A feasibility study was conducted which gathered information on type of mental health services available, organizational arrangements for services, number of persons served, staffing, and financial resources. The full scale survey is planned for 1992.

An ongoing NIMH data collection effort since 1950 includes the Annual Census of State and County Mental Hospitals, which derives its data from the annual Survey of Patient Characteristics for State and County Mental Hospital Inpatient Services. This survey provides longitudinal data on characteristics of patients who use inpatient mental health services provided by state and county mental hospitals. Data collected on patient characteristics include age, sex, and diagnosis.

In addition to organizational inventories, NIMH also conducts patient-based surveys approximately every five years. Patient-based surveys include the 1986 Client/Patient Sample Survey of Inpatient, Outpatient, and Partial Care Programs, the 1990 Longitudinal Client **Survey of Outpatient Programs, and Longitudinal Patient Data for State Mental Hospital** Inpatient Services. A patient-based survey is also planned for 1993 which will replicate the

1986 Client/Patient Sample Survey of Inpatient, Outpatient, and Partial Care Programs. The 1986 survey gathered information on demographic characteristics, psychiatric diagnosis, and median length of stay for patients admitted to and terminated from inpatient, outpatient, and partial care settings.

The 1990 Longitudinal Client Survey of Outpatient Programs is a one year longitudinal survey of sample cohorts of admissions and clients under care in outpatient mental health programs. The survey is currently gathering information on variables pertaining to service use, cost, and level of functioning, in addition to sociodemographic, and clinical variables. The full scale survey began in May 1990 and is expected to be completed by December 1991. It is anticipated that data will be available the beginning of the summer of 1992.

In addition to these data initiatives, NIMH sponsored a special supplement to the 1989 NHIS to identify severely disabled mentally ill persons in a sample of households and determine their level of functioning. Specific data gathered in this supplement includes mental health related service use, prescription medication use, and participation in the Supplemental Security Income (SSI), and Social Security Disability Insurance (SSDI) Programs.

NIMH also maintains a Health Demographic Profile System which contains a series of mental illness risk indicators for geographical areas ranging from census tracts to states. Data are obtained from the decennial US. census.

NIDA and NIAAA are also conducting several data initiatives to expand data collection activities. A substance abuse related data initiative includes the Treatment Client Data System, which will gather information on all individual client admissions to state-supported treatment programs throughout the United States. NIDA and NIAAA have provided grants to state alcohol and drug abuse agencies for the purpose of adopting national data standards in response to requirements of the Anti-Drug Abuse Act of 1988. When complete, national and

state data on the characteristics of substance abuse clients and their patterns of alcohol and drug use will be available for planning and research purposes on a semi-annual basis. Reports will be developed to disseminate the information to states and researchers. The system is expected to be fully operational in 1992.

An additional data initiative, the National Longitudinal Alcohol Epidemiologic Survey (NLAES), will provide national and regional estimates of the incidence and prevalence of alcohol use, alcohol disorders, and alcohol-related problems and consequences. The **NLAES** is a longitudinal survey of noninstitutionalized persons residing in the United States, which will oversample individuals between the ages of 18 and 29. Data from **NLAES** will provide guidance in designing prevention, intervention, and research programs to reflect the nature, magnitude, and distribution of alcohol use disorder and the associated disability in the general population. The first wave of the NLAES will be implemented in September 1991.

The Drug Abuse Treatment Outcome Study (DATOS), funded in September 1989, consists of a multi-year investigation of drug abuse treatment effectiveness based on a nationwide sample of short- and long-term methadone maintenance, short- and long-term residential treatment, and outpatient drug-free treatment programs. Data are obtained from interviews conducted at entry to treatment, during treatment, and upon leaving treatment. Client interviews are supplemented with clinical assessments of psychological, social, and physical impairments, in addition to drug and alcohol dependence. Outcomes are compared for clients entering treatment with varied patterns of drug abuse and levels of psychosocial impairment, and varied types and durations of treatment. Research questions include the treatments and services available to clients, how they are delivered, and how they are related to outcome measures such as drug use, criminality, and employment.

Ongoing data collection activities by NIDA and NIAAA include the National Drug and Alcoholism Treatment Unit Survey (NDATUS). NDATUS is an annual survey of all known

publicly- and privately-funded alcohol and drug abuse treatment units throughout the United States. NOATUS identifies the location, scope, and **characteristics** of substance abuse treatment and prevention units. The NDATUS provides information that assists federal, state, and local governments in assessing the nature and extent of private and publicly-supported treatment and prevention programs, and identifying unmet needs in programs targeted at particular population groups, such as youth.

The State Alcohol and Drug Abuse Profile (SADAP) is an ongoing annual survey of drug abuse agencies conducted by the National Association of State Alcohol and Drug Abuse Directors (NASADAD) with contract support from **NIAAA** and **NIDA**. State agencies provide summary state-level data describing the amount and sources of funding for state-funded programs, and the numbers and characteristics of clients admitted to treatment.

Major data gaps in this area relate to the effectiveness of treatment and comparative information on various treatment alternatives, although the DATOS study and the NLAES will provide an initial data source in addressing this need. Long-term outcome studies are required to conduct research in this area. Useful data collection efforts in this area must be preceded by the development of uniform definitions of treatment methods and outcomes to assess the performance of a variety of treatment programs.

Table 6 on the following two pages summarizes data needs, data availability, and data limitations/gaps specific to populations with substance abuse and mental disorders.

3. Rural Populations

Those interested in analyzing health policy issues of rural populations require data on the uses and sources of health care services for the rural population. Additional data are required on rural patterns of care, limitations in access to care, health and insurance status of **rural populations**, **health** care utilization and expenditures, and the availability of health care providers in rural communities.

TABLE 6
DATA FOR POPULATIONS WITH SUBSTANCE ABUSE AND MENTAL DISORDERS

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• <i>Data on the population with substance abuse and mental disorders are needed which describe the following:</i></p> <p>(1) limitations in access to care for substance abuse and mental health care services,</p> <p>(2) annual and lifetime expenditures for substance abuse and mental health care services,</p> <p>(3) cost effectiveness of treatment received,</p> <p>(4) ability to meet the special needs of pregnant women,</p>	<p align="center">(1)</p> <ul style="list-style-type: none"> • Inventories of State Prison and Local Jail Mental Health Services (32) • Severely Mentally Ill Persons in Households (33) - supplement to the 1989 NHIS • NLAES (39) - alcohol use only <p align="center">(2)</p> <ul style="list-style-type: none"> • Longitudinal Patient Data for State Mental Hospital Inpatient Services (31) - 6 years of data for inpatient state mental hospital services only • NLAES (39) - alcohol use only <p align="center">(3)</p> <ul style="list-style-type: none"> • DATOS (35) -methadone maintenance only • NLAES (39) -alcohol use only <p align="center">(4)</p>	<p align="center">(1)</p> <ul style="list-style-type: none"> • Currently there are no data routinely collected on limitations in access to care for substance abuse and mental health care services, although the NLAES will began collecting this information in September 1991 for treatment specific to alcohol abuse. <p align="center">(2)</p> <ul style="list-style-type: none"> • There are limited data available which describe beneficiary-specific annual and lifetime expenditures for substance abuse and mental health care services. The NLAES will assist in estimating the economic costs of alcohol related morbidity in the United States, and the Longitudinal Patient Data for State Mental Hospital Inpatient Services will provide information on patterns of care for a 6 year period, but are limited to inpatient services received at State Mental Hospitals. <p align="center">(3)</p> <ul style="list-style-type: none"> • To assess the performance of treatment programs and permit comparative analysis, uniform data collection instruments, and definitions for treatment methods and outcomes are needed. <p align="center">(4)</p> <ul style="list-style-type: none"> • There are no data collected on the ability of treatment facilities to address the special needs of pregnant women.

TABLE 6
 DATA FOR POPULATIONS WITH SUBSTANCE ABUSE AND MENTAL DISORDERS
 (continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>(5) sources of payment,</p> <p>(6) characteristics of treatment facilities according to:</p> <ul style="list-style-type: none"> - services offered and associated costs - source of operating revenues - follow-up treatment, and <p>(7) characteristics of the population with substance abuse and mental disorders according to:</p> <ul style="list-style-type: none"> - socioeconomic and demographic variables - types of drugs abused - co-morbidities 	<p>(5)</p> <ul style="list-style-type: none"> • IMHO/GHMHS (28) • Inventories of State Prison and Local Jail Mental Health Services (32) • SADAP (37) <p>(6)</p> <ul style="list-style-type: none"> • IMHO/GHMHS (28) • Inventories of State Prison and Local Jail Mental Health Services (32) • SADAP (37) • NDATUS (38) - all known publicly and privately funded alcohol and drug abuse treatment units in the U.S. <p>(7)</p> <ul style="list-style-type: none"> • NMES (17) • NHIS (27) - Drug Use Supplement, 1991. • 1986 Client/Patient Sample Survey of inpatient, Outpatient, and Partial Care Program (29) • The 1990 Longitudinal Client Sample of Outpatient Mental Health Programs (30) • Longitudinal Patient Data for State Mental Hospital Inpatient Services (31) • Severely Mentally Ill Persons In Households (33) - Supplement to the 1989 NHIS • Annual Census of State and County Mental Hospitals (34) - gathers data on age, sex, and diagnosis for additions to and resident patients of known inpatient services provided by state and county mental hospitals • DATOS (35) • Treatment Client Data System (36) - socioeconomic and demographic data on clients admitted to state-supported treatment programs • NDATUS (38) - data collection varies by state 	<p>(5-7)</p> <p>Data are unavailable or incomplete for certain provider groups such as for-profit facilities and the more informal services provided in some communities. Data on substance abuse and mental health program funded with block grant dollars are unavailable, as are complete data on state and local support for substance abuse and mental health services. In addition, data also suffer from inaccuracies in self-reporting of such behavior.</p>

There are some data available to analyze rural population health policy issues, particularly acute care hospital services. Data from Medicare administrative data bases provide information on the disabled and those over 65. State data bases are also available to analyze patterns of care for the entire population. Data gaps in this area relate to the need to identify the limitations in access to care, as well as the burden imposed by longer travel times should access to health care in rural communities be diminished. These issues should be analyzed by type of care so that the need for facilities and personnel (particularly physicians) can be determined.

Table 7 on the following page describes data needs, data availability, and data limitations/gaps for rural populations.

4. **Pregnant Women and Infants**

One goal of "Healthy People 2000" is to significantly reduce infant mortality. As part of this effort, DHHS must collect and analyze data related to pregnant women and children. Research is required not only on trends in infant mortality among various population groups, but also on the impact of particular services on infant mortality. Research is needed to determine the best methods to provide care, how much care is required, what types of care are being received, and where care is being received.

A substantial amount of funding is provided for services to women and children through block grants. In the past, states were required to submit only limited amounts of information on how funds are spent and who received services, but OBRA 1989 amendments to Title V of the Social Security Act mandate collection of specific information from programs receiving block grant funds.

Specific kinds of data to be collected by state programs **in the future include:**

- **the number of children and families eligible,**
- the number served,

**TABLE 7
DATA FOR RURAL POPULATIONS**

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p><i>Data on rural populations need to indicate the following:</i></p> <p>(1) limitations in access to care,</p> <p>(2) the health and insurance status of rural populations,</p> <p>(3) the availability of providers in rural communities,</p> <p>(4) health care utilization and expenditures, and,</p> <p>(5) patterns of care</p>	<p align="center">(1)</p> <ul style="list-style-type: none"> . The Registry (2) - aged Medicare beneficiaries only . CBS (4) - Medicare beneficiaries only . NMES (17) <p align="center">(2)</p> <ul style="list-style-type: none"> . NMES (17) <p align="center">(3)</p> <ul style="list-style-type: none"> . NCH (1) - Medicare beneficiaries only . POS file (6) - Medicare beneficiaries only . NHCS (47) <p align="center">(4)</p> <ul style="list-style-type: none"> . The Registry (2) - aged Medicare beneficiaries only . CBS (4) - Medicare beneficiaries only . NMES (17) <p align="center">(5)</p> <ul style="list-style-type: none"> . The Registry (2) - aged Medicare eligibles only . CBS (4) - Medicare beneficiaries only . NMES (17) 	<p align="center">(1-5)</p> <ul style="list-style-type: none"> . There are little data available to adequately analyze health care issues specific to the rural population, particularly those under 65 years of age. Although there are no data collection systems focusing primarily on the rural population, HCFA administrative files and surveys can be matched to provide information on the rural population over 65 years of age. NMES also has a large sample size which provides data on rural populations.

- the types of services provided,
- the extent to which the Maternal and Child Health Bureau and the states are meeting these needs,
- a set of indicators showing effectiveness of health services and health status, and
- cost of services and programs.

An additional source of data on this population will be collected from local project areas participating in a new Presidential initiative entitled "Healthy Start." The program will focus sources to reduce infant mortality in ten communities over a five-year period beginning this year. The Department is interested in the development of data requirements at the local project area level, and an evaluation design to provide a comparative assessment of the progress and impact of the Healthy Start program across communities.

A current survey data initiative includes the 1990 Longitudinal Follow-up Survey (LFS) to the National Maternal and Infant Health Survey (NMIHS), which will be used to evaluate the impact of services on child health. The LFS will create a representative longitudinal data base for analyzing the information collected during the 1988 NMIHS by re-surveying previous respondents. Topics to be included are child development, effects of low birth weight, use of the Special Supplemental Food Program for Women, Infants, and Children (WIC), child nutrition, child neglect, barriers to pediatric care, environmental hazard exposures, and injuries. Questions will also be included on illicit drug use to provide information on the link between substance use during pregnancy and child development.

Table 8 on the following page describes data needs, data availability, and data limitations/gaps for pregnant women and infants.

5. Children

Children's health issues are another focus of DHHS programs and policies. The federal government provides funding for children's health care programs through block

**TABLE 8
DATA FOR PREGNANT WOMEN AND INFANTS**

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<ul style="list-style-type: none"> • Data on pregnant women and infants need to reveal the following: (1) medical effectiveness and costs of prenatal care, (2) utilization of pre-natal services by pregnant women, (3) sites of pre-natal care, (4) the relationship between minority group and infant mortality, (5) providers of pre-natal care, (6) barriers in access to care, (7) sources of financing pre-natal care, and (8) expenditures for pre-natal care 	<p align="center">(1)</p> <p align="center">(2)</p> <ul style="list-style-type: none"> • NMES (17) <p align="center">(3)</p> <p align="center">(4)</p> <ul style="list-style-type: none"> • NMIHS (40) - only Black persons were oversampled • • • 	<p align="center">(1-8)</p> <p>OBRAardized data in the past.</p> <p align="center">a r e m e e t i n g these needs,</p> <p>Five year period beginning this year e n t , i s</p> <p>activities at the local Project Area level, and an evaluation design to provide a comparative assessment of the progress and impact of the Healthy Start program across communities.</p> <ul style="list-style-type: none"> • Data will continue to be unavailable for private support of pre-natal care (charity care) through institutions, providers, and non-profit groups.

grants, the Medicaid program, migrant health care programs, and Head Start. There are still significant gaps, however, in our understanding of the health status of children, particularly preschool children.

Data are required describing the health status and special health care needs of children and their health care utilization patterns. Data describing the characteristics of children covered by the Medicaid vaccination program and the use of these services are also required. As discussed earlier, Medicaid data are not consistently collected across states and are not compiled at the federal level, thus limiting our understanding of the needs of this particular group.

Significant gaps exist with respect to our understanding of those who receive care through the Head Start Program and those who are enrolled in Medicaid. Data are required on the number of families eligible for the Head Start Program and the incidence of diseases and injuries among Head Start Program beneficiaries. Other useful information on this population group includes school readiness of pre-schoolers, sites of day care, and sources of day care funding.

As previously mentioned, data from the LFS will assist in meeting some data needs of those analyzing health care policy issues specific to children.

Table 9 on the following page summarizes data needs, data availability, and data limitations/gaps related to children.

6. Minorities

Health care utilization and expenditure survey instruments sometimes fail to adequately define minority and ethnic sub-group categories. Minorities of interest include Blacks, Hispanics, American Indians, Asian-Pacific Islanders, and Alaskan Natives. Substantial variation in health care needs is believed to exist within some of these subgroups. Many of those interviewed wanted data for Hispanic and Asian-Pacific Islander ethnic

TABLE 9
DATA RELATED TO CHILDREN

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• Data on children need to describe the following:</p> <p>(1) special health needs of children of various age groups,</p> <p>(2) number of families eligible for the Head Start Program,</p> <p>(3) incidence of diseases or injuries among Head Start Program beneficiaries,</p> <p>(4) the ages of children covered under the Medicaid vaccination program,</p> <p>(5) health care utilization,</p> <p>(6) school readiness, and</p> <p>(7) daycare sites and sources of day care payment</p>	<p>(1)</p> <ul style="list-style-type: none"> • NMES (17) • NHIS (27) - Child Health Supplement 1988 • LFS (41) • NHCS (47) <p>(2)</p> <ul style="list-style-type: none"> • SIPP (12) • NMES (17) • NHIS (27) • LFS (41) <p>(3)</p> <ul style="list-style-type: none"> • NMES (17) • NHIS (27) - Child Health Supplement 1988 • LFS (41) • NHCS (47) <p>(4)</p> <p>(5)</p> <ul style="list-style-type: none"> • LFS (41) • NHIS (27) - Child Health Supplement 1988 • NMES (17) • NHCS (47) <p>(6)</p> <p>(7)</p> <ul style="list-style-type: none"> • SIPP (12) • LFS (41) 	<p>(1)</p> <ul style="list-style-type: none"> • There are currently limited amounts of longitudinal data on the special health care needs of children, although the LFS to the NMIHS will provide an information base from which children's health care needs can be analyzed. <p>(2-3)</p> <ul style="list-style-type: none"> • Data are not collected from the Head Start Program on a routine basis. SIPP provides the most detailed information on income and government program participation such as AFDC and SSI which would assist in identifying families eligible for the Head Start Program, but there is no central data source which describes state-specific eligibility requirements for the Head Start Program. <p>(4)</p> <ul style="list-style-type: none"> • Medicaid beneficiary-specific data are not collected consistently across states and lack detail and consistency due to state-by-state variations in services covered, eligibility requirements and type of data collected. <p>(5)</p> <ul style="list-style-type: none"> • The NMIHS is not conducted on a routine basis, therefore, longitudinal utilization information are missing. <p>(6)</p> <ul style="list-style-type: none"> • There are no data which collect information on school readiness. Standardized definitions of school readiness need to be developed before data on school readiness are collected. <p>(7)</p> <ul style="list-style-type: none"> • Specific sites where child care is provided are limited in the SIPP survey to child's home, other private home, and other. The LFS to the NMIHS will provide an additional source of information on day care.

categories in more well-defined sub-groups by national origin (e.g., Mexican, Cuban, Honduran, Korean, and Vietnamese).

To identify special health care needs of minority populations, data are needed to describe the relationship between ethnicity, health status, and need for health care; the impact of health programs on minority health; and sources of care for minority groups. For each minority group, data allowing comparisons to other population groups are required. These data would assist policy analysts in developing programs and directing funds where they are most needed.

Data on the Indian population, those eligible for Indian Health Services (IHS) programs as well as others, should include information on the insurance status of this group and the availability of health care services by region. Currently, the IHS is exploring methods of integrating services provided to the Native American population with services provided to other groups of concern (including the rural population and other minority groups). Therefore data comparing this population to the general population in certain geographic areas are required.

Significant gaps exist in our understanding of the health care needs of these groups, how these needs are met, and what health care needs are unmet. Data on these populations are thought to be critical to understand and improve the health status of these groups. Because improving minority health will be a major effort of DHHS in the 1990s, data on these populations are required to provide baseline information and to evaluate the impact of programs designed to meet the needs of these groups.

Research in the area of minorities will be sponsored by NCHS as a result of the Disadvantaged Minority Health Improvement Act of 1990. The National Center for Health Statistics (NCHS) will sponsor research which will study new methods to assess the health of minorities. This research should be useful in future survey development. Furthermore, a

National Medical Expenditure Survey (NMES) supplement (the Survey of American Indians and Alaskan Natives-SAIAN) provides data on American Indian health as well as a mechanism for comparing their health care use and expenditures to that of the general population,

Data collection related to minority groups raises some important methodological considerations. Because of the small numbers in some of these sub-groups, lack of consistent definitions, and, in some cases, geographic location, surveys of these populations are difficult. Unless oversampling is used, national sample surveys that would allow comparison of these minority groups need to be fairly large. Furthermore, longitudinal studies of these populations are sometimes difficult because of issues related to mobility.

Table 10 on the following two pages summarizes data needs, data availability, and data limitations/gaps related to minority populations.

7. **Persons with Disabilities,**

Persons with disabilities are another population group of particular interest to researchers throughout DHHS. The Medicare and Medicaid programs, and several other public programs, provide funds for services to persons with disabilities. Because of the aging population, advances in medical technology, and other factors, the population with disabilities has been growing and represents an important area of research for DHHS. Increasingly, researchers are becoming interested in specific sub-groups of those with disabilities believed to require unique services. Data are also required on those receiving community-based care as well as institutionalized care.

Research questions related to this group include the following:

- What are the health care needs of persons with disabilities?
- What is the nature and extent of formal and informal services provided to those with disabilities?
- What kinds of resources are available to persons with disabilities?
- Where do persons with disabilities receive services?

TABLE 10
DATA FOR MINORITIES

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<ul style="list-style-type: none"> • <i>Data collected on minority populations are required which indicate the following minority groups:</i> <ul style="list-style-type: none"> - Blacks, - American Indians and Alaskan Natives, - sub-groups of Hispanics by national origin, and - sub-groups of Asian/Pacific Islanders by national origin • <i>For the minority groups listed above, data need to describe the following:</i> <p>(1) special health care needs,</p> <p>(2) barriers to care,</p> <p>(3) insurance status,</p>	<p style="text-align: center;">(1)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • NMES (17) - oversampled black persons • NHIS (27) - oversamples black persons • HHANES (42) - surveyed Mexican Americans, Cuban Americans, and Puerto Rican population groups <p style="text-align: center;">(2)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only. • CBS (4) - Medicare beneficiaries only • NMES (17) - oversampled black persons <p style="text-align: center;">(3)</p> <ul style="list-style-type: none"> • CBS (4) - Medicare beneficiaries only • CPS (11) - The March survey oversamples Hispanic persons • SIPP (12) • NMES (17) - oversampled black persons • NHIS (27) - oversamples black persons 	<p style="text-align: center;">(1-7)</p> <ul style="list-style-type: none"> • Data are lacking on Hispanic and Asian/Pacific Island ethnic sub-groups. Data need to be further broken down by national origin to reveal health care needs specific to ethnic sub-groups (e.g., Cuban, Mexican, Honduran, Korean, and Vietnamese). In addition, there is a lack of behavioral data on minority populations. The major health care surveys listed only oversample the black population. Future research in the area of minority populations will be sponsored by NCHS as a result of the Disadvantaged Minority Health Improvement Act of 1990. NCHS will sponsor research which will study new methods to assess the health of minorities.

DATA FOR MINORITIES
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>(4) Sources of payment for care received,</p> <p>(5) health care utilization patterns,</p> <p>(6) health care expenditures, and</p> <p>(7) availability of Indian health services by region</p>	<ul style="list-style-type: none"> . The Registry (2) - aged Medicare beneficiaries only . CBS (4) - Medicare beneficiaries only . CPS (11) - The march survey oversamples Hispanic persons . NMES (17) - oversampled black persons (5) . The Registry (2) - aged Medicare beneficiaries only . CBS (4) - Medicare beneficiaries only . NMES (17) - oversampled black persons . NHIS (27) - oversamples black persons (6) . The Registry (2) - aged Medicare beneficiaries only . CBS (4) - Medicare beneficiaries only . NMES (17) - oversampled black persons (7) . NMES (17) - Survey of American Indians and Alaskan Natives -SAIAN 	

- What are the costs of caring for those with disabilities?
- How do persons with disabilities finance the services they receive?
- How effective are services provided to those with disabilities?

In order to address these research issues, data are required that characterize the population with disabilities according to their age, race, assets and income (including that of their families), level of education, employment status, family support, participation in disability programs such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), and the nature and extent of disability.

No large-scale population surveys on disabilities have been conducted in DHHS since the 1978 Survey of Disability and Work, conducted by the Social Security Administration (SSA). However, the 1993 and 1994 NHIS supplements are to collect information on those with disabilities. Survey definitions of the various levels of disabilities have been problematic, but a variety of functional measures, particularly those about activities of daily living, have been widely accepted. And, of course, disability can be simply defined for many policy purposes as eligibility for benefits from SSDI and SSI. Further methodological work is needed in defining cognitive impairments and measures of disability in children and translating these concepts into concrete survey questions.¹⁴

Table 11 on the following three pages describes data needs, data availability, and data limitations/gaps related to persons with disabilities.

8. The Aged Population

The aged are a large and growing segment of the population, and they consume a disproportionate amount of health care services. The health care needs of this population are changing as advances in medical care allow us to sustain life. Furthermore, the needs of the

¹⁴The Department has convened a group to study data needs related to the population with disabilities. It is anticipated that the Departmental Coordinating Group on Disability Data will complete their report by mid-December 1991.

TABLE 11
DATA FOR PERSONS WITH DISABILITIES

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• Data are needed which characterize persons with disabilities <i>by</i> sub-groups according <i>to the</i> following:</p> <p>(1) demographic variables such as:</p> <ul style="list-style-type: none"> - age - race <p>(2) socioeconomic variables such as</p> <ul style="list-style-type: none"> - assets and income (for those with disabilities and their families) - level of education - employment status 	<p style="text-align: center;">(1)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - samples Medicare beneficiaries residing in nursing homes, those with disabilities, and those greater than 85 years old • UCDS (3) - Medicare beneficiaries only • CPS (11) • SIPP (12) • NBS (13) • NMES (17) - the Institutional Population Component (IPC) surveyed nursing homes and facilities for the mentally retarded (1,500 facilities) • NLTCS (25) - surveyed non-institutionalized chronically disabled Medicare beneficiaries • NNHS (26) - surveyed nursing home residents • LSA (49) - surveyed respondents from the 1984 NHIS survey who were 55 years of age or older. Additional follow-up telephone interviews were conducted for those age 70 or older. <p style="text-align: center;">(2)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • UCDS (3) - Medicare beneficiaries only • CPS (11) • SIPP (12) • NBS (13) • NMES (17) • NLTCS (25) - Medicare beneficiaries only • NNHS (26) - sampled nursing home residents only • LSA (49) - sampled respondents from the 1984 NHIS survey who were 55 years of age or older. 	<p style="text-align: center;">(I-11)</p> <ul style="list-style-type: none"> • Data are required that can indicate specific health care needs of population sub-groups of those with disabilities according to the following: <ul style="list-style-type: none"> - Mentally Retarded/Developmentally Disabled (MR/DD), and - Adults and children with physical disabilities • No large scale population surveys on the population with disabilities have been conducted by DHHS since the 1978 Survey of Disability and Work, conducted by SSA. Except for NMES and the NHIS, other surveys listed are specific to the Medicare population. Except for the CBS, there are no surveys that characterize the under 65 population with disabilities, particularly for those not residing in long-term care institutions. The CBS includes a sample of approximately 2,000 disabled Medicare beneficiaries under 65. Meanwhile, SIPP, CPS, and the NBS sample sizes are too small to provide statistically reliable data on those with disabilities.

TABLE 11
 DATA FOR PERSONS WITH DISABILITIES
 (continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>(3) family support, and</p> <p>(4) participation in disability programs such as SSDI, and SSI</p> <p>• Additional <i>data are needed which describe the following:</i></p> <p>(5) nature and extent of disability,</p> <p>(6) effectiveness of care provided to those with disabilities,</p> <p>(7) costs of rehabilitating persons with various levels of disabilities,</p>	<p>(3)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • NMES (17) • NLTCs (25) - samples Medicare beneficiaries only • LSA (49) - sampled respondents from the 1984 NHIS survey who were 55 years of age or older. <p>(4)</p> <ul style="list-style-type: none"> • CPS (11) • SIPP (12) • NBS (13) <p>(5)</p> <ul style="list-style-type: none"> • CBS (4) - Medicare beneficiaries only • NLTCs (25) - Medicare beneficiaries only • NHIS (27) - Disability Supplement 1993 and 1994 • NMES (17) • NHCS (47) <p>(6)</p> <p>(7)</p>	<p>(5-1 1)</p> <ul style="list-style-type: none"> • In addition, there is a lack of diagnostic tools to evaluate those with disabilities in the survey setting as well as a lack of consistent standardized definitions used across surveys indicating the following: <ul style="list-style-type: none"> - level of disability, - complexity of care, - developmental disabilities, - cognitive impairments, - neurological impairments, and - activities of daily living (level of functioning)

TABLE 11
DATA FOR PERSONS WITH DISABILITIES
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>(8) costs associated with care received at home,</p> <p>(9) lifetime health care expenditures,</p> <p>(10) health care utilization patterns, and</p> <p>(11) sources of payment</p>	<p style="text-align: center;">(8)</p> <ul style="list-style-type: none"> • CBS (4) - oversamples Medicare beneficiaries residing in nursing homes, those with disabilities, and those greater than 85 years old • NMES (17) - the Institutional Population Component (IPC) surveyed nursing homes and facilities for the mentally retarded (1,500 facilities) • NLTCS (25) - samples non-institutionalized chronically disabled Medicare beneficiaries <p style="text-align: center;">(9)</p> <ul style="list-style-type: none"> • CBS (4) - oversamples Medicare beneficiaries residing in nursing homes, those with disabilities, and those greater than 85 years old <p style="text-align: center;">(10)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - oversamples Medicare beneficiaries residing in nursing homes, those with disabilities, and those greater than 85 years old • NMES (17) - the Institutional Population Component (IPC) surveyed nursing homes and facilities for the mentally retarded (1,500 facilities) <p style="text-align: center;">(11)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - oversamples Medicare beneficiaries residing in nursing homes, those with disabilities, and those greater than 85 years old • NMES (17) - the Institutional Population Component (IPC) surveyed nursing homes and facilities for the mentally retarded (1,500 facilities) 	<p style="text-align: center;">(5-1 1 continued)</p> <ul style="list-style-type: none"> • There is also a lack of data on the mentally retarded/developmentally disabled receiving care in decentralized care settings such as congregate homes.

aged population vary by age group. Specifically, the frail elderly (those over age 85) require different resources than the young elderly. Long-term care (nursing home and home health services for the chronically ill elderly) has been a major focus of research as public expenditures on long-term care have increased. Methods of financing care for the aged are being considered and explored, and data are required to address these issues.

Research in this area requires longitudinal data that characterize the aged population according to income, assets, health expenditures, consumption measures, intrafamilial transfer of funds, and utilization of services not covered by public programs. Data are also required that allow research on the changing needs of the aged as they grow older. Surveys of the elderly population must provide information on segments of the elderly including those 65-74, 75-84, and 85 years and over. Data required in this area include longitudinal information to determine how health care needs change over time. Some of this information is available from HCFA administrative data, while the CBS and the Registry will provide additional longitudinal information. Data gaps will remain, however, related to particular diagnoses, and use of services not covered by the Medicare program. Further information on the income and assets of each of these groups are also needed.

Table 12 on the following two pages describes data needs, data availability, and data limitations/gaps related to the aged population.

9. **The Long-term Care Population**

Key issues over the next five to ten years related to long-term care include:

- the viability of private long-term care financing,
- the effects of budgetary limitations on access to nursing home beds on a state-by-state basis,
- the financial burden of long-term care and its effect on the use of formal and informal care,

**TABLE 12
DATA FOR THE AGED POPULATION**

D & a Needs.	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• <i>Data are needed which characterize the aging population according to the following:</i></p> <p>(1) health status,</p> <p>(2) income and assets,</p> <p>(3) medical care expenditures,</p>	<p align="center">(1)</p> <ul style="list-style-type: none"> • The Registry (2) • CBS (4) - oversamples Medicare beneficiaries greater than 85 years old • UCDS (3) - Medicare beneficiaries only • NMES (17) • NLTCS (25) - surveyed non-institutionalized chronically disabled Medicare beneficiaries • NNHS (26) • NHCS (47) • LSA (49) - surveyed respondents from the 1984 NHIS survey who were 55 years of age or older. Additional follow-up telephone interviews were conducted for those age 70 or older. <p align="center">(2)</p> <ul style="list-style-type: none"> • The Registry (2) • CBS (4) - oversamples Medicare beneficiaries greater than 85 years old • CPS (11) • SIPP (12) • NBS (13) • NMES (17) • NLTCS (25) • LSA (49) - income only <p align="center">(3)</p> <ul style="list-style-type: none"> • The Registry (2) • CBS (4) - oversamples Medicare beneficiaries greater than 85 years old • NMES (17) • NLTCS (25) • NNHS (26) • NHCS (47) 	<p align="center">(1-6)</p> <ul style="list-style-type: none"> • There is a lack of longitudinal data describing the elderly population at various stages of aging, particularly for the oldest age group (age 85 and over). The CBS oversamples this age group and provides more descriptive data than is currently available. There are also limited data on the elderly enrolled in HMOs as well as those receiving care in decentralized settings. The NHCS will assist in providing information on the aged population receiving care in decentralized settings in the future when the survey is expanded to include board and care homes, hospices, ambulatory surgical centers, and home health agencies. • The sample sizes from the CPS, SIPP, and NBS are too small to provide statistically reliable data on the aged population.

TABLE 12
DATA FOR THE AGED POPULATION
(continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
(4) sources of payment,	<ul style="list-style-type: none"> • • CBS (4) • • NLTCS (25) • • • • CBS (4) greater than 85 years old • NMES (17) • NLTCS (25) - surveyed non-institutionalized chronically disabled Medicare beneficiaries • NNHS (26) • NHCS (47) <p style="text-align: center;">(6)</p> <ul style="list-style-type: none"> • CBS (4) - oversamples Medicare beneficiaries greater than 85 years old • NMES (17) 	

- labor supply availability in caring for the long-term care population and the substitution of technology for people, and
- the extent to which lifestyle can mediate the need for long-term care.

The characteristics of the elderly and non-elderly population requiring long-term care by race, education, and income must be determined. Data are needed that indicate the financial burden of care placed on spouses and families of those requiring long-term care, the availability of beds for the provision of long-term care by region, the impact of long-term care benefits on expenditures, and the point at which long-term care Medicaid "spend-down" occurs for new nursing home residents. To develop appropriate data collection instruments, consistent standardized definitions of activities of daily living and instrumental activities of daily living (ADLs/IADLs) are needed to indicate the level of functioning at which community care can be provided versus facility-based care.

Data continue to be required on the non-elderly population requiring long-term care services and on the characteristics of facilities providing long-term care services. Significant data gaps exist with respect to non-traditional and newly emerging types of long-term care services including board and care homes, day care, and home health care.

The National Health Care Survey (NHCS) will gather data on care received from board and care homes, hospices, and home health agencies when these sites of care are added to the Long-Term Care and Health Provider Inventory Components of the NHCS. The goals of the NHCS are to expand data collection into alternative health care settings, provide greater analytical capabilities by use of an integrated cluster sample, establish annual data collection for each health care setting, and provide patient follow-up studies. However, information will only be obtained on patients at specific facilities surveyed, and will not include care provided by a range of facilities or other health care providers. It is anticipated that all components of the NHCS will be conducted annually by 1993, although some sites of care will not be added until after this date. Data gaps will remain, however, relative to the financing of care and the

availability of these services, Furthermore, the CBS will address issues related to the income and assets of the Medicare population requiring long-term care as well as use of uncovered services which may substitute for institutionalization. The CBS will allow researchers to analyze the patterns of use leading to the need for long-term care.

Table 13 on the following two pages summarizes data needs, data availability, and data limitations/gaps related to the long-term care population.

10. Alzheimer's Patients

Individuals with Alzheimer's disease require special types of resources and increasing amounts of care over a long period of time. In our interviews, this group was specifically identified although it clearly overlaps with the population requiring long-term care (discussed above), Data collection on Alzheimer's patients creates particular problems, and this group may require different types of care than other groups requiring long-term care. As a result, researchers have a special interest in analysis of data for this population group.

Data are required related to the numbers and characteristics of individuals with the disease, the types of services required, and the associated costs. Information is also necessary on the family support provided to these patients and the availability of regional health care services to meet health care needs and other needs of these patients and their caregivers.

Data for this patient population are not currently available, although there have been several regional studies providing some of the required data. National sample surveys are probably not appropriate for this group because of the relatively small universe. However, data on a more representative population than is currently available are required.

There are substantial methodological problems associated with data collection for this group. First, diagnosis of the condition is not performed uniformly across physicians or geographic area. Second, it is difficult to identify these patients on survey data because

TABLE 13
DATA FOR THE LONG-TERM CARE POPULATION

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<ul style="list-style-type: none"> • <i>Data related to long-term care issues need to characterize the elderly and non-elderly long-term care population according to the following:</i> <p>(1) demographic variables such as race, and</p> <p>(2) socioeconomic variables such as education, and income</p> <ul style="list-style-type: none"> • <i>Data are also needed which indicate the following:</i> <p>(3) the financial burden of long-term care and its effect on the use of formal and informal care,</p> <p>(4) the availability of long-term care providers by region,</p>	<p align="center">(1)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • NMES (17) • NLTCS (24) - Medicare beneficiaries only • NNHS (26) • NHCS (47) • SIPP (12) <p align="center">(2)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • NMES (17) • NLTCS (24) - Medicare beneficiaries only • SIPP (12) <p align="center">(3)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • NMES (17) • NLTCS (24) - Medicare beneficiaries only <p align="center">(4)</p> <ul style="list-style-type: none"> • POS file (6) - Medicare beneficiaries only • NNHS (26) • NHCS (47) 	<p align="center">(1-9)</p> <ul style="list-style-type: none"> • Data are not available which adequately characterize the long-term care population, particularly those under 65 years. In addition, data are missing on facility characteristics and services received in decentralized settings such as Board and Care Homes, although the NHCS will be adding decentralized health care settings to its survey components in the future.

TABLE 13
DATA FOR THE LONG-TERM CARE POPULATION
 (continued)

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>(5) the effects of budgetary limitations on access to nursing home beds on a state-by-state basis,</p> <p>(6) the viability of private long-term care financing,</p> <p>(7) the level of functioning at which community care can be provided versus facility based care,</p> <p>(8j) the impact long-term care benefits have on expenditures, and</p> <p>(9) the time period at which Medicaid spend-down occurs for the long-term care population</p>	<p style="text-align: center;">(5)</p> <p style="text-align: center;">(6)</p> <ul style="list-style-type: none"> • CBS (2) - Medicare beneficiaries only <p style="text-align: center;">(7)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • LSA (49) - sampled respondents from the 1984 NHIS survey who were 55 years of age or older <p style="text-align: center;">(8)</p> <ul style="list-style-type: none"> • CBS (4) - Medicare beneficiaries only <p style="text-align: center;">(9)</p> <ul style="list-style-type: none"> • CBS (4) - Medicare beneficiaries only 	

diagnosis codes for Alzheimer's disease fall within the general codes for senility. Furthermore, because treatment for this disease is changing rapidly, data related to the use and cost of health care services will be quickly outdated. Those interviewed believed, however, that because of the resources that will be required over the next few years for treatment of this disease, it is important to develop methods to collect data on this population group. The best methods may include funding of special studies or disease-specific registries to gather data on this population.

Table 14 on the following page describes data needs, data availability, and data limitations/gaps related to Alzheimer's patients.

11. The HIV-Infected Population

Significant federal resources are being devoted to the HIV-infected population. This patient group requires significant health care resources over the period of the disease. Treatment advances are rapid; therefore patterns of care are changing quickly.

Because of the unique characteristics of this disease, data are required on the characteristics and health care needs of the HIV-infected population. Data are also required that indicate the relationship between behavioral patterns and disease incidence. Behavioral data will assist policy analysts in determining why trends exist and how to effect changes in high-risk behavior.

Currently there are limited longitudinal, behavioral, and prevalence data for the HIV-infected population. A new pilot study, the AIDS Cost and Service Utilization Survey (ACSUS) conducted by AHCPR, will survey a sample of approximately 2,000 adults and adolescents and 400 children. This survey will provide longitudinal data on persons with AIDS and HIV-related illness, and those HIV positive but without AIDS in the Fall of 1991. Data collected by ACSUS will include information on the following:

**TABLE 14
DATA FOR ALZHEIMER'S PATIENTS**

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• Data on Alzheimer's patients are needed to indicate the following:</p> <p>(1) the number of individuals with Alzheimer's disease,</p> <p>(2) the types of services required by Alzheimer's patients and their associated costs, and</p> <p>(3) availability of regional health care services for the provision of care to Alzheimer's patients</p>	<p style="text-align: center;">(1)</p> <ul style="list-style-type: none"> • The Registry (2) • UCDS • CBS (4) • NMES (17) <p style="text-align: center;">(2)</p> <ul style="list-style-type: none"> • The Registry (2) • CBS (4) • NMES (17) • NLTCS (25) • NNHS (26) • NHCS (47) <p style="text-align: center;">(3)</p> <ul style="list-style-type: none"> • POS file (6) • NMES (17) • NNHS (26) • NHCS (47) 	<p style="text-align: center;">(I-3)</p> <ul style="list-style-type: none"> • Diagnosis is not performed uniformly by physicians and across geographic areas. Individuals with Alzheimer's disease are difficult to identify on survey data because diagnosis codes for Alzheimer's disease falls within the general codes for senility.

- charges for the services of physicians, nurses, and other health care professionals as well as charges for drugs, medical supplies, and devices,
- services provided by volunteers,
- third-party and out-of-pocket payments for inpatient and outpatient care received in physicians' offices, ambulatory clinics, and patients' homes, and
- patient employment history and income.

ACSUS will also provide comprehensive, patient-based data including socio-demographic characteristics, HIV exposure category, severity of illness, and quality of life. Patient interview data will be supplemented by information supplied by providers and insurers. It is the intent of AHCPH to convert ACSUS into an ongoing survey of people with AIDS and other HIV-related illnesses, and those who are asymptomatic. AHCPH plans to add an additional 100 women to the sample.

An additional survey, the National Household Seroprevalence Survey (NHSS), was to sample persons aged 18 to 54 years. In addition to the collection of a blood specimen, questionnaire items included indicators for sexually-transmitted diseases, hemophilia, blood transfusions, intravenous drug use, and sexual practices and history. Although a national survey is not planned, those involved with the pilot study state that useful information was gathered on risk behaviors.

Other data collection efforts gather data from state and local health Departments, and publicly-funded HIV counseling and testing sites. Data are collected on the incidence and prevalence of cases, including demographic and risk factors. These data are used to determine trends in HIV positivity in drug users and other high-risk persons.

ACSUS will greatly assist in meeting the demand for longitudinal data on treatment outcomes and associated costs to analyze effectiveness of care provided to AIDS patients and those HIV infected. ACSUS will also provide data on sources of financing lifetime costs

of care and out-of-pocket expenditures. Despite ACSUS, gaps will continue to exist related to HIV prevalence (particularly among those asymptomatic) and behavioral data indicating high risk behavior.

Table 15 on the following page describes data needs, data availability, and data limitations/gaps related to the HIV-infected population.

12. **Summary of Significant Data Gaps**

For each of the population subgroups, major data needs were discussed along with planned data collection efforts designed to fill some of these gaps. Remaining gaps in data availability were also noted. This analysis has indicated that there is a need for a wide range of data for each of the sub-groups discussed.

In general, data are required related to:

- the health care needs of the various population groups,
- current sources of care for these groups,
- demographic and socioeconomic data, including data related to the ability of these groups to finance care, and
- use of public programs in order to obtain necessary health care.

Where a group with a particular clinical condition is considered, data on the types of care required, the effectiveness of the care, and the availability of care are also required.

Problems associated with data collection related to each of these population groups depend upon the size of the group, the availability of common definitions describing the group, and the availability of health status indicators that address their particular condition. For example, it is easier to develop a survey instrument for the various subgroups of the elderly, defined by age, than it is to collect data related to those with disabilities, where common definitions have not yet been developed.

TABLE 15
DATA FOR THE HIV-INFECTED POPULATION

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• Data on the HIV-infected and AIDS population need to reveal the following:</p> <p>(1) treatment outcomes and associated costs to analyze effectiveness of care issues,</p> <p>(2) characteristics of providers serving this population,</p> <p>(3) behavioral data to indicate trends and high-risk behavior,</p> <p>(4) sources of financing,</p> <p>(5) lifetime costs of care, and</p> <p>(6) seroprevalence of the AIDS virus</p>	<p>(1) • ACSUS (43)</p> <p>(2) • POS file (6) • NHCS (47)</p> <p>(3) • NHSS (46) • AIDS Case Surveillance (44) • NHIS - (27) 1988, 1989, 1990, 1991, and 1992 AIDS Supplement</p> <p>(4) • ACSUS (43)</p> <p>(6) • ACSUS (43)</p> <p>(6) • AIDS Case Surveillance (44) • HIV Counseling and Testing System (45)</p>	<p>(1-7) • Longitudinal and behavioral data are lacking on the HIV-infected population, although longitudinal data from ACSUS will assist in meeting many research data needs and will be available Fall of 1991. NHIS has been focusing questionnaire supplements on respondents knowledge of and attitude towards AIDS and will continue to provide additional behavioral data.</p>

The size of the particular population sub-group also has an impact on the data collection approach used and the resources required to collect the information. Some groups are so small that a separate survey would be required, and in fact, the sampling frame may be difficult to determine. For these groups, smaller sub-national research studies are required to gather enough information to enable researchers to address program and policy issues related to these groups. For other groups, national sample surveys can be used to identify these groups and obtain nationally representative samples,

All of these issues should be considered when developing recommendations regarding data collection for these groups. Criteria for determining how and how often data will be collected for each of these groups must be developed. This issue is discussed in greater detail in later sections of this report.

C. OTHER RESEARCH AREAS

Additional research areas identified in our interviews include a wide range of cross-cutting issues that affect a variety of population sub-groups and health care programs. These include the following:

- Federal and state program interactions,
- Medical effectiveness/cost effectiveness,
- State and local flow of funds, and
- Prescription drugs,

This section identifies the major research questions associated with these areas, data available for analysis as well as data initiatives addressing these research issues, and data gaps.

1. **Federal and State Program Interactions**

Individuals throughout DHHS are interested in research on the interactions between federal and state programs. Specifically, there is interest in analyzing the following interactions that affect the availability of services:

- state-by-state variability in Medicaid eligibility requirements and SSI enrollment,
- the effects of Medicaid transitional benefits and enrollment in Aid to Families with Dependent Children (AFDC),
- SSDI and Medicare utilization,
- child support and the provision of health care insurance,
- Medicaid funding of services provided by special education,
- education, health, and social services integration, and
- indicators of welfare dependency to assist analysts in better predicting welfare program enrollment levels.

To permit analyses of these various interactions, administrative records, such as HCFA administrative data, Social Security records, and Internal Revenue Service summary earnings record need to be matched. Such matching is currently hampered by confidentiality rules. In addition, consistent Medicaid data on a state-by-state basis are not available to allow adequate analysis of interactions between federal programs and state Medicaid programs,

Table 16 on the following page describes data needs, data availability, and data limitations/gaps related to federal and state program interactions.

2. **Medical Effectiveness/Cost Effectiveness**

In an effort to contain the growing national costs of providing health care, DHHS has recently initiated several programs designed to establish guidelines for particular services. These efforts were developed in response to research that indicated a wide range in the number and types of services provided across geographic regions. The development of

**TABLE 16
DATA FOR FEDERAL AND STATE PROGRAM INTERACTIONS**

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p><i>Data are needed to indicate the interaction between Federal and State programs related to the following:</i></p> <p>(1) state-by-state variability in Medicaid eligibility requirements and Supplemental Security Income (SSI) enrollment,</p> <p>(2) effects of Medicaid transitional benefits and enrollment in Aid to Families with Dependent Children (AFDC),</p> <p>(3) Social Security Disability Insurance (SSDI) and Medicare utilization,</p> <p>(4) child support and the provision of health care insurance,</p> <p>(5) Medicaid funding of services provided by special education,</p> <p>(6) education, health, and social services integration, and</p> <p>(7) indicators leading to welfare dependency to assist analysts in better predicting Welfare Program enrollment levels</p>	<p align="center">(1)</p> <ul style="list-style-type: none"> • CBS (2) • EDB (7) • Tape-to-tape (10) <p align="center">(2)</p> <ul style="list-style-type: none"> • CPS (11) • SIPP (12) <p align="center">(3)</p> <ul style="list-style-type: none"> • NCH (1) • CBS (2) • EDB (7) • SIPP (12) <p align="center">(4)</p> <ul style="list-style-type: none"> • SIPP (12) <p align="center">(6)</p> <ul style="list-style-type: none"> • HCFA 2082 report (8) • MSIS (9) • Tape-to-tape (10) for California, Michigan, Tennessee, and Georgia only <p align="center">(6)</p> <p align="center">(7)</p> <ul style="list-style-type: none"> • CPS (11) • SIPP (12) 	<p align="center">(1-7)</p> <ul style="list-style-type: none"> • There is an inability to match Health Care Financing Administration records, Social Security records and Internal Revenue Service summary earnings records due to confidentiality issues, thereby limiting analyses of federal program enrollment interactions. • Analysis of Medicare and Medicaid program enrollment interactions is also limited because beneficiary specific data are not collected consistently across states or compiled at the federal level. Meanwhile, Medicaid data which are submitted at the Federal level lack detail and consistency due to state-by-state variations in services covered, eligibility requirements, and type of data collected. • Finally, additional information on state and local programs and the associated flow of funds are needed to gather information on education, health and social service integration, See table 18 for additional data needs specific to state and local flow of funds.

treatment guidelines requires data that can be used to identify the outcomes associated with a particular course of treatment and the effectiveness of particular treatment alternatives.

Data required include longitudinal, patient-specific clinical information, such as patient health status, treatment received, and appropriate follow-up information. Data collection efforts must be preceded by the development of appropriate indicators of outcomes. A previous section described the efforts related to the study of medical effectiveness for the Medicare population. DHHS, however, is interested in extending these research efforts to other population groups. This will require the development of data bases similar to the UCDS and the Registry, but for other populations. The feasibility of such data collection is being studied, with interest focused on issues related to government use of private insurance claims data.

Smaller research studies may also be useful in developing data on the effectiveness of particular procedures and technology. These studies might be similar to traditional clinical effectiveness studies comparing various treatments using randomized clinical trials. AHCPR is currently using this approach in the PORT studies where several conditions are being carefully examined relative to treatment effectiveness and the outcomes associated with particular procedures. Other studies being sponsored by AHCPR are collecting information related to particular patient conditions.¹⁵

Individuals at DHHS are also interested in determining the cost effectiveness of particular new treatments. Data collection in this area will require detailed information on the cost of illness, population health status, incidence of particular diseases, and measures of the indirect, cost of illness.

¹⁵See Appendix D for a list of conditions studied by PORT teams.

There are major gaps in data availability related to the non-Medicare population. Despite some efforts to collect this information, these gaps are likely to remain, at least in the short term.

Table 17 on the following page summarizes data needs, data availability, and data limitations/gaps related to medical effectiveness and cost effectiveness issues.

3. **State and Local Flow of Funds**

In order to gain a better understanding of the full range of health care services provided to the U.S. population and the financing of those services, data are needed on the flow of state and local health care funds. These data should describe ways in which state and local municipalities finance the health care services they provide, what health care services are provided, and the characteristics of recipients of this care. Data on these issues are necessary to identify limitations in access to care for the uninsured, indigent, and poor. In addition to publicly funded services, a wide range of private services are provided to those who cannot afford care and members of particular population groups.

To gather such information, however, a common data set would have to be developed and collected. The first step in development of this data set is the introduction of standard definitions of population groups, types of services, and financing mechanisms. Some efforts have been made to develop common definitions, but no effort is currently underway to collect a consistent set of data from all local, regional, and state level governments.

Table 18 on the following page summarizes data needs, data availability, and data limitations/gaps related to state and local flow of funds.

4. **Prescription Drugs**

An increasing percentage of total health care dollars is spent on pharmaceuticals. This has led to interest in research focused on the cost of pharmaceuticals to consumers. The Medicare Catastrophic Coverage Act, subsequently repealed, would have expanded

TABLE 17
DATA RELATED TO MEDICAL/COST EFFECTIVENESS ISSUES

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p>• <i>In order to conduct studies on the medical/cost effectiveness of new technologies and medical procedures, data are needed which characterize specific diseases and medical conditions according to the following:</i></p> <p>(1) costs of illness (including indirect costs), morbidity, and premature mortality,</p> <p>(2) incidence, and prevalence of particular diseases,</p> <p>(3) financial burden of care,</p> <p>(4) patterns of care over time, and</p> <p>5) outcomes of care</p>	<p align="center">(1)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • UCDS (6) - Medicare beneficiaries only • PORTS (50) • PHOS (51) - Medicare beneficiaries only • NHCS (47) - patient follow-up component <p align="center">(2)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • UCDS (6) - Medicare beneficiaries only <p align="center">(3)</p> <ul style="list-style-type: none"> • CBS (2) - Medicare beneficiaries only • NMES (17) • NLTCS (25) - Medicare beneficiaries only <p align="center">(4)</p> <ul style="list-style-type: none"> • The Registry (2) - aged Medicare beneficiaries only • CBS (4) - Medicare beneficiaries only • UCDS (6) - Medicare beneficiaries only • PORTS (50) • PHOS (51) - Medicare beneficiaries only • NHCS (47) - patient follow-up component <p align="center">(5)</p> <ul style="list-style-type: none"> • NHCS (47) - patient follow-up component • PORTS (50) • PHOS (51) - Medicare beneficiaries only 	<p align="center">(1-5)</p> <ul style="list-style-type: none"> • Data are needed which contain more refined and detailed diagnostic categories. In addition, quality of life and episode of care measures need to be developed. Indirect costs associated with illness such as loss of work days are also needed. Finally, there are limited data available to analyze medical effectiveness and cost effectiveness of medical treatment for the non-Medicare population.

TABLE 18
 DATA RELATED TO STATE AND LOCAL FLOW OF FUNDS

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<p><i>Data are needed which describe the flow of funds at the state and local level, and indicate the following:</i></p> <ul style="list-style-type: none"> (1) the amount of philanthropic health care provided, (2) the amount of "pass through" funds (e.g., block grants) used in financing health care services, (3) the amount of state taxes forgone in subsidizing risk pools, (4) the amount of funds from state and local tax bases used for financing health care for the indigent and poor, (5) the amount and types of health care services being funded and the health care issues they address, and (6) characteristics of recipients of state and local health care services according to income, age, and race 		<p style="text-align: center;">(1-6)</p> <p>There are no data collected at the federal level on state and local flow of funds related to health care programs funded through block grants as well as state and local support for health care. In addition, there is a lack of data on private support for health care by institutions, providers, and non-profit groups. To gather such information, a common data set would have to be developed and collected. Standard definitions of population groups, types of services, and financing mechanisms would be required before a data collection system was implemented.</p>

Medicare coverage to include prescription drugs to relieve the financial burden imposed by the cost of drugs, particularly on the chronically ill. Unfortunately, however, there is little information on what the cost of providing this benefit would have been. Information needed to assess this cost includes data on the use of prescription drugs as well as current payment sources.

Medicaid program data would provide some of this information if claims data were available. The CBS will provide data on prescription drug utilization and spending among Medicare beneficiaries, collecting data on drug use by type of drug as well as expenditure information. A large gap exists, however, on information in this area, particularly for the low-income population.

Table 19 on the following page summarizes data needs, data availability, and data limitations/gaps related to prescription drug issues.

TABLE 19
DATA RELATED TO PRESCRIPTION DRUG ISSUES

Data Needs	Data Availability (see Appendix D for explanation of databases)	Data Limitations/Gaps
<ul style="list-style-type: none"> • <i>Data are needed which are able to describe the economic burden of prescription drug payments on the elderly and poor, and options for reimbursement of drugs in the outpatient setting</i> 	<ul style="list-style-type: none"> • NMES (17) • NHIS (27) - includes questions on prescription drug use intermittently • CBS - Medicare eligibles only (4) 	<ul style="list-style-type: none"> • Currently, there are no prescription drug utilization and expenditure data collected on a regular basis. The CBS will collect this information on the Medicare population; however, a large gap will continue to exist for the low-income population.

CHAPTER THREE

OPTIONS AND RECOMMENDATIONS

This chapter provides options and recommendations for the HHS Data Planning and Analysis Working Group to consider in addressing the major data gaps facing DHHS in the 1990s.

Options for eliminating data gaps were developed in one of two ways. First, some options were suggested in one or more interviews, or were identified in one or more of the reports reviewed. Other options were developed by Lewin/ICF in response to data gaps discussed in interviews or reports. The criteria used to develop the recommendations are presented in the next section,

It is important to note that the recommendations assume that the data collection activities already under development are implemented. These activities include the continuation and expansion of the UCDS, development of the Registry, and the refinement of the Medicare Part A and B data bases. In addition, we assume that the Current Beneficiary Survey (CBS), the National Health Interview Survey (NHIS), the National Health Care Survey (NHCS), and other NCHS data bases that are routinely collected, continue to be regularly funded. Although we made this assumption, it should be noted that those interviewed by Lewin/ICF emphasized the importance of routinely collecting and funding health care utilization and expenditure data and that ongoing surveys, such as the NHIS, not be taken for granted. Finally, where changes to these data bases are recommended, they are discussed in the recommendations.

We were also asked to identify any duplication of data collection activities or areas where excessive data were being collected. As stated earlier, no Departmental personnel interviewed were able to identify areas of data duplication, and uniformly felt that while additional data collection efforts were required, there were none that should be eliminated.

After presenting specific data collection options and recommendations, other suggestions regarding data collection efforts being undertaken by DHHS are provided. While these do not involve any new data collection efforts, they may represent changes in the methods of disseminating information or sharing of data across DHHS.

A. **CRITERIA USED TO DEVELOP AND PRIORITIZE DATA COLLECTION ACTIVITIES**

Interviews and a review of the literature identified a number of data collection activities that would assist in filling the gaps identified in the previous chapter. Recommendations have been developed based upon our assessment of the data needs of DHHS and the strategies most likely to meet these needs.

A data collection activity could be designed to fill each of the gaps identified in the previous chapter. Some, however, are not feasible or practical. As a result, we have chosen several specific areas to discuss here. Some were identified by those interviewed by Lewin/ICF, while others were based upon our review of the data needs of DHHS. The HHS Data Planning and Analysis Working Group, however, must evaluate these options and choose those that both meet data needs and match available Departmental resources.

Most of those interviewed within DHHS agreed there has been an underinvestment in data collection over the last decade. Everyone interviewed believes that policy development activities would benefit from the availability of additional information. This had led to some recent new efforts to collect necessary data, many of which have been discussed in Chapter Two. It is also clear that there are not sufficient resources to regularly collect all the data desired by researchers. Some effort must be made to prioritize these needs.

To prioritize recommendations related to data collection efforts, Lewin/ICF established three criteria. The criteria have been developed to identify collection efforts that would most effectively meet DHHS needs for health care utilization and expenditure data in the 1990s. These criteria identify data collection efforts that would accomplish the following:

- **fill data gaps that were most frequently identified in reports and interviews across organizational entities** -- Lewin/ICF reviewed a wide range of reports and conducted many interviews across DHHS. There were several data gaps that were uniformly identified across all of these sources. We believe that data collection efforts should focus on those most likely to meet the needs of a wide range of researchers and policy makers.
- **provide the data necessary to analyze the policy issues outlined in "Healthy People 2000" and the Secretary's Program Direction Plan being implemented by the Office of the Assistant Secretary for Planning and Evaluation** -- DHHS is currently engaged in several activities designed to improve the health of the American people and evaluate the impact that DHHS programs have on health status. While the primary focus is on health monitoring, "Healthy People 2000" did identify a series of goals related to health care utilization and expenditures, and we believe that it is important to collect the data that can be used to measure achievement of these goals and develop programs to achieve these goals. For example, one of the goals relates to infant mortality. In this case, we recommend the collection of data that would measure infant mortality across various populations and determine which programs might be useful in reducing infant mortality within various population groups.
- **provide data that could be used to fill the most data gaps either because the data address cross-cutting policy issues of interest to several agencies, or are relatively easy to collect by making minor changes to existing surveys or program data collection activities** -- In developing our recommendations, we identified several data collection activities that would serve the research needs of a wide range of analysts across DHHS. Cross-cutting policy issues of interest include long-term care, the population with disabilities, medical effectiveness, and managed care, in addition to general health monitoring and assessment. These issues were identified by many of those interviewed and were identified across agencies. In addition, several recommended data collection activities could fill several gaps and require relatively little additional resources.
- **provide data that are useful for general public health monitoring** -- all things being equal, surveys which provide data appropriate to monitor the health of the general population and subgroups thereof, are preferred.

In developing our recommendations to the HHS Data Planning and Analysis Working Group, we first identified data collection activities that might fill the gaps identified in the previous chapter. We then considered whether the data collection activity was feasible; in other words, if undertaken, would useful data meeting researchers' and policy makers' needs result from

the activity? We then applied the criteria above to determine the priority for data collection activities. As requested by the working group, our recommendations are based on technical considerations rather than cost.

The following section presents the major identified gaps. For each data gap, one or more options are presented, and Lewin/ICF's recommendation is identified.

B. OPTIONS AND RECOMMENDATIONS FOR DHHS DATA COLLECTION ACTIVITIES

1. Medicaid/Low-income Data

Several existing DHHS programs provide health care services to those who cannot afford health care or insurance to pay for this care. Because of this, analysis of issues related to the low-income population are a major focus of research within DHHS. Many of the data gaps identified relate to the low-income population and subgroups within this population. Issues related to this population and subgroups of this population are considered widely across all DHHS agencies. As a result, data collection related to this group is critical to policy decisions that will be required over the next decade.

There are several options that could be pursued in order to collect information about the low-income population. These include:

- collecting consistent Medicaid claims data from each state,
- routinely conducting a survey of the low-income population, and
- oversampling the low-income population in existing survey efforts,

Each of these options are discussed below.

a. Collecting Medicaid Claims *Data*

To receive federal matching Medicaid funds, regulations require that each state Medicaid agency implement and maintain a Medicaid Management Information System (MMIS). This system must include a detailed history of paid claims, including such data items

as provider and recipient identification numbers, dates and types of service utilization, diagnoses, and reimbursements for all Medicaid services.

States use their **MMIS** data systems to develop a summary report on Medicaid program activities. They are required to submit this summary report (HCFA-2082 report) unless they participate in the **MSIS** project. The 21 states that voluntarily participate in the **MSIS** project provide quarterly files of beneficiary-specific data from their **MMIS** data systems, detailing Medicaid utilization and participation. Data from **MSIS** are used by HCFA to generate aggregate information for these states that are otherwise provided in the HCFA-2082 report.

Requiring all states to participate in the **MSIS** project would provide state-by-state beneficiary-specific data on Medicaid eligibility, service receipt, **utilization**, and payment. In addition to providing national aggregate estimates, these data would allow DHHS to estimate the impact of changes to the program more accurately, analyze utilization patterns of the Medicaid population, and better forecast program expenditures.

To accomplish this objective successfully, several issues must be addressed. First, DHHS would need to redefine its role in relation to data collection at the state level and develop federal standards for state data collection. In addition, federal funding for these additionally required data collection activities would be required as well as a major effort in data quality assurance to maximize consistency and completeness. This would require a substantial change in state and federal relationships as well as agreement at the federal level that such data are required.

Second, once received, the data would have to be compiled in such a way that data could be processed efficiently. The **MSIS** data base would need to be revised so the data could be effectively used for conducting research. This may require development of methods

to generate a nationally representative data base. In addition, public use files should be developed and made available to the research community.

In many respects, this recommendation is intended to encourage the development of Medicaid data comparable to the Medicare data that have been available to researchers for many years. The Medicare data bases provide two sets of data useful for research -- the provider-based data sets and the claims-based data sets (covering both Part A and Part B claims). These data sets have been invaluable in developing information related to utilization and expenditures of the elderly population and for analyzing Medicare program policy. Similar data bases for the Medicaid population could be expected to provide a comparable wealth of information related to the indigent.

There are clearly many problems related to collection of Medicaid data. First, HCFA has worked for many years to develop Medicaid data. The current data collection system is a result of this effort. Further progress will require an even greater commitment of resources as well as a willingness to both require and support state efforts in this area.

Second, the volume of data would be very large. Therefore, methods to consolidate the information must be developed. To be useful across DHHS, data on demographic and socioeconomic status of beneficiaries would also be required, necessitating the development of consistent definitions and formats.

To provide beneficiary-specific data on utilization and expenditure trends as well as factors affecting enrollment/disenrollment in and out of the Medicaid program, beneficiary identification numbers would need to be assigned in a uniform and consistent manner throughout states. Currently, beneficiaries may receive a different identification number when they re-enroll in the Medicaid program or move out of state, making it virtually impossible to track beneficiaries over time. Therefore, state data collection effort would require the

cooperation of all states and would have to be integrated with information regarding eligibility and coverage criteria in each state.

These data could potentially provide a wealth of information on the Medicaid population receiving services under the program, as well as sub-groups of interest within this population. Because of the variety in state programs, if used with state demographic data, this data base would provide a powerful tool for program planning, budgeting, policy development, and research. The data could potentially be linked to other data bases at the federal level, including vital records, which would allow comparison of the covered and non-covered populations.

b. Conduct a survey of low-income persons

Conducting a survey of low-income persons is a second option for collecting data on this population. A survey of the low-income population would be useful in obtaining information on both the Medicaid population and the potentially eligible population. A longitudinal survey of this population would also provide valuable information on enrollment and receipt of a wide range of public programs including Medicaid.

Several issues need to be considered in determining whether a separate survey of low-income persons would address existing data gaps. In addition, there are a number of methodological issues related to development of such a survey. First, it must be determined whether the survey should provide cross-sectional and/or longitudinal data and whether state-specific or only national data are desired. Periodic cross-sectional surveys may allow for more detailed questions and a larger sample-size, while a longitudinal survey would allow a detailed analysis of changes, vital for evaluation of program design issues. Longitudinal surveys of the low-income population may be difficult to design because of the mobility of this population, which makes follow-up over **long periods of time difficult**.

State-specific data would permit analysis on a state-by-state basis, an important consideration since Medicaid programs vary widely by state, but would require a substantially larger sample size than a national survey. A national sample would require a much smaller sample and may be designed using NCHS sampling frames (which would allow closer integration with NCHS surveys).

A survey of the low-income population would have to include information on the income and assets of the population, a wide range of demographic variables, and information on the use and financing of health care services. In addition, questions related to access to care would have to be developed as well as a comprehensive set of questions regarding the receipt of public program services. It is possible that a survey of the individuals themselves would have to be supplemented by surveys of their health care providers. Such a survey would resemble the expenditures surveys conducted by AHCPH, which are frequently expensive and require long time frames to design, conduct, and evaluate.

A separate survey of the low-income population would meet many of the data needs of DHHS. It could provide valuable information on several of the large minority groups as well as the information required to analyze access to care. It would not, however, allow for comparisons to other population groups unless matches are made to other surveys. It would provide useful information in program planning and would be particularly useful to researchers. A major advantage over Medicaid claims data is that it would provide information on low-income persons who do not participate in the Medicaid program.

c. ***Oversample low-income populations and sub-groups (low-income, disabled, and minorities) in existing national surveys***

A final option available to provide data on low-income populations is to oversample these populations in existing national surveys such as the NHIS, the expenditure surveys conducted by AHCPH, or the Survey of Income and Program Participation (SIPP). Some of these national surveys are currently not large enough to analyze many sub-groups such as

the low-income groups. Oversampling population groups of particular interest (perhaps on a rotating basis) such as the low-income population, persons with disabilities, and minority groups, may be a manageable option for gathering data on these groups.¹⁶ Rotating these population groups would fill data gaps specific to population sub-groups without significantly adding to the annual sample. However, longitudinal data would not be available for any particular group unless follow-up interviews are conducted of the subgroup after the initial sub-group survey.

There are several limitations to this approach. First, it would significantly increase the size of the survey sample and the types of questions that must be addressed by the survey. Second, it may substantially increase both the cost and the time required to conduct these surveys. One of the primary advantages to the NHIS is that data are routinely available on a timely basis. Additional data collection requirements would delay the processing of data collection and the time required for release of public use tapes. This is a particular problem when collecting expenditure data which requires substantial follow-up to obtain complete information. The problem is not insurmountable, however, if the expenditure portion of the data was released separately. Third, in order to oversample, the survey must include questions related to the variable to be used for selection -- in this case income. Income information is collected on the NHIS and therefore, the opportunity for oversampling exists. Income questions used, however, may have to be examined to ensure that the detail is appropriate for research needs. Other variables of interest may not be included, such as reliable indicators for minority status. These would have to be added if oversampling were to be feasible.

¹⁶The NHIS and NMES surveys oversample the Black population, but fail to oversample Hispanic and Asian/Pacific Islanders by race or national origin. An option might be to oversample individuals from a primary sampling unit (PSU) with a disproportionate number of minorities. Meanwhile, the CBS will oversample Medicare beneficiaries with disabilities, but will fail to survey those with disabilities under 65 years old who do not qualify for Medicare or are awaiting eligibility.

d. Lewin/ICF Recommendation

We recommend that DHHS provide the funds necessary to develop and collect uniform data on the Medicaid population from the states. First, it is likely that the authority for this data collection activity exists, but has not been utilized. Second, the data already exist at the state level, and may require less effort to collect than other potential options. Third, it would meet several DHHS needs related to program design, budgeting, and research. Fourth, it would provide comprehensive data on a wide range of low-income population subgroups of particular interest to DHHS. Finally, it would result in data parallel to that available for the Medicare population. We believe that development of this data should be a priority.

There are, however, limitations and problems related to choice of this option. First, because of variations in eligibility and coverage across states, there will be differences in the data collected. In addition, states use various definitions of the population served and the services covered. It would be difficult to develop common definitions and an enormous effort for states to reprocess their data. If common definitions are not used or if some method is not developed to compensate for the different definitions such as making imputations, the data would be of limited utility.¹⁷ Some of this can be solved by merging data with information on state-specific definitions and coverage policies. We believe, however, that while the problems are significant, the value of the data base would be enormous.

Options related to surveys of the low-income population should also be explored, particularly related to specific population subgroups. Oversampling of particular groups in existing surveys appears to be a more attractive option, because it would not require the development of additional survey instruments. Oversampling the low-income population is especially attractive if issues regarding expansion of the Medicaid-eligible population are of interest.

¹⁷Data could be collected and analyzed even if common definitions are not developed as long as researchers and analysts recognize the differences.

2. Medicare Managed Care Data

Medicare beneficiaries currently have the option of enrolling in a managed care plan. Frequently, these plans provide more comprehensive services than traditional Medicare fee-for-service coverage. Managed care plans provide a full range of services; in exchange, enrollees must receive their care from a pre-determined set of providers. Because of these financial incentives, it is believed that managed care plans have an incentive to provide more preventive care, and that managed care plan enrollees have lower utilization of certain health care services. Because of these advantages, DHHS has encouraged Medicare beneficiary enrollment in managed care plans for many years.

Some federally-qualified managed care plans are required to submit financial, enrollment, and utilization reports on a quarterly or annual basis. From these reports, certain data elements are entered into the NDRR subsystem, a system that provides HCFA with a central data base of plan-specific information. The data submitted by federally qualified managed care plans need not provide beneficiary-specific information; therefore, there are no data currently available that permit analysis of the utilization patterns of Medicare beneficiaries enrolled in HMOs or that allow comparisons of the utilization patterns of managed care enrollees to the general Medicare population. Therefore, it is difficult to determine the "success" of DHHS efforts to increase enrollment in managed care plans.

It is critical to assess this situation. First, for many years, DHHS has encouraged enrollment in managed care plans, but little is known about how the services provided to these beneficiaries differ from services provided to those receiving care in the fee-for-service system. Second, a data base that includes, for a sample of the Medicare population, detailed information regarding all of the health care services received over a particular period of time would be useful for analysis of issues related to Medicare program design and expansion. Third, because Medicare enrollees are followed by the plan, these data would provide an

opportunity to identify the effect of services on beneficiary health status. Fourth, data from managed care plans would allow researchers to analyze the full range of services required by beneficiaries with particular conditions.

To adequately analyze prepaid health issues, two options could be pursued. These are:

- developing a claims data set, and
- oversampling Medicare beneficiaries enrolled in managed care plans in Medicare beneficiary-based surveys.

Each of these options are discussed below.

a. *Development of a Claims Data Set*

The development of a claims data set is one option for collecting data to compare care provided to Medicare beneficiaries under fee-for-service with prepaid health plans. These data should be designed to be somewhat comparable to claims information collected on the general Medicare population and would provide useful clinical information on managed care enrollees.

Managed care plans are currently not required to submit claims data to the Medicare fiscal intermediary. Furthermore, managed care plans are not required to maintain data in a similar fashion to other providers. For example, information on the costs to provide a particular service are not likely to be available from managed care plans. Therefore, careful consideration would have to be given to the data elements requested, and managed care plane would have to be consulted in developing the data base.

Several steps would be required to collect this information. First, individuals at DHHS would have to work with representatives of managed care plans to develop a feasible design for data collection. To meet the objectives of this recommendation, the data collection effort must be designed so that data for a particular patient could be linked over time. Second, a plan to begin data collection and to finance the costs of obtaining these data would need to

be developed. Third, DHHS may want to consider developing a mechanism to survey beneficiaries who withdraw from managed care programs and follow their pattern of utilization over time using traditional Medicare claims data. This could be accomplished through the Disenrollment Survey which is currently in the pilot testing phase at the HCFA. As planned, the Disenrollment Survey will provide HMO-specific information on the number of Medicare prepaid health enrollments and disenrollments, including reasons for disenrollment.

b. *Oversample Medicare beneficiaries enrolled in managed care plans in Medicare beneficiary-based surveys.*

The CBS and the Registry are two surveys sampling Medicare beneficiaries enrolled in fee-for-service and prepaid health plans.. Although the focus of the two surveys differ, they could provide some data for comparison of fee-for-service with prepaid health plans if those Medicare beneficiaries enrolled in prepaid health plans are oversampled. This is necessary due to the relatively small number of Medicare beneficiaries enrolled in prepaid health plans (1.8 million Medicare beneficiaries were enrolled in prepaid health plans in July 1989 compared to 31.2 million enrolled in fee-for-service plans).

The CBS will provide detailed data on Medicare beneficiary demographic and socioeconomic characteristics as well as their costs, utilization, and expenditure patterns on an annual basis for the same sample of individuals. This information could be used to compare characteristics and service utilization of the fee-for-service population to managed care enrollees, but would not provide information to compare the cost of services for patients in prepaid health plans, because these plans do not submit bills.

The Registry, if implemented, will also collect longitudinal data on Medicare beneficiaries and could provide a source of data for comparing the health status of those enrolled in prepaid health plans to those receiving care in the FFS sector. A primary focus of the Registry is to collect data on Medicare beneficiaries health status at two- to five-year intervals to allow analysis of health and disease among the Medicare population, including

quality of life, well-being, functional status, and the prevalence, incidence, and progression of illness, and changes in health over time. One limitation to the Registry, however, is the long interval between surveys which may fail to recognize Medicare beneficiary movement in and out of managed care plans.

c. **Lewin/ICF Recommendations**

We recommend that DHHS oversample Medicare beneficiaries enrolled in prepaid health plans in Medicare beneficiary-based surveys. First, the CBS and the Registry are already under development. Oversampling those enrolled in prepaid health plans could be implemented more expeditiously than the development of a claims data set. Second, each survey provides valuable data to respond to specific research issues. The HHS Data Planning and Analysis Working Group will need to decide whether to oversample Medicare beneficiaries in one or both of the surveys. We believe that adding to the CBS would be the recommended approach because it can provide a wide range of data to compare expenditures and utilization of managed care and fee-for-service beneficiaries,

Although the development of a claims data set is not our recommended option, primarily due to the length of time and difficulty in planning and assembling such a data set, DHHS should consider this option for gathering data for future comparison of managed care and fee-for-service plans.

3. **Health Care Expenditure Data**

Health care expenditure data across the entire population were mentioned by many of those interviewed as a major Departmental data requirement. These data are required in order to determine the cost of particular illnesses, the ability of particular populations to finance health care, and the patterns of health care utilization and expenditures. Periodic health surveys (such as the NHIS) do not collect information on health care expenditures and patterns of health care financing, although this information is clearly necessary to develop

and analyze public programs in many areas. For example, information on expenditures for pharmaceuticals was not available to determine the potential cost of adding drug coverage under the Medicare program. Data on expenditures and financing are also required in order to analyze issues related to the uninsured and the cost of programs designed to ensure access to health care. Currently, these data are collected on an irregular basis and are frequently not available in a timely fashion to allow analysis of related policy issues. In addition, past surveys have not always provided the detail required to analyze particular population groups.

Two options can be considered for improving the collection of health care expenditure data:

- expanding NHIS or other surveys to collect annual expenditure and financing data, and
 - conducting the NMES survey (or other health care expenditure survey) more frequently (see Appendix E for information on NMES).
- a. ***Expanding the National Health Interview Survey***

One option for gathering expenditure data on a regular and timely basis is by adding health care expenditure questions to the NHIS every 3 to 5 years as a questionnaire supplement. The entire NHIS survey population or a subset of this population could be asked health care expenditure-related questions. Another option would be to add a sample to the NHIS for the specific purpose of asking expenditure-related questions. Finally, a follow-up health care expenditure survey (similar to the Longitudinal Study on Aging), could be conducted for NHIS respondents of interest (the low-income, minority, or disabled respondents). This option would provide annual data, tie cost and financing data more closely to utilization data and trends, build on the NHIS survey design, and allow integration with other NCHS surveys, such as the National Health Care Survey (a survey including four NCHS provider-based surveys -- the National Hospital Discharge Survey, the National

Ambulatory Medical Care Survey, the National Nursing Home Survey, and the National Master Facility Inventory -- that have been restructured to provide a more comprehensive picture of medical care provided in the United States).¹⁸ Use of a subsample might greatly reduce the ability to analyze population sub-groups, although two or three years of data could be merged to provide larger sample sizes of population groups of interest. Furthermore, because NHIS includes personal identifiers, it would be possible to link records to other HCFA files as well as other NHIS surveys.

The disadvantage of this approach is that the addition of expenditure data will greatly increase the complexity of the survey design as well as the time needed to prepare the data. Many of those interviewed were opposed to the addition of expenditure data to the NHIS for this reason. Therefore, we recommend that if this approach is taken, it should be done so that the "core" survey can be released on a timely basis.

b. Conducting more frequent *expenditure surveys*

A second option for collecting medical expenditures data is to conduct the health care expenditure surveys more frequently and make the data available within DHHS sooner. Many of the individuals interviewed stated that there was a long lag between the time of the survey and the release of data. Furthermore, many of those interviewed believed that the length of time between surveys was too long. While none suggested an annual survey, most believed that surveys were required on a routine basis (every three to five years).

c. **Lewin/ICF Recommendation**

We recommend more frequent collection of information related to health care expenditures for several reasons. First, it is clear that these data are required across DHHS for many research and policy-making purposes. Data previously available have been used widely in the research community, both inside and outside DHHS. Second, we are reluctant

¹⁸The NHCS will utilize an integrated cluster sample design based on geographic areas used for the NHIS to allow comparison of data between the two surveys.

to recommend the addition of substantial amounts of data collection to the **NHIS** (or any other NCHS data base). One of the advantages of the **NHIS** is the fact that these data are consistently collected and made available on a timely basis. We believe that addition of expenditure data would impede successful completion of the **NHIS**. Therefore, we believe that a separate survey is required.

We make this recommendation, however, with several caveats. First, we believe that a "core" expenditures survey should be developed that would eliminate much of the complexity of the most recently completed survey. This "core" survey should be considered in much the same way as the **NHIS** "core" survey questions and should be developed based upon DHHS experience on previous expenditure surveys. This core survey would remain essentially unchanged from one survey to the next and would allow longitudinal research. Second, while we believe that the survey should be completed more frequently, an annual survey is not required or feasible. Every three to five years should be sufficient for collection of this information. Finally, consideration should be given to making these surveys consistent with those conducted by NCHS related to the sample selection and survey design so that matches can be made between the utilization and expenditure surveys so that health care utilization with expenditures data can be tied together for a given episode of care.

Because HCFA will be collecting comprehensive expenditure data on the Medicare population through implementation of the CBS, the focus of an expenditure survey should be on the under-65 population. The CBS will oversample the 85 and over population as well as those with disabilities and the nursing home population. Additional health care expenditure data collection of the over 65 year age group may lead to redundant data collection, or data collection which could be conducted more efficiently through the CBS.

4. Data on the Mentally Retarded/Developmentally Disabled (MR/DD)

Many individuals interviewed by Lewin/ICF expressed interest in analyzing issues related to the health care needs of the mentally retarded/developmentally disabled (MR/DD), particularly the non-elderly. Although this group consumes substantial amounts of medical care, little data are available to analyze their utilization and expenditure patterns or their special health care needs. Data on this population are difficult to obtain because it is almost impossible to identify this group in a national survey. Frequent movement of this population across care settings makes this sub-group difficult to follow over time and means that they may not be included in most nationally-based surveys. In order to gather utilization and expenditure data for this group, their next of kin and health care providers must be surveyed, and extensive interviews would be required because of the wide range of services they use. The MR/DD population is, therefore, one of the more challenging groups for which to collect data.

Options available for gathering data on this group include the following:

- conduct a separate survey of the MR/DD population, and
- oversample the MR/DD population in national surveys.

Each of these options is discussed below.

a. ***Conduct a separate survey of the MR/DD population***

Conducting a separate survey of the MR/DD population is one option for gathering data on this group. Several issues need to be considered when implementing an independent survey of the MR/DD population. It must be determined whether the survey is conducted on a periodic or longitudinal basis and what level of data analysis is desired (national or regional estimates). Periodic surveys will allow for more detailed questions and a larger sample size, while a longitudinal survey will allow for year-to-year comparisons, often vital for evaluating program changes or providing data on time-sensitive topics.

b. Oversample the *MR/DD* population in national surveys

Oversampling the *MR/DD* population in national surveys is another option for gathering data on this group. As previously discussed, oversampling would provide data for analyses for population groups that would otherwise not be adequately sampled in national surveys, such as *NHIS*. Oversampling of this group is difficult, however, because they are not well identified or represented on national surveys. Therefore, prior to development of this option, a separate study to identify an appropriate population would be required.

To oversample the *MR/DD* population in a survey, a separate component would need to be developed, similar to the Institutional Population Component (IPC) in the *NMES* survey (see Appendix E for information on *NMES*). This is necessary to address the unique challenges of data collection for this group. Data would need to be gathered through next of kin and health care provider interviews, which vary substantially from the methods used in nationally represented population-based surveys.

c. *Lewin/ICF* Recommendation

We recommend that the *DHHS* conduct a separate survey of the *MR/DD* population. First, this group requires detailed interviewing of next of kin and health care providers to accurately gather data on service utilization, expenditures, and patterns of care in a variety of care settings. Interviewing procedures would vary significantly from those interviewed in a national population-based survey. Second, oversampling this group in a national health care survey would increase the workload substantially and possibly delay survey data availability and would be difficult since it is impossible to identify this population on national surveys. Finally, collecting longitudinal data necessary for evaluating patterns of care and effectiveness of care issues would require a follow-up survey, and would be difficult to incorporate into an ongoing population-based survey such as the *NHIS*, which collects data on a weekly basis.

The HHS Data Planning and Analysis -Working Group will need to consider whether data should be collected intermittently or on a longitudinal basis.

We also recommend that diagnostic tools and uniform standardized definitions be developed to evaluate the **MR/DD** population and other persons with disabilities in the survey setting. For instance, there are no uniform definitions to indicate an individual's level of disability, functional status, or complexity of care. Therefore, it is difficult to assess the nature and extent of disabilities, effectiveness of care, and cost of rehabilitating persons with disabilities.

It is also recommended that the Department focus future data collection activities for the population with disabilities on those under 65 years old. As previously stated, the CBS will oversample Medicare beneficiaries with disabilities. Meanwhile, the Registry could also facilitate collection of data on the Medicare population with disabilities on account of its sampling frame which could be used to select samples of Medicare subgroups such as those with disabilities. Further data collection on the over 65 year old population with disabilities may lead to duplicate or inefficient data collection efforts.¹⁹

5. Data on **Minority** Populations

As described in Chapter Two, data on various minority groups are required to develop information related to their special health care needs, utilization patterns, access to care, and ability to finance care. Many of the Secretary's initiatives of "Healthy People 2000" require that particular attention be paid to the health care needs of minority groups. For example, achievement of goals related to infant mortality may require that information be developed related to each of several **minority** groups (including Black and Hispanic populations) where infant mortality rates remain high. These groups may require certain types of health care or

¹⁹The Departmental Coordinating Group on Disability Data is studying data needs related to the population with disabilities and will complete their report September 1991.

may experience particular difficulties in obtaining access to care. Data are therefore required to address this issue. Options for collecting data on minority groups include:

- oversampling ethnic minority groups, including indicators for national origin, in national sample surveys, and
- conducting special research studies for particular population groups.

Existing national health care surveys collect the kinds of information needed for many minority groups, such as data on access to care and utilization and expenditure patterns and may be adequate for certain groups.

a. *Oversampling Minority Groups*

One option for collecting data on minorities which was suggested in our interviews is to expand current national surveys to adequately sample these groups. Current sample surveys **provide information** on race, but not on ethnic status or national origin. Many of those interviewed suggested that more information is required for more defined subgroups.

Oversampling of minority groups would require that specific data indicators of race and ethnicity be developed and included on the survey. In addition, once these groups are identified, special surveys may be required. This option is only feasible for the large minority populations.

b. *Special Studies*

For smaller groups including (but not limited to) Cubans, Mexicans, Hondurans, Koreans, and Vietnamese sub-groups, special studies may be required to collect information. These studies could build off national surveys, but may also be separate research studies of particular groups. Such studies may be encouraged by a current mandate for NCHS research grants in this area.

c. *Lewin/ICF Recommendation*

Lewin/ICF recommends oversampling ethnic groups in surveys where possible, although there are many questions related to collection of minority data **that** were unresolved

by our interviews and must be considered. First, a realistic list of minority groups for which data are required should be developed. This list should be developed in conjunction with other Departments including the Department of Commerce and the Department of Labor so that matching to other data bases is possible and so that all government agencies are using consistent definitions of minority groups. Second, the frequency of required data collection must be determined. It would not be feasible to collect information on each minority group annually, and it is not clear that this would be necessary. Periodic oversampling in surveys, gathering a basic set of information, may be sufficient. Basic data collection requirements appropriate for all minority groups must be developed so that health care utilization and expenditure patterns can be compared across groups.

DHHS should further consider collecting information on smaller minority groups through smaller, geographically limited special studies when researchers need data on special health issues specific to a minority group.

6. **Matching of Departmental Administrative Databases and Surveys**

Matching administrative data bases and surveys offers great potential for analysis of many of the issues presented in this report. For data bases to be matched exactly, beneficiary identification numbers must be the same between the data bases being matched. In some cases, DHHS agencies have developed matching of data bases which have been useful for analysis and program administration (e.g., SSA and IRS, HCFA and SSA, and Medicare with the National Death Index). Additional matching of Medicare administrative databases, Social Security records, and Internal Revenue Service summary earnings records would facilitate analysis of enrollment interactions between federal programs and provide detailed income-data for those groups filing income data (which would exclude the poor). Survey data could also be matched to administrative data bases if uniform beneficiary identification numbers were used. This would allow validation of medical expenditure survey

data of the elderly population by matching Medicare administrative data bases with national sample survey data which is currently done to validate eligibility status and claims information received from Medicare beneficiary respondents included in the CBS and NMES surveys.

There are both methodological and confidentiality issues that make development of exact matching of data bases difficult. As previously mentioned, beneficiary identifiers such as social security numbers must be identical across data bases for exact matching to occur. Surveys and administrative data bases often lack identical and consistent beneficiary identification numbers, which prevents matching within and between these data sets, In addition, matching between administrative data bases is sometimes prevented due to issues of confidentiality, and frequently these data bases cannot be made available to researchers for similar reasons.

More thought should be given in survey development to include social security numbers on the questionnaire. It may be possible to develop a matched data set to be used for research purposes that would complete the match using the identifying numbers and then eliminate any information that would allow individual identification. In addition, matching of beneficiary and provider files should be considered. This is currently done on a limited basis for Part B Medicare claims, but expansion of this concept should be considered.

Alternatively, data bases could be "statistically matched" where data for individuals with similar characteristics in different data bases are combined. Specific characteristics which must remain consistent between databases being statistically matched include demographic variables (e.g., age, race, and sex) as well as socioeconomic variables (e.g., assets and income) in order to yield valid data for comparison. **Development** of statistically matched data bases that could be used internally would provide an extensive source of data for health care expenditure and utilization data for a wide range of population groups. However, if data bases being matched do not represent similar characteristics of the sample populations,

erroneous conclusions from matching data bases may be reached. A first step would be to match data bases which are developed internally, then to add data from other Departments.

7. **Block-Grant Funded Program Data**

Data from block-grant funded programs would provide additional opportunities for analysis of a variety of issues. Currently, states and local municipalities frequently do not submit data on the types of services they offer or on the populations they serve because of resource constraints. In other areas, few reporting requirements exist. Providing funds and requiring block grant-funded programs to provide data would permit analyses of those population groups that use their services (such as low-income persons, minorities, pregnant women and infants, children, and those with disabilities) and the effect of programs on health status. However, the premise of the block grant programs was that money would be given to the states to spend as they wished within the scope of the block grant. Consequently, states may balk at the imposition of new federal requirements, especially without adequate funding.

Data from block-grant funded programs would need to include information on providers of services and characteristics of recipients. Information collected from providers would need to include services **offered, associated costs, and utilization rates. Information** collected from recipients would need to include socio-demographic variables, health status indicators, and utilization by type of service.

Many of the issues associated with gathering state Medicaid data also apply here. To accomplish this objective successfully, the federal government will need to take several steps. First, a uniform format for the collection of data should be designed along with a schedule for data submission. One requirement should be that states use a consistent beneficiary identification number (social security number) to allow analysis of patterns of care over time. **The federal government will need to redefine its role in relation to data collection at the state level and develop federal standards for state data collection, so the data can be effectively**

used for conducting research. In addition, staffing positions and computer capabilities will need to be re-assessed to allow efficient data processing and analysis. Finally, if other recommendations contained in this report are followed, significant new data may be collected.

C. OTHER FINDINGS AND RECOMMENDATIONS

While not the primary focus of the interviews, suggestions related to data collection activities across DHHS were provided by those interviewed. These ranged from issues related to commitment to data collection to the methods used to share and disseminate information within the agency as well as availability of data sets to outside researchers.

First, several of those interviewed discussed issues related to data sharing across DHHS agencies. Many believed that, while useful data may be available, in many cases it was not shared, either because of an unwillingness to provide the data, or because there was no effort to inform researchers in other agencies that the data were available. In several cases, issues related to data confidentiality were the reasons provided for the unwillingness to share information. In addition, it is clear that in many cases, resources are not available to ensure that data are publicly available (including the development and support of "public-use" data bases, and the technical support provided to those using the information). We believe, however, that this issue should be discussed by the HHS Data Planning and Analysis Working Group, and issues related to confidentiality should be resolved.

Second, issues were raised related to the timeliness of data collection and availability. These issues were raised particularly with respect to data bases generated for research purposes. Some of those interviewed believed that such data are not shared soon enough with other HHS staff, and some of these individuals suggested that data collection responsibilities be separated from research, with the functions being housed in separate components of HHS. However, agencies that currently collect data and perform research indicated that the delays result from demands for special analyses requested by high-level

officials. The HHS Data Planning and Analysis Work Group should consider this issue further to determine the best way of assuring that data are available in a timely manner.

Finally, as discussed several times in this report, all of those interviewed believed that much more information on health care utilization and expenditures is needed for research and policy development. They encouraged the HHS Data Planning and Analysis Working Group to support additional investment in data collection activities across the Department.

APPENDIX A
INTERVIEW PARTICIPANTS

APPENDIX - A

INTERVIEW PARTICIPANTS

* Indicates members of the Interdepartmental Data Planning and Analysis Working Group

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Gooloo Wunderlich Ph.D.	-	Study Director
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APPENDIX B
INTERVIEW GUIDE

APPENDIX - B

INTERVIEW GUIDE

1. What is your office's interest in issues with regard to analysis of health care policies and programs which affect utilization and expenditures? What issues or programs are you specifically involved with?
2. Which health care policies or program issues related to utilization and expenditure do you believe will be of major importance in the **90's**?
3. What kinds of data/information do you need to produce an adequate analysis or response to these policy and program questions?
4. What sources of data/information do you currently use for analysis of these issues? If surveys are used, which portions of the survey are most useful? least useful? How do you use these data/information?
5. To what extent do these data/information meet your needs in terms of:
 - content,
 - detail,
 - precision,
 - reliability,
 - timeliness,
 - accuracy,
 - scope of data, and
 - presentation?

Are there any available data/information which you find is not useful?
6. What changes in available health care utilization and expenditures data would improve your ability to analyze related policies and programs?
7. What additional sources of information and data analysis would be helpful to you? Who should provide these data?
8. In which areas (related to expenditures and utilization) are **data** most deficient or inadequate? To what do you attribute these deficiencies? Is it cost, complexity of the questions or issues, sample size, organizational, technical or other problems? Could more coordination or cooperation among Federal agencies help to overcome these problems?
9. Are there any major new or proposed Federal initiatives, policies or programs which affect the scope or type of health care data you will need in the near future? What types of data are needed to analyze these issues?
10. Who would you expect to meet these emerging data needs? What type of data would you expect or require?

APPENDIX C
DHHS REPORTS AND STUDIES

APPENDIX - C

DHHS REPORTS AND STUDIES

Data Systems of the National Center for Health Statistics. Vital and Health Statistics. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, Series 1. No. 23, March 1989.

Health of an Aging America: Issues on Data for Policy Analysis. Vital and Health Statistics. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, Series 4, No. 25, December 1988.

Healthy People 2000: National Health Promotion and Disease Prevention Objectives. Conference Edition, U.S. Department of Health and Human Services, September 1990.

The Aging Population in the Twenty-First Century: Statistics for Health Policy. National Research Council, 1988.

The Secretary's HHS FY 1991 and 1992 Program Directions Plan Summary. Department of Health and Human Services, Office of the Secretary, November 7, 1990.

U.S. Public Health Service: Improving Drug Abuse Statistics. Report of the PHS Task Force on Drug Abuse Data, February 1990.

APPENDIX D

EXPLANATION OF DATABASES

APPENDIX - D

EXPLANATION OF DATABASES

(1) NCH - National Claims History Database

The National Claims History Database (NCH) is a series of databases supported by the Common Working File (CWF), a large scale distributed transaction processing system which controls the payment of Medicare claims. The NCH includes Medicare claims data, quality control and edits of the data, and creation of on-line, near-line, and off-line claims databases, summary databases, a program liability database, and a control file. NCH data will be available upon payment authorization and in most cases, information will be sent to the Bureau of Data Management and Strategy (BDMS) prior to payment being mailed from the contractor site. The NCH has been designed to include data from the current year plus three prior years, and will initially contain data from 1988.

NCH will not only include all Medicare claims processed, including those for which denial of payment resulted, but will also include all of the information provided on the claims with line item information on all services. BDMS has devised a system for monitoring the quality of the claims data transmitted to the NCH database. The monitoring system will validate data transmission, duplicate host edits including consistency, duplicate claims and entitlement checks, and compare summary results to expected values derived through trend, analysis. Part B Medicare claims data will be enhanced by including services and charges before the deductible is met, procedure and diagnosis codes, denials of service, adjustments to claims, complete detail on each type of service, place of service, procedure billed, and unique identification of physicians by service. Those interested in looking at data prior to 1 O/I /91 will need to refer to MADRS, MEDPAR, and BMAD files.

Anency: Health Care Financing Administration

Status: Full access to the various databases which compose NCH is anticipated after October 4, 1991 when training sessions for HCFA personnel begin.

(2) The Registry - Medicare Beneficiary Health Status Registry

The Medicare Beneficiary Health Status Registry will provide a longitudinal data base containing information on elderly Medicare beneficiaries which will be formed by joining health status information obtained by survey to the administrative files maintained by HCFA. The survey, as planned, will gather previously unavailable information regarding the health status of approximately 2.5 percent (40,000) of the elderly as they enter the Medicare program and at two- to five-year intervals thereafter (ages 65, 70, 75, 79, 82, 84, 86 ...). Through self-administered questionnaires supplemented by telephone interviews, data will be gathered on the following:

- risk factors;
- functional status;
- sociodemographic variables;
- medical history, and
- quality of life.

EXPLANATION OF DATABASES (continued)

The primary goals of the Registry are to provide data to:

- measure the relationship of Medicare reimbursed services to the health status of Medicare beneficiaries;
- describe, analyze, and understand health and disease including quality of life, well-being, functional status, and the prevalence, incidence, progression of illness, and decline in health longitudinally in successive cohorts of Medicare beneficiaries;
- monitor access to care of special populations;
- describe, analyze, and understand the use and costs of services, long-term utilization patterns, and lifetime Medicare costs of individual cohorts;
- provide a detailed sampling frame which can be used to select highly efficient samples for studies of special subgroups of the Registry sample;
- provide information to monitor existing DHHS "Healthy People 2000" objectives and to develop additional ones; and
- develop equitable payment adjustments for HMOs, PPOs and providers in rural areas.

The development of the Registry is directed by the Epidemiology Branch, Office of Research, HCFA. Support and consultation for the design, development and field testing of the Registry is provided by the Office of Science and Data Development at AHCPR.

Agency: Health Care Financing Administration, funded by the Agency for Health Care Policy and Research

Status: The survey is in the developmental stage. It is anticipated that the survey will be field tested in Fall 1991 and implemented the beginning of fiscal year 1994.

(3) UCDS - Uniform Clinical Data Set

The Uniform Clinical Data Set (UCDS) is a new data collection and case finding system that has been developed by the Health Standards and Quality Bureau with several goals in mind. Traditional Peer Review Organization (PRO) review relates to the individual case under examination and only in a general way to broader issues of clinical concern about the appropriateness of the medical care being provided. Further, the judgments made by the first level PRO reviewers are not uniform. The result is very different outcomes for PRO review from state to state, bearing no apparent relationship to the probable incidence of unnecessary or substandard care that may exist. What UCDS does is to collect a standard set of data about each hospitalization, subject that data to an expert system, and provide to the physician reviewer a case summary that reflects the specific areas which are being questioned and highlights the issues that need to be addressed. The goal is to select cases for physician review in each state by identical standards, thus eliminating the differences in PRO review results attributable to individual judgment. Further, the data collected will be matched to other Medicare data files to enable detailed longitudinal analysis. This is expected to yield information about the effectiveness of different medical interventions, and may lead the PRO program away from the necessity of performing case-by-case review, toward a broader based epidemiologic analysis of health care paid for by the Medicare program.

EXPLANATION OF DATABASES (continued)

The UCDS data acquisition software is interactive and designed to be used by a trained abstractor to collect data from a patient's medical record using desktop or portable computer hardware. The clinical data elements collected include the following:

- Administrative Information (e.g., patient identifying information, diagnosis and procedure codes, discharge disposition);
- Sociodemographic Data;
- Admission Status;
- Admission Medication History;
- History of Permanent Anatomic Changes;
- History and Physical;
- Laboratory Findings;
- Selected Diagnostic Tests;
- Endoscopic Procedures;
- Operative Episodes;
- Non-Invasive Treatment Interventions;
- Hospital Course (e.g., special care unit day);
- Patient Discharge Status; and
- Discharge Planning

In the UCDS, algorithms, using the data abstracted from the medical record, "decide" whether or not a case should be referred for physician review. Rules governing the algorithms are grouped into three modules; one which evaluates the necessity of the admission, a second which embodies the HCFA Generic Quality Screens, and the third which contains the PRO discharge screens.

Agency: Health Care Financing Administration

Status: Since February 1, 1991, seven Peer Review Organizations have been abstracting data from a 10 percent sample of Medicare beneficiaries receiving hospital based care, It is anticipated that in September 1991 all PROs will sign contracts and implement the system by April 1, 1992.

(4) CBS - Current Beneficiary Survey

The Current Beneficiary Survey (CBS) will yield both longitudinal and cross-sectional data sets. The CBS consists of a series of interviews with a representative sample of the Medicare population, Data will be collected on Medicare beneficiaries' patterns of health care use and cost over time, sources of coverage and payment, assets and income, demographic characteristics, health and functional status, current work status, and family supports. Information will also be collected on health insurance status, and whether the source of health insurance is through a present or past employer. The CBS will also include information on household composition (including community caregivers and family/neighbor support), and home health care (including familial and professional support).

The CBS focuses on issues that are of key concern to HCFA, such as health care use, its determinants, and its cost. The survey is continuous in that the same sample of individuals will be contacted every four months for several years to observe, monitor, and record changes in use with changes in coverage and processes that can only be observed

EXPLANATION OF DATABASES
(continued)

over time, **such as institutionalization or spending down** of assets. The survey will be designed to meet "real time" needs for information, both in providing rapid feedback of results and in being able to add new questions or subject matter as new issues or problems emerge. (See Appendix E for additional information.)

Agency: Health Care Financing Administration

Status: National implementation of Round 1 began September 1991 with a new round starting every four months thereafter.

(5) UPIN Directory - Unique Physician Identification Number Directory

The Unique Physician Identification Number Directory contains information on physicians who provide services for which payment is made under Medicare. Included are physicians as defined in Section 1861 (r) of the Social Security Act; e.g., medical doctors, osteopaths, doctors of dental surgery or dental medicine, podiatric medicine, optometry, and chiropractors.

Congress authorized both the unique numbering of physicians and the publication of this directory. Section 9202 of the Consolidated Omnibus Budget Reconciliation Act of 1985 required HCFA to establish a unique identifier for each physician who provides services for which payment is made under Medicare. HCFA developed the six-place alpha-numeric UPIN, which was assigned to all physicians, whether in solo or group practice. Section 4164 of the Omnibus Budget Reconciliation Act of 1990 required HCFA to publish the directory of UPINs which will be used within the health care community to encode the UPIN of the referring or ordering physician on the Medicare claim form in specific cases.

This directory contains information on all physicians who provide services for which claims are submitted to the Medicare Part B carrier, i.e., the fee-for-service system. Physicians practicing solely with health maintenance organizations or other prepaid capitation systems are not included. Neither residents nor interns are included, although HCFA expects to enumerate residents and interns in the near future, after which a supplement of these UPINs will be released.

The directory is arrayed in state order; physicians within a state are arrayed in physician name order. Many physicians have multiple lines of information, indicating multiple "practice settings." A practice setting is defined as a specific location at which a physician renders service, and can be identified as physically separate from any other location in which he or she renders service. The following information is provided for each practice setting:

- Physician full name - last, first and middle
- Physician name suffix - e.g., Jr, Sr
- Credentials -type of physician; e.g., MD, DDS
- UPIN- the unique number assigned to the physician
- State - the state of practice setting
- Zip code - the ZIP code of practice setting
- Provider Identification Number - the PIN is the carrier assigned provider number, also known as the Medicare billing number. The number shown is the individual's number; in the case of groups or clinics, a PIN

EXPLANATION OF DATABASES (continued)

may not be the group's billing number, but a number which identifies the individual's affiliation with the group.

- Specialty - Specialties within Medicare are self-nominated.

Agency: Health Care Financing Administration

Status: To be implemented by Fall of 1991.

(6) POS File - Provider of Service File

The Provider of Services File (POS file) is a by-product of the Medicare/Medicaid Automated Certification System (MMACS). The POS File contains information on approximately 7,000 hospitals, 5,200 skilled nursing facilities (SNFs), 3,000 home health agencies, 3,500 independent laboratories, and 1,600 other Medicare participating facilities. Data from Medicare certification applications and surveys form the basis for this file, which is updated on a daily basis with new certification/recertification information. Recertification information replaces pre-existing information, which is then placed in a history file.

The POS record varies with each kind of facility and includes some data specific to the particular provider type. Among the data included are:

- facility location (e.g., city, state, county, Standard Metropolitan Area, HCFA region, responsible professional standard review organizations);
- facility type;
- total number of beds;
- number of certified beds;
- services offered; and
- number of registered nurses, licensed practical therapists, speech therapists, physical therapists, and other employees.

The data for each facility in this file are identified by the same provider number used in billing and claims records, making it possible to link these data to the provider records. The data are collected through HCFA regional offices. The file contains an individual record for each Medicare-approved provider.

Agency: Health Care Financing Administration

Status: Ongoing.

(7) EDB - Enrollment Database

The Health Insurance Master Enrollment Record File (Enrollment or HIM File) contains information supplied to HCFA by SSA. It includes basic identifying and demographic information about Medicare Part A beneficiaries and also indicates whether the beneficiary is covered under Part B of Medicare (Supplementary Medical Insurance), the extent to which certain limited benefits are still available to the beneficiary, and the beneficiary's current status regarding deductible and coinsurance;

EXPLANATION OF DATABASES
(continued)

The HIM File is updated frequently to reflect changes in beneficiaries' eligibility for benefits. All hospital claims arriving at HCFA are passed against the appropriate beneficiary's record within a few days, and in that process, some information about the beneficiary is also appended to claims records for use in the claims files. The HIM File also contains current information on Medicare inpatient admissions, because with each admission the hospital makes a "query" to HCFA through the fiscal intermediary to confirm the patient's eligibility for Medicare coverage. This query is answered by checking the HIM File, and in that process, the beneficiary's record is flagged as a current hospitalization.

During the next two years, the HIM file will be integrated with other enrollment data sets maintained by HCFA to form the EDB (a database of all non-redundant eligibility data required by the Agency).

The EDB will serve the following objectives:

- Collect enrollment data;
- Migrate enrollment data to the database environment;
- Protect data integrity;
- Support all data linkages and reporting functions;
- Support on-line query and limited update transactions processing;
- Provide linkages to the utilization data base; and
- Allow development of beneficiary enrollment only and enrollment/utilization samples from keyed and non-keyed fields.

Agency: Health Care Financing Administration

Status: The integration of additional enrollment data bases with the EDB has begun. It is anticipated that the final data bases will be integrated in January 1992. The schedule for integration of additional enrollment data bases is summarized below:

- | | |
|---|-------------|
| • EDB available | 1/91 - 3/91 |
| • Development and implementation of an ad hoc query code | 8/90 - 9/91 |
| • Consolidation of SSA input records | 5/90 - 1/91 |
| • Consolidation of GHO history database with EDB | 5/91 |
| • Consolidation of ESRD medical evidence record with EDB | 7/91 |
| • Consolidation of third party history master file with EDB | 11/91 |
| • Consolidation of direct billing master file with EDB | 1/92 |

(8) HCFA-2082 - Statistical Report on Medical Care

Form HCFA-2082, Statistical Report on Medical Care: Eligibles, Recipients, Payments, and Services, contains Medicaid cost and utilization data provided annually by states, territories, and the District of Columbia. The report captures summary data on Medicaid

EXPLANATION OF DATABASES
(continued)

eligibles, recipients, service utilization, and Medicaid vendor payments from the states, Beginning in Fiscal Year 1984, states were given the option of using a "new" HCFA-2082 form dated October 1984, or participating in the "tape option" project (Medicaid Statistical Information System-MSIS).

Agency: Health Care Financing Administration.

Status: Ongoing.

(9) MSIS - Medicaid Statistical Information System

The Medicaid Statistical Information System (MSIS-Tape Option, previously known as MEDSTAT), was begun in 1985 and captures Medicaid information at the individual claim level rather than in aggregate as the HCFA-2082 does. Participating states provide information on their Medicaid eligible population along with copies of all medical services claims reimbursed with Medicaid (Title XIX) dollars. These data are furnished on a federal fiscal year quarterly schedule, which begins October 1 of each year. Three distinct systems of records are generated from the state files submitted for inclusion into the Medicaid Statistical Information System:

1. Detailed validated (VALID Tapes) files contain the individual eligible and claim records submitted by the states.
2. PERSONAL SUMMARY RECORD FILE. An Eligible (Personal) Summary file is compiled for each state, for the current ("year to date") federal fiscal year.
3. Tape Option HCFA-2082 TOTALS FILE. These data are in a highly aggregated format in an on-line database, which contains summarized eligibility, recipient, and claim expenditure information similar to the HCFA-2082 report.

Data from the **MSIS** is used for operational purposes only. Currently twenty-one states participate in the **MSIS** project and include the following: Alabama, California, Delaware, Georgia, Hawaii, Indiana, Iowa, Kansas, Kentucky, Maine, Mississippi, Montana, Nevada, New Hampshire, New Jersey, North Dakota, Utah, Vermont, Washington, Wisconsin, and Wyoming.

Agency: Health Care Financing Administration

Status: Ongoing.

(10) Tape-to-Tape - National Unit Record Medicaid Database

Tape to Tape National Unit Record Medicaid Database: This data collection effort currently involves four states: California, Michigan, Tennessee, and Georgia, A fifth state-- New York--was originally part of the effort, but dropped out. This effort involves an attempt to develop person-based unit-records from state paid claims, eligibility, and provider files. Data are currently available for the four states for the period 1980-present. State **MMIS** (Medicaid Management Information System) tapes have been acquired and used to develop state specific files containing all of the non-duplicative information from the state tapes in standard coded form and format, and sorted and stored by individual Medicaid eligible, uniquely identified over time. Tape-to-tape data are used for research purposes only.

**EXPLANATION OF DATABASES
(continued)**

Agency: Health Care Financing Administration.

Status: Ongoing.

(11) CPS - Current Population Survey

The Current Population Survey (CPS) is the source of the official Government statistics on employment and unemployment. The CPS has been conducted monthly for over 40 years. Currently, 56,500 households are interviewed monthly, scientifically selected on the basis of area of residence to represent the nation as a whole, individual states, and other specified areas. Each household is interviewed once a month for four consecutive months one year, and again for the corresponding time period a year later. Although the main purpose is to collect information on the employment situation, an important secondary purpose is to collect information on the demographic status of the population, such as age, sex, race, marital status, educational attainment, and family structure. From time to time additional questions are included on such subjects as health, income, and previous work experience. The March CPS, also known as the Annual Demographic File, contains the basic monthly demographic and labor force data, plus additional data on work experience, income, **noncash** benefits, and migration. Questions on **noncash** benefits include indicators for health insurance coverage. (See Appendix E for additional information).

Agency: U.S. Department of Commerce, Bureau of the Census and U.S. Department of Labor, Bureau of Labor Statistics

Status: Ongoing.

(12) SIPP - Survey of Income and Program Participation

The Survey of Income and Program Participation (SIPP) is a multi-panel longitudinal survey of adults, measuring their economic and demographic characteristics over a period of 2 1/2 years. The adults followed in each panel of the survey are by a nationally representative survey of households in the civilian noninstitutionalized population. The first panel began in October 1983 with the adults in 19,878 households interviewed. The second and subsequent panels begin in February of each calendar year (subsequent panels have had smaller sample sizes). Persons selected into the SIPP sample continue to be interviewed once every four months over the 2 1/2 year life of the panel. The major goals of SIPP include the following:

- improving the accuracy in reporting and classifying income sources;
- obtaining subannual information on income reciprocity and program participation;
- examining interactions among transfer programs, labor force participation, and living arrangements;
- obtaining information to improve the simulation of eligibility under the major means-tested cash and in-kind transfer programs; and
- obtaining improved measures of assets and liabilities.

(See Appendix E for additional information).

**EXPLANATION OF DATABASES
(continued)**

Agency: US. Department of Commerce, Bureau **of the Census.**

Status: Ongoing.

(13) NBS - New Beneficiary Survey

The New Beneficiary Survey (NBS) is a nationally representative, cross-sectional, household survey using samples randomly selected from the Social Security Administration's (SSA's) Master Beneficiary Record. The **NBS** interviewed persons in October-December, 1982, and linked their responses to administrative data on benefits status. The NBS contains representative samples of new Social Security beneficiaries as retired workers, as disabled workers, as wives, widows, divorced wives, and surviving divorced wives. The NBS also contains a representative sampling of persons aged 65 and over who were entitled to Medicare benefits but who had not yet received Social Security cash benefits as of July 1982.

The survey questionnaire designed by SSA includes the following topics:

1. Household composition
2. Employment history
3. Job characteristics
4. Other employment not covered by Social Security
5. Health
6. Topics 2 through 5 for the respondents' spouse if married
7. Sources of income and amounts of income received **in the last three months (asked separately** for unmarried respondents and for married respondents and their spouses)
8. Asset holdings and income from assets (asked jointly for married respondents and their spouses)
9. Marital history
10. Child care

(See Appendix E for additional information).

Agency: Social Security Administration, Office of Policy, Office of Research, Statistics, and International Policy.

Status: Conducted October through December, 1982. A follow-up survey was conducted of surviving respondents and/or spouses during the winter of 1990 through the spring of 1991. It is unknown at this time whether the survey will be conducted again.

(14) ESRD-PMMIS - End-Stage Renal Disease Program Management and Medical Information System

The End Stage Renal Disease Program Management and Medical Information System (PMMIS) captures patient-specific data on Medicare ESRD beneficiaries. The system also captures certification and other types of information on providers approved by Medicare to furnish kidney dialysis and transplant services, and contains aggregate patient population counts. Provider certification and characteristics data are updated as received; aggregate

EXPLANATION OF DATABASES (continued)

patient population data are updated from the batch files, Recurring tabulations, analysis, and reports are prepared on a monthly and annual basis. Special reports are prepared to respond to requests from other components of **HCFA** and **DHHS**, the Congress, the renal professional community, the media, and various research organizations.

Agency: Health Care Financing Administration

Status: Ongoing.

(15) HCRIS - Hospital Cost Report Information System & Section 223 Cost Limit File for SNFs and HHAs

The Hospital Cost Report Information System (HCRIS) is a new automated database of selected information extracted from Medicare cost reports. The cost report is submitted annually by each hospital within 4 months of the end of its fiscal year to the fiscal intermediary. The cost report has changed frequently and become more complex in response to changes in law and regulations pertaining to hospital reimbursement. For the most part, changes in the cost report form have represented the addition of **more** detailed data or reorganization of existing data.

The cost report consists of a number of worksheets (analogous to tax forms) which require the hospital to provide both statistical and financial data and to perform calculations to arrive at a level of reimbursement. The data items included in HCRIS are those identified by HCFA as necessary to meet the highest priority data needs. The Medicare cost reports include the following basic elements:

- hospital statistics - selected characteristics of the hospital, including:
 - type of ownership or control
 - number of beds available
 - inpatient days
 - average number of employees on payroll
 - number of admissions
- operating expenses by hospital cost center;
- depreciation expenses by type (e.g., movable equipment, buildings, and fixtures);
- capital expenditure data by project;
- total charges by cost center;
- Medicare charges by cost center;
- routine inpatient nursing salary costs;
- malpractice costs; and
- standard financial statement information - assets, liabilities, income, etc.

Hospitals must submit a cost report to their fiscal intermediary within 3 months of the close of their fiscal year; they routinely receive a 30-day extension. The fiscal intermediary then has up to 1 year to review, audit, and finally settle on the amount due to the hospital. In this process, some data items on the cost report as submitted may be challenged and changed by the fiscal intermediary. Thus, the final settled cost report data present a more accurate picture of allowed hospital costs than do the submitted reports, but they also involve a substantial lag time (one additional year).

EXPLANATION OF DATABASES (continued)

The expected time frame for the completion of the **HCRIS** file for final settled cost reports is at least 17 months from the end of the hospital's fiscal year: 4 months for hospitals to submit, 12 months for fiscal intermediaries to settle, and 1 month for the fiscal intermediaries to transmit.

The Hospital Cost Report Information System (HCRIS) is the national data base for Medicare hospital report data. The data base contains specific financial and statistical cost report data from Medicare certified hospitals and hospital/health care facility complexes beginning with hospital fiscal years ending on or after January 1, 1982. HCRIS also contains Title V and/or Title XIX data to the extent that Medicare Fiscal Intermediaries (FIs) are responsible for processing and settling the hospitals' cost reports for these federal programs.

Section 223 Cost Limit File for Skilled Nursing Facilities (**SNFs**) and Home Health Agencies (**HHAs**) contains data abstracted from cost reports submitted by **SNFs** and **HHAs**. The file is processed to develop the limits on Medicare payments to these institutions, as mandated by Congress.

Agency: Health Care Financing Administration

Status: Ongoing.

(16) CMHS-5% - The Continuous Medicare History 5% Sample

The Continuous Medicare History Sample-5% Sample is a longitudinal file that contains beneficiary and utilization summary data. Selection is based on a five percent sample of ever-enrolled (1974 and on) beneficiaries regardless of utilization activity. It includes aged, disabled, and end-stage renal disease (ESRD) beneficiaries. Once a beneficiary is included in the CMHS sample, the record remains on the file permanently regardless of activity or death. The summary file links data covering all Medicare benefits on a continuous annual basis. Beneficiary characteristics and summarized Part A and Pan B utilization data are included. The file can be used as a longitudinal statistical data base to study beneficiary utilization of all Medicare benefits.

Agency: Health Care Financing Administration

Status: Ongoing.

(17) NMES - National Medical Expenditure Survey

The major components of the NMES provide measures of health status, insurance coverage, use of services, out-of-pocket expenses, and sources of payment for the 1987 calendar year for the civilian population of the United States. NMES consists of a household survey, a survey of American Indians and Alaskan Natives (SAIAN), and an institutional population component (IPC). The household survey samples 36,400 individuals in approximately 15,000 households and has a long-term care supplement which provides estimates of persons with functional disabilities and impairments, their use of formal home and community services, and financial burden of care provided by family and friends.

EXPLANATION OF DATABASES
(continued)

The **SAIAN** provides a basis for comparing the use of health services by the American Indian and Alaskan native population eligible for care through the Indian Health Service and the use of traditional medical care.

The IPC surveys nursing homes and facilities for the mentally retarded gathering information on newly admitted and long-time residents related to health care use and expenditures both within the institution and in the community. Information on health and functional status, demographic characteristics, living arrangements, and insurance coverage were obtained from facility administrators, designated staff, and respondents' next of kin or other knowledgeable person in the community to obtain additional personal history and related information. (See Appendix E for additional information).

Agency: Agency for Health Care Policy and Research, Public Health Service

Status: NMES is a one time survey. Two other health care expenditure surveys have been conducted in the past. These include the 1977 National Medical Care and Expenditure Survey (NMCES), and 1980 National Medical Care Utilization and Expenditure Survey (NMCUES).

(18) Group Health Plan Master File

The "Group Health Plan Master" (GHP) is a data base which contains information about Medicare beneficiary membership in coordinated care plans under contract with HCFA. The data includes the beneficiary's plan enrollment and disenrollment dates, and status indicators of the beneficiary, such as end-stage renal disease (ESRD), hospice, Medicaid, institutionalization, and payment information.

The McCoy - "Managed Care Option Information" is an on-line data base system which is part of the GHP system. It is used by regional and central office staff to record beneficiary enrollments, disenrollments, status indicators and residence information in the GHP data base. It also allows view capability of nearly all information in the data base.

Agency: Health Care Financing Administration

Status: Ongoing.

(19) Cost Reports for Cost HMOs

All cost-based plans (Health Maintenance Organizations and Health Care Prepayment Plans - HMO's and HCPP's) must submit a yearly budget and enrollment forecast 90 days prior to the beginning of each contract period. From this report, an interim rate is established and the plan is paid monthly based on this rate. A cost HMO submits four quarterly cost reports and a certified final cost report. The quarterly report is due 60 days after the close of each quarter and the certified report is due 180 days after the close of the contract period. An HCPP submits a semiannual cost report and a final cost report. These reports are submitted 60 days and 180 days respectively after each period covered. The final cost report does not have to be certified.

EXPLANATION OF DATABASES
(continued)

Agency: Health Care Financing Administration

Status: Ongoing.

(20) ACR - Adjusted Community Rate Proposals

The Adjusted Community Rate (ACRs) proposals are required to be submitted by TEFRA risk plans to HCFA 45 days prior to the start of each plan's contract period. They are submitted to Office of Financial Management (OFM) auditors on disk with hardcopy supporting the ACR. Each ACR is logged and tracked as it flows through the review process. When the auditor receives the ACR, they review the support data for the base rate, adjustments, volume and complexity factors and adjusted community rate. Each line of the ACR proposal is checked by the OFM auditor. The auditor reviews the previous year's ACR and compares it.

OFM's data base is also used to compare the plan's ACR with not only its prior year data, but also with data belonging to other health plans in the area. The data base was developed by OFM to assist auditors during their review of the ACR. The data base was created by utilizing statistics gathered from ACRs submitted in 1987, and has been updated each succeeding year. Examples of the data in the ACR data base include the following:

- various service categories, i.e., inpatient hospital physician services;
- volume and complexity factors;
- variations between ACR years;
- premium information, i.e., copayments deductibles, and
- average payment rates.

Adjusted Community Rate (ACR) Proposals are submitted by HMOs and include the estimated costs of services they offer in addition to what they charge for those services.

Agency: Health Care Financing Administration

Status: Ongoing.

(21) NDRR - National Data Reporting Requirements

The National Data Reporting Requirements (NDRR), are the financial, enrollment, and utilization reporting requirements for federally qualified health maintenance organizations (HMOs) and competitive medical plans (CMPs). The Department of Health and Human Services instituted these requirements to monitor HMOs according to Title XIII of the Public Health Service Act. Each Federally qualified HMO and CMP is required to submit data on a quarterly or annual basis depending on its financial status. Certain data elements are entered into a mainframe data base called the NDRR subsystem which is linked to PICS (Plan Information Control System, a mainframe system that provides the Office of Prepaid Health Care with a central data base of plan specific information). This database is used by the Office of Compliance within the Office for Prepaid Health Care (OPHC) for overseeing and monitoring of federally qualified HMOs and CMPs.

EXPLANATION OF DATABASES
(continued)

Data elements entered into the NDRR include the following:

- total assets;
- total liabilities;
- contingency reserve;
- premium and related revenue;
- total revenue;
- total medical and hospital expense;
- total administrative expense;
- income;
- total members at end of period;
- total member ambulatory encounters for the year by physician and non-physician visit;
- total hospital patient days incurred;
- claims payable (reported and unreported); and
- information concerning activities of insurers and HMO members of a holding company group.

Aoency: Health Care Financing Administration

Status: Ongoing.

(22) The Disenrollment Survey

The Disenrollment Survey provides information on the number of Medicare prepaid health PLAN disenrollments from April 1985 to July 1987, including reasons for disenrollments. The survey is being used to assess the quality of services received by Medicare beneficiaries enrolled in Prepaid Health Plans.

Aoency: Health Care Financing Administration

Status: Results from the Survey are currently being analyzed.

(23) BITS - Beneficiary Inquiry Tracking System

BITS, which stands for Beneficiary Inquiry Tracking System, is a mainframe system accessible to all the regional offices and the Office of Prepaid Health Care. The system is used primarily by the regional offices to collect data about the type and disposition of inquiries and complaints from and on behalf of Medicare beneficiaries enrolled in Health Maintenance Organizations and Competitive Medical Plans (HMOs/CMPs). BITS provides the regions with a means of tracking and monitoring beneficiaries' inquiries throughout the resolution process. The system also provides aggregated data helpful to the regions and the Office of Prepaid Health Care in identifying potential problems within specific health care plans. BITS also provides the Office of Prepaid Health Care with a national database for conducting comparative studies on the various types of prepaid health plans, e.g., cost versus risk plan, staff models versus IPAs.

Aoency: Health Care Financing Administration

Status: Ongoing.

EXPLANATION OF DATABASES
(continued)

(24) PICS - Plan Information Control System

PICS, which stands for Plan Information Control System, is a mainframe system that provides the Office of Prepaid Health Care with a central data base of plan-specific information. The system maintains data on a variety of plan areas such as financial status, utilization, Medicare contract operations, and corrective actions. The other systems within HCFA that PICS interfaces with are the Group Health Plan System (GHP), the Automated Plan Payment System (APPS), the Beneficiary Inquiry Tracking system (BITS), the National Data Reporting Requirements, and the Reconsideration System (RECONS). The information collected from these various sources assists the Office of Prepaid Health in qualifying and monitoring prepaid health plans and Medicare contractors.

Aoency: Health Care Financing Administration

Status: Ongoing.

(25) NLTCs - National Long-Term Care Survey

The 1982, 1984, and 1989 National Long Term Care Surveys (NLTCs) were designed to provide a data base which describes the population of non-institutionalized chronically disabled elderly persons in terms of their health and functional status, and their patterns of use of hospital, home health services, and institutional care. The 1982 and 1984 NLTCs are detailed household surveys of persons aged 65 and over who manifest some chronic Activity of Daily Living (ADL) or Instrumental Activity of Daily Living (IADL) impairment. The major content areas covered by the questionnaire for community dwelling persons are:

- Medical status (diagnosis);
- Functional status (presence of ADL, IADL, or other functional impairment including equipment or caregivers used by the person to deal with impairments);
- Income and assets;
- Use of health care services and sources of payment; and
- Housing and living arrangements.

In addition, the surveys contain detailed questions on the number and type of informal caregivers., (See Appendix E for additional information).

Aoency: National Institute on Aging, Health Care Financing Administration, and Office of the Assistant Secretary for Planning and Evaluation.

Status: The NLTCs is planned to be conducted again in 1992. The intent of the NIA is to conduct the survey every four years.

(26) NNHS - National Nursing Home Survey

The National Nursing Home Survey (NNHS) was designed as an ongoing series of **surveys to** satisfy the diverse data needs of those who establish standards **for, plan, provide,** and assess long-term care services. The first NNHS was conducted between August 1973 and April 1974; the second from May through December 1977. The third and most recent

EXPLANATION OF DATABASES
(continued)

survey was conducted from August 1985 through January 1986. There were 5,243 current residents, 6,023 discharges, and 2,763 registered nurses responding from the 1,079 nursing homes that participated in the survey. This nationwide sample survey of nursing and related care homes, their residents, and their staff is conducted by the National Center for Health Statistics (NCHS). (See Appendix E for additional information).

Agency: National Center for Health Statistics, Centers for Disease Control

Status: The NNHS is to be incorporated into the National Health Care Survey (NHCS) which will be conducted annually beginning in 1993.

(27) NHIS - National Health Interview Survey

The NHIS is a continuous nationwide sample survey in which data are collected on the incidence of acute illness and injuries, the prevalence of chronic conditions and impairments, the extent of disability, the utilization of health care services, and other health-related topics. The survey consists of basic core questions asked every year which gather information on doctor visits and hospital stays, chronic and acute conditions, health status indicators, limitation of activities, injuries and impairments, and work-loss and school-loss days. Since 1989, annual data have been collected on family resources, income, and federal program participation. Supplements include current topics of interest such as health promotion and disease prevention, knowledge of and attitude toward AIDS, smoking, health insurance, risk factors, child health, and aging. Future supplements to the NHIS include the following: "Year 2000 Objectives," "AIDS Knowledge and Attitudes," "Income," and "Drug Use" for the 1991 supplement; "Cancer," "Youth Risk Behavior," "AIDS," and "Family Resources" for the 1992 supplement; "Disability," and "Child and Maternal Health" for the 1993 and 1994 supplement, and "Year 2000 Objectives" for the 1995 supplement. (See Appendix E for additional information).

Agency: National Center for Health Statistics, Centers for Disease Control

Status: Ongoing.

(28) IMHO/GHMHS - The 1990 Inventory of Mental Health Organizations and General Hospital Mental Health Services

This is a periodic, complete enumeration survey of specialty mental health organizations, designed to collect information on organizational, program, and patient characteristics, patient movement statistics, staffing, revenues, and expenditures.

The 1986 IMHO/GHMHS marked the beginning of major improvements in the NIMH Inventory by combining the Inventory of Mental Health Organizations (IMHO) with the Inventory of General Hospital Mental Health Services (IGHMHS), previously conducted separately. This simplified data collection, decreased response burden, and allowed for the development of a common core form with three versions -- one for specialty mental health organizations, one for general hospitals with separate psychiatric services, and a brief screening form for **general hospitals without separate psychiatric services**.

EXPLANATION OF DATABASES (continued)

The inventories include questions on the following:

- types of services provided (e.g., inpatient, outpatient, and partial care);
- number of inpatient beds;
- number of inpatient, outpatient, and partial care additions;
- average daily and end of year inpatient census;
- expenditures;
- staffing by type of discipline; and
- revenue by sources (after 1983 only).

The following organizations are included in the IMHO/GHMHS:

- outpatient mental health clinics;
- psychiatric hospitals (private and public);
- residential treatment centers for emotionally disturbed children (RTC);
- mental health partial care organizations;
- multiservice mental health organizations; and
- general hospitals with separate psychiatric service(s)

In 1988, the Inventory was expanded to cover community residential organizations, and questions were added on case management services.

Aagency: National Institutes of Mental Health.

Status: The Inventory is conducted every two years. The 1990 Inventory was sent to the field at the beginning of 1991, and data will be available the summer of 1992.

(29) 1986 Client/Patient Sample Survey of Inpatient, Outpatient, and Partial Care Programs

This sample survey gathered data from eight types of organized mental health settings which include the following:

- state and county mental hospitals;
- private psychiatric hospitals;
- multiservice mental health organizations;
- Veterans Administration medical centers;
- non-Federal general hospitals with separate psychiatric services;
- residential treatment centers for emotionally disturbed children;
- freestanding outpatient mental health clinics; and
- freestanding partial care organizations

The survey was designed to make inferences nationally about the number and characteristics of persons admitted to and terminated from these organizations during April 1986, and about persons under care in these organizations on April 1, 1986. Specific data gathered on patients currently receiving care as well as patients admitted to and terminated from the mental health settings which were surveyed include the following:

EXPLANATION OF DATABASES (continued)

- demographic characteristics, such as sex, race, and age;
- principal psychiatric diagnosis; and
- median length of stay

The target population included all clients/patients admitted, readmitted, discharged (including deaths), and transferred into and out of inpatient, outpatient, or partial care programs during the month the survey was conducted. The sampling frame used for the survey was the 1983 Inventory of Mental Health Organizations (IMHO) and the 1983 Inventory of General Hospital Mental Health Organizations (IGHMHS).

Agency: National Institute of Mental Health.

Status: This survey was conducted during April through July of 1986. Data from this survey appears in Mental Health, United States, 1990.

(30) The 1990 Longitudinal Client Sample Survey of Outpatient Mental Health Programs

The 1990 Longitudinal Client Sample Survey of Outpatient Programs is the first effort by NIMH to collect information on patterns of outpatient service use by individual clients. The survey includes a sample of no more than 8 client admissions and 8 clients continuing care in each sample outpatient program.

At the beginning of the survey, sociodemographic, and clinical data are collected on each sample client. This information provides data that describe clients served in outpatient programs. Changes in these characteristics are assessed at the time of termination and readmission, if these events occur during the survey period.

A major focus of the survey is the development of statistical information on service use, including services received, the costs of these services, and the types of clinicians who deliver these services. The information is being collected monthly throughout the survey period for any sample client who continues to receive care.

Information is also being gathered on the adaptive functioning of sample clients such as ability to engage in instrumental or social activities, and behavioral problems or psychiatric symptomatology.

Agency: National Institute of Mental Health.

Status: A one-year longitudinal survey which began in May 1990 and is expected to be completed by December 1991. It is anticipated that data will be available the beginning of summer 1992.

(31) Longitudinal Patient Data for State Mental Hospital Inpatient Services

This is a full enumeration survey of all episodes of care in state mental hospital inpatient services in fifteen states for the period from FY 1984 to FY 1989. The fifteen states

EXPLANATION OF DATABASES (continued)

participating in the project include Colorado, Maryland, Missouri, New Jersey, North Carolina, Massachusetts, Nebraska, Ohio, Oklahoma, Oregon, Tennessee, Texas, Utah, Virginia, and Washington.

Specific data items required for submission by these states include the following:

- organization identifier (a code specific to each state mental hospital);
- record identifier (a unique algorithm generated for the patient responsible for the episode of care, consisting of initials for the first and last name, code for sex, and date of birth);
- code for county of residence at time of admission;
- date of birth;
- race;
- **Hispanic** origin;
- date of admission for the episode;
- whether transferred from another state mental hospital inpatient program;
- whether a readmission to the hospital;
- indication of receipt of prior mental health care and whether prior care was inpatient or other;
- diagnosis at admission;
- discharge status; and
- date of discharge, death, transfer

There are additional data elements which states have the option to submit depending on whether they routinely collect the data. This data base permits longitudinal analysis of care patterns for individual patients.

Agency: National Institute of Mental Health.

Status: Five additional states which are informally participating include the District of Columbia, New York, Rhode Island, South Carolina, and Vermont. It is anticipated that all states will soon have six years' worth of longitudinal patient-specific data for FY 1984 through 1989.

(32) Inventories of State Prison and Local Jail Mental Health Services

The Inventories of State Prison and Local Jail Mental Health Services are complete enumeration surveys designed to collect information parallel to that of the Inventory of Mental Health Organizations and General Hospital Mental Health Services (IMHO/GHMHS). The 1988 Inventory of State Prison Mental Health Services has been completed and results have been checked by the State Departments of Correction. Data from the Inventory will be included in Mental Health, United States, 1992.

The Local Jail Mental Health Services survey has been designed and pre-tested. This feasibility study on local jail mental health services was designed as a companion to the 1988 Inventory of State Prison Mental Health Services. The pretest gathered information on type of mental health services available, organizational arrangements for services, number of persons served, staffing, and financial resources.

EXPLANATION OF DATABASES
(continued)

Aaency: National Institute of Mental Health.

Status: A full scale survey is planned for 1992, and will sample approximately 3,300 local and county jails. It is anticipated that data will be available summer 1993.

(33) Severely Mentally Ill Persons in Households

NIMH sponsored a NHIS supplement in 1989 entitled "Serious Mental Illness." The purpose of this NHIS survey supplement was to estimate the prevalence, demographic and socioeconomic characteristics, and level of functioning of the non-institutionalized seriously mentally ill population in the United States. Information obtained in this survey includes recent use of mental health related services, prescription medication use, and participation in Supplemental Security Income (SSI), and Social Security Disability Insurance (SSDI) Programs. Information gathered on functional limitations relate to the following:

- work;
- school;
- personal care;
- instrumental activities of daily living (managing money, doing everyday household chores, shopping, and getting around outside the home); and
- social and cognitive activities (forming friendships, keeping friendships, concentrating to complete tasks, coping with day-to-day stress)

Information about a mental or emotional disorder diagnosis was determined using a checklist of specific severe mental disorders and a **followup** question about the presence of "any other mental or emotional disorder" that seriously interfered with a person's ability to work or attend school or to manage their day-to-day activities.

Questions are also asked about if and when the disorder was diagnosed by a doctor, if and when a mental health or other health professional was last seen for the disorder, the type of mental health professional last seen, and the use of prescription medication for the disorder.

Aaency: National Institute of Mental Health.

Status: Data from the 1989 NHIS supplement are currently available on Public Use -Tapes. NIMH has considered conducting a **followup** survey to this supplement to gather information on costs, family burden and changes in disability levels over time, however, a **followup** survey is currently not funded.

(34) Annual Census of State and County Mental Hospitals

The annual Survey of Patient Characteristics for State and County Mental Hospital inpatient Services serves as the source of information for the Annual Census of State and County Mental Hospitals. This survey collects aggregate data on age, sex, and diagnosis by state, for additions to and resident patients of known inpatient services provided by state and county mental hospitals.

EXPLANATION OF DATABASES (continued)

Agency: National Institute of Mental Health

Status: Annual on-going survey conducted since 1950.

(35) **DATOS - Drug Abuse Treatment Outcome Study**

The Drug Abuse Treatment Outcome Study (DATOS) consists of a multi-year investigation of drug abuse treatment effectiveness based on a nationwide sample of short- and long-term methadone maintenance, short- and long-term residential treatment, and outpatient drug-free treatment programs. The sample consists of 20,000 individuals entering one of 50 drug abuse treatment programs over a two-year period. Data are obtained from interviews conducted at entry to treatment, during treatment, and upon leaving treatment. Client interviews will be supplemented with clinical assessments of psychological, social, and physical impairments, in addition to drug and alcohol dependence. Outcomes are compared for clients entering treatment with varied patterns of drug abuse and levels of psychosocial impairment, and experiencing varied types and durations of treatment. Research questions include what treatments and services are available to the client, how these are delivered, and how they are related to outcome measures such as drug use, criminality, and employment.

A sample of 4,500 individuals chosen from those entering treatment are interviewed after leaving. The follow-up sample is selected to represent specific strata of drug abuse patterns, levels of impairment, and types of treatment. Outcome criteria include use of the primary problem drug, use of other drugs, criminal behavior, and employment. The criteria will be compared with performance during treatment, and with pre-treatment baseline measures. Clients who drop out of treatment prematurely will be compared with those who successfully comply with treatment.

As the first large-scale study of treatment outcomes since the implementation of block-grant funding, DATOS will yield valuable information about the characteristics of individuals in treatment and the effectiveness of treatment as it presently exists, and will suggest strategies to improve treatment.

Agency: National Institute on Drug Abuse, Alcohol, Drug Abuse, and Mental Health Administration

Status:

- DATOS has been sent to the Office of Management and Budget for clearance. It is anticipated the study will be fielded July 1991 and collect data for a 5-year period. Follow-ups to the survey are planned.
- Currently under development is a longitudinal outcomes study of adolescents in drug abuse treatment. This study will follow the model established for DATOS. Approximately 6,000 adolescents will be entered into the study at intake to treatment, and a sample of approximately 1,200 of these will be followed after treatment.

(36) **Treatment Client Data System**

The Treatment Client Data System, will consist of a national data set for the collection of information on admissions for treatment of alcoholic and drug abuse problems. States will

EXPLANATION OF DATABASES (continued)

modify their client systems to accommodate a minimum set of variables and will supply data on those variables to National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA). The system for client treatment data will consist of data on all individual client admissions to state-supported treatment programs throughout the United States. NIDA and NIAAA have provided grants to the state alcohol and drug abuse agencies for the purpose of adopting national data standards to implement the minimum data set in response to requirements in the Anti-Drug Abuse Act of 1988. State-by-state implementation in the national data base began in June 1990 and continues through September 1991. When complete, national and comparative state data on the characteristics of substance abuse clients and their patterns of alcohol and drug use will be available for planning and research purposes on at least a semi-annual basis. Feedback reports will be developed for the states, and recurring statistical reports will be developed to disseminate the data to other users.

Agency: National Institute on Drug Abuse; National Institute on Alcoholism and Alcohol Abuse; Alcohol, Drug Abuse, and Mental Health Administration

Status: The system is expected to be fully operational in 1992.

(37) **SADAP - State Alcohol and Drug Abuse Profile**

SADAP is an annual survey of state alcohol and drug abuse agencies conducted by the National Association of State Alcohol and Drug Abuse Directors (NASADAD) with contract support from NIAAA and NIDA. Through annual meetings, the states provide consultation on SADAP content and procedures. From their existing data systems and records, the state agencies provide summary state-level data pertaining to amount and sources of funding for state funded programs, and numbers and characteristics of clients admitted to treatment. Narrative descriptions of major policy issues, unmet needs, and recent changes in state services are also provided. Since the data collected are derived from individual state sources, they are not strictly comparable among the states.

Agency: National Institute on Drug Abuse; National Institute on Alcoholism and Alcohol Abuse; Alcohol, Drug Abuse, and Mental Health Administration

Status: Ongoing.

(38) **NDATUS - National Drug and Alcoholism Treatment Unit Survey**

NDATUS is an annual survey of all known publicly and privately funded alcohol and drug abuse treatment units throughout the United States. The NDATUS was implemented by NIDA in 1974, and originally only collected data from drug abuse treatment programs. The NDATUS was expanded to include alcohol programs and has been conducted with NIAAA since 1979. NDATUS identifies the location, scope, and characteristics of substance abuse treatment and prevention units. The NDATUS provides information which assists federal, state, and local governments to assess the nature and extent of private and publicly-supported treatment and prevention programs and to identify unmet needs in programs targeted at particular subpopulations, such as youth. The survey is conducted through the active participation of the state drug and alcohol authorities. A major mechanism for information dissemination is the National Directory of Drug Abuse and Alcoholism Treatment

EXPLANATION OF DATABASES
(continued)

and Prevention Programs. A report presenting data findings is also published. Preliminary data are available within six to nine months of the point prevalence data.

Agency: National Institute on Drug Abuse; National Institute on Alcoholism and Alcohol Abuse; Alcohol, Drug Abuse, and Mental Health Administration

Status: NDATUS is an ongoing annual survey.

(39) NLAES - National Longitudinal Alcohol Epidemiologic Survey

The NLAES is a longitudinal survey of noninstitutionalized persons residing in the contiguous United States who will be randomly selected using statistical methods of probability. Oversampling will occur for those between the ages of 18 and 29.

The NLAES will serve varied NIAAA needs. NIAAA needs current, reliable national and regional estimates of the incidence and prevalence of alcohol use practices, alcohol use disorders, and alcohol-related problems and consequences. The extent and distribution of alcohol-related treatment utilization and unmet needs in the general population is also required. The data will be used for the following:

- estimate the economic costs of alcohol related morbidity in the United States;
- identify subgroups of the population at high risk of developing alcohol use disorders, alcohol-related problems, and associated disabilities;
- identify factors influencing the abstinence, remission, incidence, and chronicity of alcohol use disorders and alcohol-related problems;
- estimate the incidence and prevalence of concurrent and simultaneous use of alcohol with other drugs;
- increase the understanding of the natural history, nature, and processes underlying the initiation and maintenance of alcohol use disorders and their consequences; and
- understand the relationships between alcohol use practices, alcohol use disorders, and other alcohol-related morbidity.

Using these data, specific prevention, intervention, and research programs will be designed to reflect the nature, magnitude, and distribution of alcohol use disorders and their associated disabilities in the general population.

Agency: National Institute on Alcohol Abuse and Alcoholism, ADAMHA

Status: Approximately 50,000 interviews will be conducted with the first wave of the NLAES to be implemented in September 1991. Two follow-up surveys of respondents will be conducted at two year intervals.

(40) NMIHS - National Maternal and Infant Health Survey

The 1988 National Maternal and Infant Health Survey (NMIHS) is the most recent of a series of related surveys. The earlier surveys include the National Mortality Followback Surveys (1961-68, 1986), the National Natality Followback Surveys (1963, 1964-66, 1967-69,

EXPLANATION OF DATABASES (continued)

1972, 1980), the National Fetal Mortality Survey (1980), and the National Infant Mortality Survey (1964-66). The 1988 National Maternal and Infant Health Survey incorporates components from all of these earlier surveys.

The NMIHS is conducted to gather information on causes of low birth weight and infant death; barriers and facilitators to prenatal care; the effects of maternal smoking, marijuana and cocaine use, and drinking on pregnancy outcome; and use and evaluation of public programs, such as The Special Supplemental Food Program for Women, Infants, and Children (WIC) and Medicaid, by mothers and infants.

The 1988 NMIHS consists of three components: a natality survey based on 10,000 certificates of live birth, a fetal mortality survey based on 4,000 reports of fetal death, and an infant mortality survey based on 6,000 infant death certificates.

Agency: National Center for Health Statistics, Centers for Disease Control

Status: It is anticipated that the next NMIHS will be conducted in 1995.

(41) LFS - 1990 Longitudinal Followup Survey

The longitudinal **followup** survey will create a representative longitudinal data base for analyzing the information collected during the 1988 NMIHS by re-interviewing respondents. Topics included are child development, effects of low birth weight, use of WIC foods, child nutrition, child care, child neglect, barriers to pediatric care, environmental hazard exposures, and injuries. The design features include re-interviews with 10,000 mothers of live births (5,000 black, 3,000 low birth weight), questionnaires to pediatricians, questionnaires to hospitals (6,000 mothers of infant deaths, and 4,000 mothers of stillbirths). The questions on drug abuse included in the interview will inquire about the use of marijuana and cocaine and will be basically the same as those in the baseline study. The questions included on illicit drug use will provide data on the association between substance use during pregnancy and child development.

Agency: National Center for Health Statistics, Centers for Disease Control

Status: The LFS will be fielded for about 1 1/2 years beginning in 1990. Public use data tapes will be available within 1-2 years after the field work has been completed.

(42) HHANES - Hispanic Health and Nutrition Examination Survey

The HHANES **was** a multipurpose health and nutrition survey conducted from 1982-1984 on the Mexican American, Cuban American, and Puerto Rican populations of United States. The primary purpose was to estimate the prevalence of selected diseases and conditions, to describe nutritional status, and generally to provide data on the Hispanic population that was comparable to that collected from the general population in previous surveys. There were two major areas of emphasis. The first was health status assessment, with a focus on such health conditions such as diabetes, heart disease, obesity, dental diseases, vision, alcohol consumption, aspects of mental health, and drug abuse. The second area was nutritional status assessment, including diet, anthropometry, and

EXPLANATION OF DATABASES
(continued)

hematological and biochemical determinations. Additionally, the survey included an assessment of exposure to selected toxic chemicals. The HHANES was the sixth in a series of examination surveys conducted by NCHS since 1960 and the first to target specific population subgroups and include questions on the use of illicit drugs and nonmedical use of sedatives in the private interview given as part of the physical examination. The overall response rate was approximately 74 percent and the examined sample included 7,462 persons in the Mexican American sample, 1,337 in the Cuban American sample, and 2,834 persons in the Puerto Rican sample.

The questions in the HHANES drug abuse component were sponsored by ADAMHA for the purpose of estimating the duration and frequency of illicit use of marijuana, cocaine, and inhalants, and lifetime prevalence of use of sedatives for nonmedical purposes.

Aaencv: National Center for Health Statistics, Centers for Disease Control

Status: Completed in 1984. Public use tapes available.

(43) ACSUS - AIDS Cost and Service Utilization Survey

The Agency for Health Care Policy and Research (AHCPR) has awarded a contract to Westat, Inc. to conduct the AIDS Cost and Service Utilization Survey (ACSUS) to collect data on the utilization and costs of health and social services for persons with AIDS and other HIV-related illnesses. It is designed to overcome many of the limitations of previous studies on the cost of HIV illness.

ACSUS will fill gaps in existing knowledge by providing comprehensive and detailed data for patients from both high- and low-prevalence cities, HIV exposure categories, and diverse socioeconomic backgrounds. Over an 18-month period, interviews will be conducted every three months with the sample consisting of approximately 2,000 adults/adolescents and 400 children drawn from ten cities. To address the full spectrum of HIV illness, approximately half the ACSUS sample will have a diagnosis of AIDS at the time of enrollment, and half will be HIV positive but without AIDS. The latter group will include individuals who are asymptomatic.

ACSUS will provide comprehensive, patient-based data including sociodemographic characteristics, HIV exposure category, severity of illness, and quality of life. In addition to medical services, ACSUS will address the use of mental and oral health services, social services, informal social support, barriers to care, and satisfaction with care. Patient interview data will be supplemented by information abstracted from patient records and information supplied by providers and insurers.

In addition, ACSUS will provide data on both the direct and indirect costs of medical and support services. Data collected in this survey will include information on the following:

- charges for the services of physicians, nurses, and other health care professionals, as well as charges for drugs, medical supplies, and devices;
- services provided by volunteers;

EXPLANATION OF DATABASES
(continued)

- third-party and out-of-pocket payments for inpatient and outpatient care received in physicians' offices, ambulatory clinics, and patients' homes; and
- patient employment history and income

ACSUS final products will include the following:

- estimates of the national and regional costs of HIV illness (based on the results of ACSUS and other comparable studies);
- reports and publications examining utilization, cost, and access across HIV exposure categories, stages of illness, demographic characteristics, geographic areas, and sources of payment;
- data to support policy analyses and formulation;
- data tapes for use by the research community; and
- data useful for needs assessments and service provision

Agency: Agency for Health Care Policy and Research, Public Health Service

Status: Screening and interviewing was begun March 20, 1991. It is anticipated that data will be made available Fall 1991. It is the intent of AHCPR to convert ACSUS into an ongoing survey of people with HIV illness and sample an additional 100 women.

(44) AIDS Case Surveillance

Data are collected on the incidence and prevalence of cases meeting the AIDS Case Surveillance definition, including demographic and risk factor data on cases. Data are reported to state and local health departments and forwarded to the Centers for Disease Control (CDC) monthly. Data are collected on intravenous (IV) drug use as a risk factor for HIV infection. Nationwide data since 1984 are available. Data are reported monthly.

Agency: Center for Infectious Diseases, Centers for Disease-Control

Status: Ongoing.

AIDS Case Surveillance (supplemental)

This supplemental surveillance effort collects detailed surveillance information on illicit drug use. Targeted surveillance will be conducted in four city/county health departments and one state. Data will be collected by patient interviews as an extension of routine AIDS surveillance. Interviews will include all cases of AIDS in injection drug users and either a sample or all cases in persons with other risk factors.

Information to be collected by patient interviews will include information on drug use by injection and other modes of use.

Agency: Center for Infectious Diseases, Centers for Disease Control

Status: Planned.

**EXPLANATION OF DATABASES
(continued)**

(45) HIV Counseling and Testing System

This system gathers data on all publicly funded HIV counseling and testing. It receives quarterly HIV counseling and testing statistical reports from 63 state, territorial, and local health jurisdictions covering the entire country. Data have been collected since 1988 with 960,000 reports from July 1988 through July 1989. Results will be provided to the reporting site quarterly, and results will be published in the Morbidity and Mortality Weekly Report at least annually. Data will be used to determine trends in HIV positivity in drug users and other high risk persons.

Agency: Center for Prevention Services, Centers for Disease Control

Status: Ongoing.

(46) NHSS - National Household Seroprevalence Survey

The objective of the NHSS was to estimate the prevalence of human immunodeficiency virus (HIV) in the noninstitutionalized civilian population of the United States ages 18-54 years. The survey would have provided information which could have been used to plan effective treatment and prevention strategies and to target intervention efforts and resources to those Americans at highest risk. In addition to the collection of a blood specimen, questionnaire items included indicators for other sexually transmitted diseases, hemophilia, blood transfusions, intravenous (IV) drug use, and sexual practices and history.

The NHSS has currently concluded a series of pilot tests designed to develop field procedures and methodologies and determine the feasibility of a national study. If the main study was fielded, interviews would have been conducted with approximately 50,000 household respondents. The decision not to field the main study was made in early in 1990. Data collected by questionnaire would have been linked to the results of the HIV test.

Much attention is being paid to developing mechanisms to assess the impact of non-response in the NHSS, particularly for high risk groups. The questions on IV drug use had been included in the NHSS primarily as an indicator that associated high risk groups had been adequately represented in the study.

Agency: National Center for Health Statistics, Centers for Disease Control

Status: NHSS pilot tests are completed. It was determined that a national study is not feasible due to associated costs and difficulty estimating the seroprevalence of AIDS. Those involved with the pilot study state that useful information was gathered on risk behaviors.

(47) NHCS - National Health Care Survey

As a major initiative in the fiscal year 1988 Public Health Service Planning Process, NCHS examined the changes occurring in the health care delivery system, the impact of these changes, and the implications of these changes for the types of surveys of health care that are needed. This examination resulted in a plan for restructuring of the Center's current

EXPLANATION OF DATABASES (continued)

surveys of health care utilization into a National Health Care Survey that is expected to provide a more comprehensive picture of the medical care provided in the United States. The Center's four existing surveys of health care providers (the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, the National Nursing Home Survey, and the National Master Facility Inventory) are being modified into components of the NHCS. The scope of these surveys is being expanded to include alternative sites of care and a greater continuity of resources is being achieved by moving periodic surveys to an annual basis. In part, this is being accomplished by reducing historical levels of sample size for health care providers covered in existing surveys and reducing or modifying the content of each provider component. The capability to conduct routine and specialized patient follow-up studies is being instituted through a patient follow-up component in order to address outcome and quality of care issues. Greater analytic utility is expected through the use of an integrated cluster sample approach. (See Appendix E for additional information.)

Aaency: National Center for Health Statistics, Centers for Disease Control

Status: It is anticipated that all components for the NHCS will be conducted annually by 1994. The status or planned date for administering each of the components of the NHCS is summarized below.

- **National Health Provider Inventory Component: 1991**
- **Hospital and Surgical Care Component: in field**
- **Ambulatory Care Component: in field**
- **Long-Term Care Component: 1994**
- **Patient Follow-up Survey (Nursing Home Residents): 1990**
- **Patient Follow-up Survey (Other Patients): 1994**

(48) **NVSS - National Vital Statistics System**

The National Vital Statistics System is the mechanism for collecting and publishing data on births, deaths, marriages, and divorces in the U.S. The National Center for Health Statistics (NCHS) receives information on births and deaths from the registration offices of all states, New York City, the District of Columbia, the U.S. Virgin Islands, and Guam. Content and arrangement of birth and death certificates conform closely to the standard certificate recommended by NCHS.

Beginning in 1988, infant mortality data became available in files that link the characteristics of the infant at death (as reported on the death certificate) with the characteristics of the same infant at birth (as reported on the birth certificate) in a linked file of infant deaths and live births. This provides a resource for studying infant mortality by the characteristics of the mother and the infant at the time of birth.

Cause of death is coded according to the International Classification of Diseases, which is promulgated by the World Health Organization at the most detailed (four-digit) level. Since 1968, information has been available for both underlying and multiple causes of death.

EXPLANATION OF DATABASES
(continued)

Agency: **National Center** for Health Statistics, CDC

Status: On-going. Data are published in "Vital Statistics of the United States," Monthly Vital Statistics Reports, and in "Vital and Health Statistics," Series 20 and 21. Annual mortality data tapes are available approximately 15 months after the end of the calendar year.

(49) LSA - Longitudinal Study of Aging

The Longitudinal Study of Aging, a collaborative project of the National Center for Health Statistics (NCHS) and the National Institute on Aging (NIA), is designed to measure change among a cohort of older Americans. The study is based on the 1984 National Health Interview Survey (NHIS) Supplement on Aging (SOA). Information was obtained for 16,148 persons ages 55 years and over in the SOA (96 percent of the eligible people interviewed during the 1984 NHIS household survey). Ninety-two percent answered all questions for themselves.

The SOA was designed to obtain extensive information on the following:

- family structure and frequency of contacts with children;
- housing (including barriers to movement, length of time in residence, ownership and rental information);
- use of community and social supports;
- occupation and retirement (including sources of retirement income);
- ability to perform work-related functions;
- conditions and impairments; and
- functional limitations (activities of daily living and instrumental activities of daily living) and providers of help in those activities.

The Longitudinal Study of Aging includes three follow-up telephone interviews, conducted in 1986, 1988, and 1990, to obtain information about changes for those age 70 and older. The interviews were designed to measure the following:

- death rates by social, economic, family, and health characteristics;
- changes in functional status (ability to perform work-related activities, activities of daily living, instrumental activities of daily living) and the provision of help;
- changes in living arrangements, including movement toward living alone or with others in the community or into nursing homes;
- changes in coverage by public insurance, and
- use of hospitals and nursing homes by individuals over time.

Their records were matched with the National Death Index (to ascertain date of death), and cause-of-death records. This enables the study of survival and death in relation to social, demographic, family support, and health conditions. In addition, respondents were asked for their health insurance claim numbers and for permission to match their interview records with the Medicare records maintained by the Health Care Financing Administration. The matches have been made, and the first information was included in the 1988 release of the public-use files.

EXPLANATION OF DATABASES (continued)

The 1988 and 1990 interviews were designed to continue measuring the same changes. They repeat some questions that were asked in 1984 survey to gather information on conditions that changed over 4 (or 6) years.

Agency: National Center for Health Statistics, and the National Institute on Aging

Status: This one time study has been completed. Data are published in "Vital and Health Statistics," Series 10. Public use data tapes are released through the Division of Health Interview Statistics, National Center for Health Statistics.

(50) PORTS - Patient Outcome Research Teams

PORTS projects are designed to identify and analyze the outcomes and costs of alternative practice patterns for a specific condition, determine the best strategy for treatment or clinical management, and develop and test methods for reducing inappropriate variations in practice. PORTS evaluate the effectiveness and cost-effectiveness of alternative services or procedures for the prevention, diagnosis, treatment, and management of specific clinical conditions. Considered in the analysis are any pertinent medical, surgical, nursing, or pharmacological interventions, including the possibilities of decisions not to treat ("watchful waiting"). Patient outcomes to be addressed include objectively measured clinical outcomes as well as patients' perceptions of their functional ability, health status, and quality of life. PORTS projects generally include the following components:

- Review and formal synthesis: The team conducts a comprehensive literature review and formal synthesis of available research findings. This is the basis for the refinement of research hypotheses, specification of needed data, and finalization of instruments, measures, and procedures to collect the data.
- Collection and analysis of data: PORTS acquire the data needed to identify and explain variations in clinical practice and in outcomes. Sources of secondary data include enrollment and claims data maintained by the Health Care Financing Administration, hospital discharge abstracts, state health department records, patient registries, and insurance records. These data are supplemented by primary data collected via surveys of patients and providers or by abstracting patient records.
- Dissemination of findings and recommendations: PORTS draw conclusions and make recommendations regarding the effectiveness and appropriateness of alternative clinical practices. Methods and materials are designed to disseminate findings and recommendations to health care providers and the public. Dissemination methods include print, audiovisual, and video productions for students and specialized groups of health professionals as well as presentations for patients and lay audiences.
- Evaluation of effects on clinical practices: PORTS conduct studies to identify effective strategies for producing desired changes in clinical practices (reductions in unwarranted variations). This includes testing alternative

EXPLANATION OF DATABASES
(continued)

methods to present and disseminate information to various audiences and evaluating subsequent changes in practice or, when possible, changes in patient outcomes.

Agency: Agency for Health Care Policy and Research

Status: As of September 30, 1990, 11 PORTS had been awarded. These PORTS include the following:

- Back Pain Outcome Assessment Team,
- Assessing and Improving Outcomes: Total Knee Replacements,
- The Consequences of Variation in Treatment for Acute Myocardial Infarction,
- Variations in Cataract Management: Patient and Economic Outcomes,
- Assessing Therapies for Benign Prostatic Hypertrophy and Localized Prostate Cancer,
- Outcome Assessment Program in Ischemic Heart Disease,
- Outcome Assessment of Patients with Biliary Tract Disease,
- Analysis of Practices: Hip Fracture Repair and Osteoarthritis,
- Variations in the Management and Outcomes of Diabetes,
- Assessment of the Variation and Outcomes of Pneumonia, and
- Obstetrical Decisionmaking in Labor and Delivery

An additional three PORTS that are likely to be awarded before the end of calendar year 1991 include those for the analysis of Chronic Obstructive Pulmonary Disease (COPD), Congestive Heart Failure (CHF), and Prevention of Stroke.

(51) PHOS - Post Hospitalization Outcomes Study

The Agency for Health Care Policy and Research (AHCPR) and the Health Care Financing Administration (HCFA) are jointly sponsoring a new project, the Post-Hospitalization Outcomes Studies (PHOS) as part of the federal outcomes and effectiveness initiative. The PHOS are designed to provide information on elderly Medicare beneficiaries following hospitalization for specific conditions or procedures.

The goals of these studies include the following:

- identification of the types and rates of both positive outcomes and complications following hospitalization,
- determination of the impact of the hospitalization/procedure on the progression of illness and the maintenance of health and functional status, and
- development of indicators of patients who are at high risk for complications following hospitalization.

EXPLANATION OF DATABASES
(continued)

Data for the PHOS are obtained from telephone interviews with Medicare beneficiaries who have recently been hospitalized, their medical records, and Medicare claims data. Data will be analyzed by staff from the Epidemiology Branch at HCFA in collaboration with AHCPR.

Anency: Funded by the Agency for Health Care Policy and Research (AHCPR)

Status: On May 22, 1991, the PHOS Governmental Advisory Group selected total hip replacement and cholecystectomy as the two conditions to be field tested and fully implemented in a clustered sample of the nation's hospitals. Survey instruments are being developed containing both general and specific outcomes measures related to each condition. The field test is scheduled to start in the fall of 1991 with the full survey beginning in the late summer of 1992.

APPENDIX E

DETAILED DESCRIPTIONS OF MAJOR SURVEYS

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

GENERAL SURVEY INFORMATION	
survey Components	<ul style="list-style-type: none"> . Household Survey • Survey of American Indians and Alaskan Natives (SAIAN) • Institutional Population Component (IPC) <ul style="list-style-type: none"> - Surveys of Next of Kin (SNK) - Surveys in Institutions (SII)
Questionnaire Supplements	<p>The Household Survey and SAIAN include the following supplements:</p> <ul style="list-style-type: none"> • Health and Functional Status (Self-administered questionnaires) • Community-based Long-Term Care and Informal Caregiving (excluding SAIAN) • Access to Care • Income, Assets, and Housing • Taxes and Miscellaneous Topics (excluding SAIAN) <p>The IPC covers these topics although questions vary. Differences will be noted in these tables.</p>
Sponsoring Agency	Agency for Health Care Policy and Research (AHCPR)
Frequency	NMES is part of a series of health care expenditure surveys conducted intermittently (approximately every 3 to 7 years).
Past Years Conducted	<ul style="list-style-type: none"> • 1987 NMES • 1989 National Medical Care Utilization and Expenditure Survey (NMCUES) • 1977 National Medical Care Expenditure Survey (NMCES)
Future Years Planned	It is currently anticipated that the next medical expenditure survey will be conducted in 1999.
Data Release	See NMES Public Use Tape Information on pages E-1 1 through E-14.
Description of Population (Sample Size)	<ul style="list-style-type: none"> • Household Survey: Civilian, non-institutionalized population of the United States (15,139 households/36,400 individuals) • SAIAN: Population eligible for care through Indian Health Service and living on or near reservations (2,018 households) • Institutional Population Component: Persons resident in or admitted to long-term care facilities: nursing homes and facilities for the mentally retarded (1,500 facilities; 7,909 current residents; and 3,500 new admissions)
smallest Area of Analysis	Census regions.
Response rate	Information gathered in the Household Survey for 1987 was obtained from approximately 80 percent of the households in the sample. For 89 percent of the residents and new admissions sampled in nursing homes, at least one survey of next of kin interview was completed with a community respondent. For the sample of the mentally retarded, only 55 percent of the current resident sample and 58 percent of the new admission sample had at least one survey of next of kin interview completed (Refer to: "Data Collection Procedures" in General Survey Information for additional information).
Description of Survey	The major components of the NMES provide measures of health status, insurance coverage, use of services, expenditures, and sources of payment for the period January 1 to December 31, 1987, for the civilian population of the United States. The reports of health care expenditures and insurance coverage obtained in the household surveys were verified and supplemented by additional surveys. Most important among these are the Health Insurance Plan Survey of employers and insurers of consenting Household Survey respondents and the Medical Provider Survey of physicians, osteopaths, and inpatient and outpatient facilities reported as providing services to consenting members of the noninstitutionalized population sample. The Medical Records Component survey was done to provide a record check on the 1987 eligibility status and claims information of all Medicare beneficiaries, including those in the institutional population.

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

GENERAL SURVEY INFORMATION (continued)	
Sample Selection	<ul style="list-style-type: none"> • The Household Survey can be characterized as a stratified multistage area probability design with four stages of selection: <ul style="list-style-type: none"> • the selection of geographic areas as primary sampling units (PSU); • the selection of small geographic areas, or segments, within PSUs; • the selection and screening of households within segments; and • the selection of individuals with particular demographic characteristics and all others within their housing units from the set of screened households. The sample frame comprised 165 PSUs, representing 127 distinct geographic areas. <p>The Household Survey oversampled population segments known to be at risk of needing long-term care services, particularly the elderly. Oversampling was also directed at the poor, low-income families, and black and Hispanic minorities.</p> • The SAIAN sample was intended to represent the population of American Indians and Alaskan Natives living on or near reservations and eligible for services from or sponsored by the Indian Health Service. The sample is a stratified area probability design with three stages of sample selection: <ul style="list-style-type: none"> • selection of primary sampling units, which are counties or groups of contiguous counties; • selection of segments within PSUs; and • selection and screening of dwelling units within segments. The sample frame included all counties in the United States including or adjacent to reservations of federally recognized tribes or Alaskan Native villages. • The IPC sample was selected using a three-stage probability design. Individual facilities were selected in the first two stages. The inventory of Long-Term Care Places, conducted in 1986 served as the sampling frame. Three explicit criteria were selected for the facility sample: <ul style="list-style-type: none"> • nursing and personal care homes with three or more beds; • intermediate care facilities for the mentally retarded with 3-15 beds; and • all remaining facilities for the mentally retarded with more than 15 beds. <p>Additional implicit stratification variables included the following:</p> <ul style="list-style-type: none"> • Census region, • certification status, • type of ownership, • number of beds, • number of admissions, and • States and ZIP Codes <p>Within explicit strata, facilities were sorted by these variables and selected with probability proportional to size. The second stage of facility selection involved subsampling to reduce field costs associated with an otherwise unclustered sample. The IPC facility sample consisted of 810 cooperating nursing and personal care homes and 691 cooperating facilities for the mentally retarded. The third stage of sampling was the selection of sample persons. Two types of residents were selected within sampled facilities:</p> <ul style="list-style-type: none"> • current residents, or persons residing in sampled facilities January 1, 1987, and • new admissions, or persons admitted to sample facilities between January 1 and December 31, 1987. <p>The estimation procedures and associated sampling weights were designed to yield unbiased national and regional estimates for the following:</p> <ul style="list-style-type: none"> • all 1987 institutional users; • current residents of nursing and personal care homes and of facilities for the mentally retarded; • the transitional population crossing between the institutional and noninstitutional populations during the year: <ul style="list-style-type: none"> • IPC-eligible facilities; • institutional stays; • other events of care, such as hospital stays and ambulatory care in the community or in clinics; and • new admissions to nursing and personal care homes.

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

GENERAL SURVEY INFORMATION (continued)	
<p>Data Collection Procedures</p>	<ul style="list-style-type: none"> • Household Survey data collection began with a screening interview, conducted in person with occupied households in a national area probability sample. The screening interview asked for the household characteristics selected for disproportionate sampling of population groups that were of particular policy interest for the full panel survey. The initial step in the panel survey was to identify reporting units within each household. The primary reporting unit in a household included the (main) person who owned or rented the housing unit and all related persons living at that address. The secondary reporting unit consisted of persons living at that address who were unrelated to the primary reporting unit members. Reporting units identified and agreeing to participate were interviewed over five rounds. The first four rounds were at intervals of about 3 months. Following the first round interview, respondents were asked to record medical events in a calendar/diary that was reviewed as part of the interviews in rounds 2-4. Finally, the core interview in rounds 2-4 included review of and reference to a summary of responses from previous interviews. In addition to the core interview, each interview round included one or more supplementary questionnaires. Interviews in rounds 1, 2, and 4 were conducted in person, with a few exceptions such as students living far from any interviewer. Rounds 3 and 5 interviews were conducted over the telephone whenever possible, to help control survey costs. Rounds 1 and 4 included a long-term care supplement: round 2 included a caregiver and a care receiver supplement; supplement 3 in round 3 focused on access to care; and supplement 4 In round 4 asked about income and assets. The round 5 iterview consisted solely of supplement 5, covering a variety of topics. Between round 1 and round 2 interviews, participating repotting units were mailed self-administered questionnaires, one for each family member, that asked about health status, attitudes, and habits. • SAIAN data collection procedures were designed to resemble those used in the Household Survey as closely as possible. The SAIAN sample was based on an area probability frame of areas on or near reservations or Alaskan Native villages. Eligible households were those that included one or more American Indians or Alaskan Natives eligible for Indian Health Service (IHS) care. The SAIAN included only three rounds of interviewing, corresponding to round 1, round 2 and 3, and round 4 of the Household Survey, respectively. Because telephone interviews were not feasible with a large percentage of the sample, the final Household interview was not included in the SAIAN. • IPC data collection was divided into two sets of surveys. Surveys in Institutions (SII) were conducted for all sample persons to cover periods of institutionalization in 1987 by means of staff interviews in sample facilities. Since study objectives required data that facility staff could not be expected to provide, the IPC design also included Surveys of Next of Kin (SNK). These surveys comprised a set of questionnaires administered to community respondents who knew about sampled persons and their lives outside of institutions. While these community respondents were most often literally next of kin, unrelated persons such as caseworkers, accountants, and companions also provided information. Names of potential respondents were obtained from facilities. When no suitable community respondent could be identified, facillii staff were asked a subset of these questions. Designed as a set of surveys essentially independent of the facility interviews, SNK interviews for this component were done by telephone, using a computer-assisted telephone interviewing system. For SII, interviews were conducted in person but with a different set of interviewers and supervisors than the SNK. The need for repeated visits to facilities for sampling, the desirability of controlling the length of recall periods for items such as health status and use of noninstitutional medical services, and the need for health status data at several points during the reference period led to the creation of three operational phases for the IPC surveys. For facilities, these three phases translated into four visits from interviewers at approximately 4-month intervals. For community respondents, the division could mean contact as often as five times, depending on when the sample person was selected in the SII.
<p>Groups Oversampled</p>	<ul style="list-style-type: none"> • The household survey oversampled population segments known to be at risk of needing long-term care services, particularly the elderly and those functionally impaired. Oversampling was also directed at the poor, low-income families, and Black and Hispanic minorities.

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

	PERSON SPECIFIC INFORMATION
Age	Indicated by date of birth.
Sex	Indicated.
Race	Indicated by the following: <ul style="list-style-type: none"> • American Indian, • Alaskan Native • Asian or Pacific Islander • Black • White • Other Tribal membership included in SAIAN.
Ethnicity	Indicated by the following: <ul style="list-style-type: none"> • Puerto Rican, • Cuban, • Mexican, Mexicano, Mexican-American, • Other Latin American • Other Spanish.
Marital Status	Indicated-by Married; Widowed; Divorced; Separated.
Family Structure (Living Arrangement)	Respondents are asked the name of each household member and their relationship to the reference person (reporting unit).
Social Support (Caregivers)	<p>To explore the use of community-based services by people in need of long-term care and the provision of informal caregiving by Household Survey and SAIAN participants, the Long-Term Care and Informal Caregiving questionnaire supplement gathered the following information:</p> <ul style="list-style-type: none"> • use of community services, • financial help received from someone outside the household, • caregiving burden (for disabled person within household), • survey participants caring for a disabled person outside the household, • description of person(s) outside the household receiving help, • financial help provided to person(s) outside the household, and • caregiving burden (for disabled person(s) outside the household). <p>To evaluate the effect of the presence of informal caregivers on the decision to institutionalize, the SNK personal history questionnaire obtained information about the availability and use of informal caregiving just before institutionalization for all sample persons in the IPC who last lived in a non-institutional setting after January 1, 1999. The Community based Long-Term Care and Informal Caregiving questionnaire supplement reveal the following:</p> <ul style="list-style-type: none"> • Identification of Caregivers <ul style="list-style-type: none"> - those that assist with ADLs, - payments made to non-relatives for assistance received (amount and source of payment), and - primary caregiver demographics and general health status • Caregiving activities and burden <ul style="list-style-type: none"> - frequency of visits, - mode of transportation and travel time, - length of an average stay, - ADL/IADL assistance provided, - burden scale (an eight-point caregiving burden of scale, including questions on the inconvenience of helping, physical strain, family and emotional adjustments, time, pressure, upsetting physical or behavioral changes, and feelings of inability to cope.) • Use of community-based long-term care services.
Veteran Status	Included.
Education	Indicated by each year of education completed through 18 or more years.

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

PERSON SPECIFIC INFORMATION (continued)	
Income and A s s e t s	<p>For the Household Survey and SAIAN the Income, Assets, and Housing questionnaire supplement revealed the following:</p> <ul style="list-style-type: none"> • income of survey participants (includes probes for wages or salaries, tips, farm income earned/lost, money earned, lost, veteran's payments, unemployment insurance, worker's compensation, supplemental security income (SSI), social security, Aid to Families with Dependent children (AFDC or ADC) and other public assistance, railroad retirement benefits, private pensions, military retirement benefits, federal government employee pensions, state or local government employee pensions, estates or trusts, annuities, royalties, alimony, child support, regular cash contributions, interest from investments, dividends, net gain/lost from sale of property or other assets, net rental income/lost, and other sources); • housing (type of unit, financing); • amenities (running water, flushable toilet, regular trash and garbage collection), and length of residence (for SAIAN only); • services for older persons; and • transfer of home. <p>For the nursing home sample of the IPC component, the following information was gathered:</p> <ul style="list-style-type: none"> • 1986 income of sample person and spouse (source of income and total amount) • 1986 family income (total amount) <p>For the mentally retarded sample, the following information was gathered:</p> <ul style="list-style-type: none"> • 1986 income of sample person and parents (sources of income and total amount) • 1986 income of sample person only (sources of income and total amount).
Insurance Status	<p>Includes questions on the following:</p> <ul style="list-style-type: none"> • public health insurance (Medicare, CHAMPUS-CHAMPVA, Medicaid, and other public assistance); • private health insurance (source of coverage; primary insured person; use of HMO; coverage of responding unit family members; coverage through employers); • special plans (dread disease and extra cash). • transition to Medicaid (spend-down for IPC only).
Disability Benefits	Included in Income, Assets, and Housing questionnaire supplement (See Income and Assets).
Communication	<ul style="list-style-type: none"> • As part of the Health and Functional Status questionnaire supplement for the Household Survey and SAIAN, questions are asked related to problems with hearing, speech, vision, and communication. • As part of the Health and Functional Status questionnaire supplement for the IPC component, more specific questions are asked which focus on understanding others and making oneself understood.
Mental Status	Included in Health and Functional Status questionnaire supplement (Refer to: "Health Status/diagnostic indicators" in the Patient Specific Information Tables).

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

PERSON SPECIFIC INFORMATION (continued)	
Health Status (Diagnostic Indicators)	<p>The main objectives in collecting information about health status in the Household Survey were:</p> <ul style="list-style-type: none"> • to focus on medical and related conditions, disabilities, and impairments that were most directly related to needs for acute and long-term care, and • to capture as broad a range of health status indicators as possible. <p>Because the SAIAN was not expected to include sufficient persons in need of long-term care for separate analysis, the SAIAN included those health status questions most relevant to acute care services.</p> <p>The core interview collected the following information:</p> <ul style="list-style-type: none"> • days in bed, • days lost from work or school, and • days of restricted activity associated with medical problems. <p>Medical conditions associated with medical services were collected and asked about in detail. Information about health status in the NMES IPC focused on medical related conditions, functional disabilities, and impairments which were most directly related to needs for acute and long-term care. Detailed health status questions included the following:</p> <ul style="list-style-type: none"> • ADL items to permit functional assessments; • checklists of specific impairments and disabilities, mental disorders, and levels of mental retardation to permit assessment of social and psychological functioning; • diagnoses for medical conditions associated with institutional and hospital stays; • items relating to communication abilities; and • checklists of other specific long-term chronic problems. <p>In addition, a self-administered questionnaire was given to Household and SAIAN survey participants to gather self-assessed information on the following:</p> <ul style="list-style-type: none"> • health and other functional status, • health habits (height/weight, eating, sleeping, smoking, seat belt use, checkups, dental hygiene), • medical conditions and symptoms, • problems with hearing, speech, vision, and communications, • aspects of social and psychological functioning, • preventative care (checkups; pap smear/breast exam, mammogram, immunizations), • dental health, and • health attitudes .
Employment Status	<p>To gather more complete information on employment, particularly for persons with multiple or changing jobs during 1987, the employment section was designed to accomplish the following:</p> <ul style="list-style-type: none"> • elicit the employment status of each participant 16 years of age and older, • identify periods with and without jobs for comparison with periods of health insurance coverage, • obtain a complete list of employers in 1987 for each participant, and • identify holders of multiple jobs. <p>The NMES Household Survey and SAIAN includes detailed questions on the following:</p> <ul style="list-style-type: none"> • employment history, <ul style="list-style-type: none"> • reason for not working, • labor union membership, • employer related questions (self-employed, industry, occupation, and establishment size) • benefit/compensation related questions (health benefits, paid time off/sick leave, wage/salary) <p>In addition, the NMES IPC obtained employment and training data for those sample persons who were in facilities for the mentally retarded at the sample admission date and include the following:</p> <ul style="list-style-type: none"> • current employment status (non-handicapped co-workers, job environment, hourly wage, hours per week), • last job (non-handicapped coworkers, job environment, hourly wage, hours per week, period of employment), and • training (type, location, hours Per week)

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

PERSON SPECIFIC INFORMATION (continued)	
Functional Status	<p>Functional status is assessed by means of a long-term care supplement with questions that determine whether the sample person had difficulty performing a set of critical daily activities without help because of a mental or physical health problem. Functional status was seen as a critical determinant of the need for long-term care in both the NMES Household Survey and the IPC. To insure a high level of precision in obtaining this information, use of the original ADL concepts as developed by Katz was stressed in developing questionnaire items and their sequence. Four concepts were emphasized:</p> <ul style="list-style-type: none"> • difficulty (e.g., pain or trouble), • help (from other people or from special equipment), • cause (physical or mental health problems), and • observed behavior (what the person actually does, rather than what the person might be able to do or might need help doing) <p>The primary ADL items as adapted for the NMES included six activities basic to independent living:</p> <ul style="list-style-type: none"> • bathing, • dressing, • toileting (getting to the toilet room, getting on and off the toilet or carrying a bedpan after elimination, and arranging one's clothes), • transfer (getting in and out of beds or chairs), • feeding oneself, and • walking across the room. <p>For each item, interviewers asked if the sample person had difficulty performing the activity without help because of a physical or mental health problem. If so, follow-up questions determined whether the sample person performed the activity at all; whether someone else usually helped with the activity by providing physical assistance, supervision or instruction; and whether special aids or equipment were used. For persons 18 years and older, a second set of questions addressed instrumental activities of daily living, activities which, although not basic requirements of independent living, enhance life in important ways. This scale consisted of six items:</p> <ul style="list-style-type: none"> • using the telephone, • managing money, • shopping for personal items, • getting around the community (using any means of transportation to go beyond walking distance from one's home), • preparing meals, and • doing light housework. <p>An additional series of questions addressed the use of special equipment. The series included questions about the use of a colostomy bag, help from another person in taking care of the device, accidents or difficulty controlling bowels, and the frequency of the problem. Parallel questions were asked about urination including the use of a urinary catheter, help from others, accidents or difficulty, and frequency.</p>
Impairment (disability)	<p>A set of questions were included in the Household Survey and SAIAN to identify persons with developmental disabilities in the sample for comparisons with the institutionalized mentally retarded in the IPC. In order to address the range of physical and mental conditions and associated impairments and disabilities prevalent in both nursing homes and facilities for the mentally retarded, the health status section of the person-level questionnaires addressed a number of separate items. In the case of facility respondents, these questions were to be answered from medical records or other patient records to the extent possible; in the case of the personal history questionnaire (a questionnaire revealing demographic characteristics), information was sought from next of kin or other knowledgeable persons. For each sample person, interviewers asked a series of questions to determine whether, according to the medical records, the sample person had any developmental disabilities or psychiatric conditions. For sample persons who were mentally retarded, the respondent was asked to indicate the degree of retardation. Questions also included several lists of items to measure how the sample person functioned socially and psychologically in the facility in 1987.</p>

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

HEALTH CARE UTILIZATION DATA	
Access to Care (Provider Site)	The Household Survey and SAIAN asked questions revealing the following: <ul style="list-style-type: none"> . usual source of medical or dental care, . method of transportation to the health care provider, . native language, and . barriers to care.
Providers surveyed	Includes providers of those sampled in the IPC and physicians, osteopaths, and inpatient and outpatient facilities reported as providing services to consenting members of the non-institutionalized population sample in the Medical Provider Survey (Refer to: "Sample selection" and "Description of Survey" in General Survey Information Tables).
Characteristics of Provider facility	Only for the IPC which includes questions on the following: <ul style="list-style-type: none"> . type of ownership, . number of facilities, . SNF status, . ICF and ICF-MR status, . number of beds, . supervision and personal care services, . type of facility and primary group served, . accreditation status, . number of residents last night, . Alzheimer's Disease Units (capacity, staff characteristics, plans).
Dates of encounter	Included (not asked for traditional medicine).
Types of Medical Service Use	The Household Survey and SAIAN Include indicators of the following: <ul style="list-style-type: none"> . dental visits, . hospital emergency room visits, . hospital outpatient department visits, . long-term institutional stays, . inpatient hospital stays, . home health visits, . medical provider visits, and . traditional medicine (SAIAN only) <p>The IPC includes information on the following services:</p> <ul style="list-style-type: none"> . facility services used; . hospital care received; <ul style="list-style-type: none"> - inpatient, - emergency room, and - out-patient . home health care received; . medical care received; <ul style="list-style-type: none"> - dental care, - mental health care, - medical doctors, - tests, shots, and x-rays, - therapists, and - other non-MD/DO providers . prescribed medicines

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

HEALTH CARE UTILIZATION DATA (continued)	
Disability Days	Included in Health and Functional Status questionnaire component (Refer to: "Health Status/Diagnostic indicators" in Patient Specific Information tables).
Information about Medical Service Use	The Household Survey, SAIAN and IPC gather information on the following: <ul style="list-style-type: none"> • provider, • dates of encounter (except for traditional medicine), • place, • person seen, • circumstances of visit, • reason for visit (except for long-term institutional stays), • services provided (except for long-term institutional stays), • repeat visits (for dental, hospital outpatient department, home health, and medical provider visits only), • IHS/tribal facilities (SAIAN only; not asked for long-term institutional stays, or home health visits), • doctors seen (for hospital related visits only), • other details of visit (for hospital emergency and home health visits only) <ul style="list-style-type: none"> - mode of transportation to emergency room, - amount of time spent traveling-to emergency room, - amount of time spent in emergency room, - time of day home health services received, - amount of time home health care provider spent with patient, and • private duty nursing (for in-patient hospital stays only)
Prescribed Medicines	Included.
Principal reason for visit expressed by Patient	Included (not asked for long-term institutional stays).
Principal diagnoses rendered by physician	Gathered when providers or medical records were surveyed (Refer to: "Description of Survey" in General Survey Information Table).
Prior visit status	Included; (refer to: " Information about medical service use " in Health Care Utilization Data table).
Referral status	Not included.
Diagnostic services/Procedures ordered or provided	Included.
Discharge Destination	Only included for 1987.
Episodes of Care	Only for care received in 1987.

NATIONAL MEDICAL EXPENDITURE SURVEY (NMES)

HEALTH CARE EXPENDITURES DATA	
Health Care Charge per Service	<p>The Household Survey and SAIAN ask questions about service charges and sources of payment for the following:</p> <ul style="list-style-type: none"> • dental visits, • hospital emergency room visits, • hospital outpatient department visits, • inpatient hospital stays, • home health visits, • medical provider visits, • traditional medicine (for SAIAN only, not included for long-term institutional stay) • doctors seen in the hospital setting, and • private duty nursing for inpatient hospital stays <p>In addition, the IPC asks questions pertaining to long-term care facility charges as follows:</p> <ul style="list-style-type: none"> • source of payment for basic charges at the start of the sample person's stay in order to identify Medicaid spend-down persons, • admission status of sample person as a skilled nursing facility (SNF) or intermediate care facility (ICF) patient or neither, • the basic charge for the sample person, • services provided without charge, • facilities break down of basic charges by calendar month • uncompensated care, • when Medicaid began to pay for the sample person's care, and • whether additional charges were also billed during the reference period.
Charges per practitioner	Included for hospital services received.
Source of Payment	Included.
Prescribed Medicines	Included in the Household Survey, SAIAN and IPC. Information is gathered on prescribed medicines bought or otherwise obtained by survey participants.
Other medical expenses	<p>Other medical expenses include the following:</p> <ul style="list-style-type: none"> • expenses for eyeglasses or contact lenses, • orthopedic items, • hearing aids or similar devices, • diabetic equipment or supplies, • ambulance services, • prostheses, • medically necessary alterations to a house or car, and • any other medical equipment.
Out-of-Pocket Expenses	Included.
Financial assistance from someone outside household	Included in Community-based long-term care and informal caregiving supplement.

DATA FROM THE 1987 NATIONAL MEDICAL EXPENDITURE SURVEY

Public Use Tape Information as of June 21, 1991

The Agency for Health Care Policy and Research is releasing data from the 1987 National Medical Expenditure Survey (NMES) to the public through the National Technical Information Service, 5285 Port Royal Road, Springfield, VA 22161, (703) 487-4650. As of this point in time, 41 NMES Public Use Tapes are planned for release.

For additional information on NMES public use tapes, call the Agency for Health Care Policy and Research, Center for General Health Services Intramural Research at (301) 443-4836.

The Following Data Sets Are Available:

NMES Public Use Tape 1, The 1988 Inventory of Long-Term Care Places (ILTCP). This data set is a comprehensive listing of nursing and personal care homes, and facilities for the mentally retarded in the 50 states and the District of Columbia and constitutes the unedited sampling from for the Institutional Population Component of NMES.

NMES Public Use Tape 2, Institutional Population Component, Phase 1. Provides data obtained from a nationally representative sample of nursing homes and facilitates for the mentally retarded and their residents on facility and patient characteristics as of 1 January 1987. The facility level data on this tape have since been replaced by the data on NMES Public Use Tape 6 and the person level data have been replaced with the data on NMES Public Use Tape 8.

NMES Public Use Tape 3, Round 1 Household Survey Population Characteristics and Home Health Provider Data. Provides two data sets on a nationally representative sample of the civilian noninstitutionalized population. The first contains data on household and individual characteristics of the household sample participants for the first months of 1987, including demographic, insurance and employment information and Indicators of functional status related to the need for and provision of long-term care. The second set provides data on characteristics and services of home health care providers linked to the household sample population for Round 1 of the Household Survey. The first data set will be replaced with the round 1 data soon to be released on NMES Public Use Tape 13. The second data set has been replaced with the data released on Public Use Tape 10.

NMES Public Use Tape 4, 1987 Prescribed Medicine Event and Person Level Data for Medicare Beneficiaries. This data set from the NMES Household Survey Component provides full-year information on prescribed medicines obtained by the civilian noninstitutionalized Medicare population during 1987, as well as related conditions and demographic and insurance information.

NMES Public Use Tape 5, Institutional Population Component, Facility Questionnaire Supplement. Provides data for a nationally representative sample of nursing and personal care homes and facilities for the mentally retarded on facility characteristics from the phase 3 Facility Questionnaire Supplement. The data supplement the information elicited in the phase 1 facility questionnaire (Public Use Tape 2). The data file includes information on current and projected Alzheimer's Disease units in nursing and personal care homes and on accreditation status, resident census, and whether the facilities were part of life care communities.

NMES Public Use Tape 8, Institutional Population Component, Facility Questionnaire Weight Update. Updates the facility questionnaire file of the Institutional Population Component, released as Public Use Tape 2, by including a revised weight variable. All other variables remain unchanged.

NMES Public Use Tape 7, Institutional Population Component, Baseline Questionnaire Data for the Current Resident Population, Update. These data were released as part of NMES Public Use Tape 8. No NMES Tape 7 will be released.

NMES Public Use Tape 8, Institutional Population Component, Baseline Questionnaire Data for the Institutional Population. Provides person-level baseline questionnaire data and sampling weights for a nationally representative sample of persons institutionalized at anytime in 1987 in nursing and personal care homes and facilities for the mentally retarded. By adding admissions over the course of 1987, this data replaces Public Use Tape 2, which provided data only for current residents as of January 1, 1987. Also included is a revised current resident weight which has been adjusted for sampling frame duplication. In conjunction with the appropriate weight, the data can be used to make unbiased national estimates for 1987 for the following institutional population, including their demographic characteristics and health and functional status: (1) all persons who spend one or more nights in a IPC eligible nursing or personal care home or a facility for the

DATA FROM THE 1997 NATIONAL MEDICAL EXPENDITURE SURVEY
(continued)

Public Use Tape Information
as of June 21, 1991

mentally retarded at any time during 1987; (2) persons who were residents of IPC eligible facilities on January 1, 1987; (3) persons with one or more admissions to a nursing or personal care home during 1987; (4) all admissions in 1987 to nursing or personal care homes. Because of the relatively small number of annual admissions to facilities for the mentally retarded, the IPC was not designed to provide separate estimates of persons admitted to MR facilities during 1987.

The following public use tapes have been completed but are not yet released by NTIS. Prompt access to the documentation can be obtained by calling the Agency for Health Care Policy and Research, Center for General Health Services Intramural Research at (301) 4434936.

NMES Public Use Tape 9, Household Survey, Health Status Questionnaire and Access to Care Supplement Data.

Contains person level data from the Household Survey health status questionnaire and the access to care supplement. This file contains one record each for a total of 30,038 Household Survey respondents who provided information for their entire period of survey eligibility and responded to a minimum set of items in both the health status questionnaire and the access to care supplement. Children less than age 1 as of December 31, 1987 are excluded from the file. The health status questionnaire elicited information on current and past health status, as well as health related behaviors, including care seeking and preventive care, and immunizations for children under age 18. The access to care supplement contained questions about usual sources of medical and dental care, including characteristics of the usual source of care and reasons for the lack of a usual source of care. The file also contains basic demographic characteristics for respondents which replace data items previously released in Public Use Tape 3.

NMES Public Use Tape 10, Household Survey, Long-Term Care Supplement Data. This public use data set contains two data files. File 1 contains a person-level record for the **34,459** sampled persons who were eligible for the NMES household survey and responded for their entire period of eligibility and includes person identifiers, demographics data, dates of interview, and weights variables. The demographic data on this file replace corresponding data items previously released in Public Use Tape 3. The population on file 2 is a subset of persons on file 1. File 2 contains long-term care supplement data for 33,971 round 1 respondents and 33,988 round 4 respondents who were eligible when the supplement was administered. The long-term care (LTC) supplement contained a series of questions relating to functional status including activities of daily living and instrumental activities of daily living, continence, and the use of special equipment, as well as the use of adult day care, senior centers, home-delivered and congregate meals, special transportation, and telephone assurance for those having at least one ADL or IADL difficulty. In addition, the supplement provides information about prior nursing home stays for this group of respondents. These data replace LTC data items previously released on Public Use Tape 3. The round 1 and round 4 weights released with these data will be replaced with the round 1 and round 4 weights related as part of Public Use Tape 13.

Forthcoming NMES Public Use Tape Releases:

A series of public use tapes from the household, institutional and SAIAN components is in preparation. These tapes will provide full year data on demographic characteristics, employment and insurance status, full year health service use and expenditures, including sources of payment and conditions associated with service use and expenditure.

Releases Planned through Early 1992:

June 1991

11, Round 1, Survey of American Indians and Alaskan Natives (SAIAN): Demographics, Employment, and Health Insurance. Will mirror the Round 1 household tape (Public Use Tape No. 3) were possible.

July, 1991

13, Rounds 14 Household Survey: Population Characteristics and Person-Level Utilization. Rounds 1-4 constructed person-level utilization, health insurance status, employment, family relationship, demographics, disability days, poverty status, and total family income.

DATA FROM THE 1987 NATIONAL MEDICAL EXPENDITURE SURVEY
(continued)

Public Use Tape Information
as of June 21, 1991

Summer through the Fall, 1991

14. Household Survey: Event Level Utilization, Expenditures, Source of Payments and Condition Data. A set of public use tapes at the event level. All would be completed by Fall, 1991. The set will include, one tape each for dental visits, hospital stays (inpatient), prescribed medicines, a combined tape for home health visits and other medical expenses (one file each), and a combined tape for emergency room visits, hospital outpatient visits, and medical provider visits (one file each). Up to four conditions will be provided on each event record.

Target Completion Dates:

- 14.1 Prescribed Medicines - July, 1991
- 14.2 Home Health Visits and Other Medical Expenses - November, 1991
- 14.3 Dental Visits - October, 1991
- 14.4 Hospital Stays - August, 1991
- 14.5 Ambulatory Care Visits - September, 1991

October, 1991

15, Household Component: Premium Data from the Health Insurance Plan Survey. Edited Health Insurance Plan Survey questionnaire data. These data will link to the household survey person- and event-level files and the abstract insurance data files.

December, 1991

16, Household Component: Abstract Data for Plans Held from the Health Insurance Plan Survey. Unedited abstract data from the Health Insurance Plan Survey. These data will link to the household survey person- and event-level files and the insurance premium data files.

February, 1992

17, 1987 Facility Use and Expenditures by Nursing and Personal Care Home Residents. Data for persons sampled as current residents and admissions in nursing and personal care homes. The tape would have person- and facility stay-level data. Person-level variables would include income, health insurance status and miscellaneous demographic variables.

March, 1991

29, Household Survey: Disability Days and the Condition File. Three data files will be provided on this tape. (1) An event level file containing data on disability days including work loss days, school loss days, bed days, and the dates associated with the events. (2) A file of reported medical conditions as determined from disability day data, and the event-level data (Public Use Tapes 14.1-14.5) (3) A link file that permits linking condition data to the respective event or person-level file.

Release Dates Not Yet Planned:

12, SAIAN: Health Status Questionnaires and Access to Care Supplement Data. Will contain data from the Health Status Questionnaires and the Access to Care Supplement for the round 1 SAIAN population. Maybe postponed indefinitely and replaced with Public Use Tape 21.

18, Household Survey: Total Expenditures, Sources of Payment, income, Assets and Tax Filing Status. A person-level file. Source data for the aggregated expenditures and sources of payment data are the previously released event level data (Public Use Tapes 14.1-14.5). This tape will also include information from Round 4 income and assets supplement including housing information and Round 5 tax data. May also include miscellaneous Round 5 population characteristics data.

**DATA FROM THE 1957 NATIONAL MEDICAL EXPENDITURE SURVEY
(continued)**

**Public Use Tape Information
as of June 21,1991**

19, Pm-Admission Residence History, Personal History and Health Status for Nursing and Personal Care Home Residents and Reported by the Survey of Next of Kin. This would be a subset of Personal History Questionnaire data for the NH sample only.

20, SAIAN Rounds 1-4: Population Characteristics and Person-Level Utilization Data. Similar to household Use Tape No. 13,

21, SAIAN Se&Accessed Health Status, Health Habits, Preventive Care, Health Attitudes and Access to Care Data, Update. Replaces Public Use Tape No.12. The population of interest changes from the Round 1 population to the full year SAIAN population.

22, 1987 Facility Use and Expenditures by Residents in Facilities for the Mentally Retarded. Same as Public Use Tape No. 17 but for the MR sample.

23, SAIAN: Utilization, Expenditures, Source of Payments and Condition Data. A set of five tapes, similar to household Public Tapes 14.1-14.5 except, these will include a variable that indicates if use was at an IHS facility or an IHS contract facility.

24, Household Component: Abstract Data for Optional Plans Held from the Health Insurance Plan Survey. Same as Public Use Tape No. 16 except for **optional plans held**.

25, 1987 Hospital Stays by Nursing and Personal Care Home Residents. A constructed hospital stay file that uses HCFA, facillii and next-of-kin reported data.

26, SAIAN: Total Expenditures, Sources of Payment, Income, Assets and Tax Filing Status. A person-level file. Source data for the aggregated expenditures and sources of payment data are the previously released event level data (Public Use Tapes 23.1-23.5). The tape will also include data from the Round 3 income and assets supplement including housing information and may include miscellaneous health status and person characteristics variables from the round 3 supplemental.

27, 1987 Residence History Data for Persons who Resided at Least One Day In a Nursing or Personal Care Home or a Facility for the Mentally Retarded. This file was constructed from facility and next-of kin reported data as our best estimate of 1967 residence history for IPC sampled persons. It includes stays in sampled facilities, transfer facilities, hospitals, ineligible facilities and the community.

28, Use of Health Care Providers by Residents in Nursing and Personal Care Homes and Facilities for the Mentally Retarded as Reported by the Facility. Physician visits, TO, PT, etc. as reported by the facility.

30, SAIAN: Disability Days and the Condition File. Same as Public Use Tape No. 29 but for the SAIAN population.

31, Household Survey: Caregiver and Care Receiver File. This tape will contain information collected with the caregiver and care receiver supplements as well as some of the caregiver and care receiver data collected with the 4 Long-Term Care Supplement and the Home Health Booklet.

32, Institutional Population Component: End of the Year Questionnaire Data. This tape will contain data collected with the End of the Year Questionnaire for the population in nursing and personal care homes and facilities for the mentally retarded.

33, Household Component: Premium Data for the Optional Plan Survey. Same as Public Use Tape 15 except for optional plans held.

For additional information on NMES public use tapes, call the Agency for Health Care Policy and Research, Center for General Health Services intramural Research at (301) 4434636.

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

GENERAL SURVEY INFORMATION	
Survey Components	The NHIS has a set of basic health and demographic questions which are asked annually.
Questionnaire Supplements	<p>One or more sets of current health topics are added each year to the NHIS basic questionnaire. The current health topics generally change each year. These changes facilitate a response to the need for population-based data on current or emerging health issues and cover a wide variety of topics. Past, current, and future health topics added to the NHIS include the following:</p> <ul style="list-style-type: none"> • 1988 Child Health/AIDS Knowledge and Attitudes/Occupational Safety and Health/Alcohol Consumption/Medical Device Implants • 1989 Diabetes and Associated Risk Factors/Digestive Disorder/Dental Health/Orofacial/Mental Health/Health Insurance/AIDS • 1990 Health Insurance/AIDS/Health Promotion and Disease Prevention/Podiatry/Assistive Devices • 1991 Year 2000 Objectives/AIDS Knowledge and Attitudes/Income/Drug Use • 1992 Cancer/Youth Risk Behavior/AIDS/Family Resources • 1993 and 1994 Disability/AIDS/Family Resources • 1995 Year 2000 Objectives
Sponsoring Agency	National Center for Health Statistics (NCHS).
Frequency	Annual.
Past Years Conducted	Since 1957.
Future Years Planned	NHIS is a continuous annual survey.
Data Release	Approximately 1 year after survey is conducted.
Description of Population (Sample Size)	The US. civilian noninstitutionalized population (38,998 to 47,998 households/92,000 to 125,909 persons depending on the year).
Smallest Area of Analysis	Census regions.
Response rate	The response rate has been approximately 95 to 98 percent over the years.
Description of Survey	<ul style="list-style-type: none"> • The NHIS is a multi-purpose, cross-sectional survey conducted to comply with the NCHS mandate to secure statistical information on the incidence of acute illness and injuries, the prevalence of chronic conditions and impairments, the extent of disability, the utilization of health care services, and other health related topics. • Different samples are chosen to be interviewed each week of the year for a one-time interview.

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

GENERAL SURVEY INFORMATION (continued)	
Sample Selection	<p>The sampling plan of the NHIS follows a multistage probability design that permits continuous sampling of the civilian noninstitutionalized population residing in the United States. The survey is designed in such a way that the sample scheduled for each week is representative of the target population, and the weekly samples are additive over time.</p> <p>In 1985, the NHIS adopted several new sample design features which include the following:</p> <ul style="list-style-type: none"> • reducing the number of primary sampling locations from 376 to 198 to improve sampling efficiency, • oversampling the black population to improve the precision of statistics for blacks, • subdividing the NHIS sample into four representative panels to facilitate linkage to other NCHS surveys, • using an all-area frame so that the NHIS sample frame can be used for other NCHS population-based surveys (Prior to use of the all-area frame, a list frame was used from lists of addresses compiled at the time of the decennial census. Due to confidentiality restrictions, these sample addresses could only be used for surveys conducted by the U.S. Bureau of the Census), and • selecting two PSU's per non-self-representing stratum to allow for more efficient variance estimation methodology. <p>Stane 1: For the first stage of the sampling design, the United States is considered to be a universe composed of approximately 1,900 geographically defined primary sampling units (PSUs). A PSU consists of a county, small group of contiguous counties, or a metropolitan statistical area (MSA). The PSUs collectively cover the 50 States and the District of Columbia. The 52 largest PSUs are selected into the sample with certainty and are referred to as self-representing PSUs. The other PSU's in the universe are referred to as non-self-representing PSUs. These PSUs are clustered in 73 strata, and 2 sample PSUs are chosen from each stratum with probability proportional to population size. This gives a total of 198 PSUs selected in the first stage.</p> <p>Staae : Within a PSU, two types of second-stage units are used:</p> <ul style="list-style-type: none"> - area segments, and - permit area segments <p>Area segments are defined geographically and contain an expected eight households, Permit area segments cover geographical areas containing housing units built after the 1980 census. The permit area segments are defined using an updated list of building permits issued in the PSU since 1980 and contain an expected four households. Wiihin each segment all occupied households are targeted for interview. On occasion, a sample segment may contain a large number of households. In this situation the households are subsampled to provide a manageable interviewer workload.</p>

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

GENERAL SURVEY INFORMATION (continued)	
Groups Oversampled	In 1985, NHIS began oversampling the black population.
Data Collection Procedures	<ul style="list-style-type: none"> • Most households in the sample are contacted by mail before the interviewers arrive. Interviewers make repeated trips to a household when a respondent is not immediately found. When contact is made, the interviewer attempts to have all family members of the household 19 years of age and over present during the interview. When this is not possible, proxy responses for absent adult family members are accepted. In most situations, proxy respondents are used for persons under 19 years of age. Persons 17 and 18 years of age may respond for themselves, however. • Each week of the year a different sample is surveyed. The survey is designed in such a way that the sample scheduled for each week is representative of the target population, and the weekly samples are additive over time. Because interviewing is done throughout the year, there is no seasonal bias for annual estimates. • The weekly samples are consolidated to produce quarterly files (each consisting of data for 13 weeks). Weights to adjust the data to represent the U.S. population are assigned to each of the four quarterly files. These quarterly files are later consolidated to produce the annual file, which is the basis of most tabulations of NHIS data • NHIS uses various reference periods to reduce the amount of bias associated with respondent memory loss. A P-week reference period is used in collecting data on the incidence of acute conditions, restriction in activity due to a health problem, and physician contacts. Each of these measures health events that may be forgotten soon after they occur. Either a 12- or 6-month (depending on the type of statistic) reference period is used for hospitalization data because hospitalization ordinarily involves a major event in a person's life and is not quickly forgotten. Chronic condition prevalence estimates are based on a 12-month reference period.

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

PERSON SPECIFIC INFORMATION	
Age	The age recorded for each person is the age at last birthday. Age is recorded in single years and grouped in a variety of distributions.
Sex	Included.
Race	Race is indicated as follows: <ul style="list-style-type: none"> • Aleut, Eskimo, or American Indian, • Asian or Pacific Islander, • Black, • White, • Other (specified) (observed 1989-79 and self-reported 1988-present).
Ethnicity	Ethnicity includes the following categories: <ul style="list-style-type: none"> • Puerto Rican, • Cuban, • Mexican/Mexicano, • Chicano, • Other Latin American, • Other Spanish
Marital Status	Indicated by the following ; under 14, married (spouse in household, spouse not in household), widowed, divorced, separated, never married.
Family Structure (Living Arrangement)	Household members' relationship to the reference person are included.
Social Support (Caregivers)	Not included.
Veteran Status	Included.
Education	Indicated by year completed up to 18 years and beyond.
Income and Assets	Each member of a family is classified according to the total income of their family. Within the household, all persons related to each other by blood, marriage, or adoption constitute a family. Unrelated individuals are classified according to their own income. The income recorded is the income received by members of the family (or by an unrelated individual) in the 12-month period preceding the week of interview. <ul style="list-style-type: none"> • Income is indicated in two ways: <ul style="list-style-type: none"> -- total combined family income being greater or less than \$20,000 during the past 12 months, and -- total combined family income by increments of \$1,000 up to \$20,000 then increments of \$5,000 up to \$50,000 at which a \$50,000 and over indicator is used for total combined family income during the past 12 months. Respondents are asked to consider income from the following sources: jobs, social security, retirement income, unemployment payments, public assistance, interest, dividends, net income from business, farm, or rent, and any other income received such as assistance from relatives. In addition, for each family member 14 years old or over (including those in the Armed Forces living at home) the following income information is obtained: <ul style="list-style-type: none"> • whether or not a job is held and the number of hours worked per week, • amount of income before deductions in a specified month; and if person is self-employed.

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

PERSON SPECIFIC INFORMATION (continued)	
Income and Assets (continued)	<ul style="list-style-type: none"> • amount of income from social securii or railroad retirement, • amount of income from supplemental securii income, • amount of income from other disability pension, • amount of income from other retirement or survivor pension, • amount of income from public assistance or welfare payments, • amount of income from AFDC, • total value of food stamps received, if any, • total amount of monthly interest earned from a savings or bank account earning interest, • total amount of monthly income from dividends, rental property or trusts, and • total monthly income from any other sources. <p>• Assets are not included.</p>
Insurance Status	<p>Periodically. For each member of the family, the following health care coverage information is obtained:</p> <ul style="list-style-type: none"> • Medicare coverage, • Medicaid coverage, • military health coverage, and • private health insurance (includes health maintenance organbations) <ul style="list-style-type: none"> -- whether private insurance is obtained through an employer or union, and -- did employer or union pay for all, part, or none of the cost of the insurance plan.
Disability Benefits	Not included.
Communication	Not included.
Mental Status	Not included.
Employment Status	<p>Persons 18 years of age and over who reported that at any time during the 2-week reference period they either worked at or had a job or business are currently employed. Information gathered includes the following:</p> <ul style="list-style-type: none"> • name of employer, • type of business or industry, • type of work being done, • job activities or duties, • classification of worker (federal, state, or local government employee, self-employed, private company employee)

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

PERSON SPECIFIC INFORMATION (continued)	
Health Status (Diagnostic Indicators)	<p>The NHIS uses the general term "condition" to include any specific illness, injury, or impairment. Condition data are derived from the survey in two ways.</p> <ul style="list-style-type: none"> • respondents are asked to identify any conditions that caused certain types of impact associated with health, such as a visit to a doctor or a day spent in bed, and • respondents are read lists of selected chronic conditions and asked whether they or any family members have any of these conditions. <p>At a later point in the survey, a series of questions are asked about each of the conditions identified in either of the two ways just described. The information obtained on each condition helps to clarify the nature of the condition and whether medical services have been involved in its diagnosis and treatment. All conditions except impairments are coded according to the ninth revision of the International Classification of Disease, with certain modifications adopted to make the codes more suitable for information derived from a household survey.</p> <p>A condition is considered <u>acute</u> if it meets the following criteria:</p> <ul style="list-style-type: none"> • it was noticed no longer than 3 months before the reference day of the interview, and • it is not one of the conditions considered chronic regardless of the time of onset. However, any acute condition not associated with either at least one doctor visit or at least one day of restricted activity during the reference period is considered to be of minor consequence and is excluded from the final data produced by the survey. <p>A condition is considered <u>chronic</u> if it meets the following criteria:</p> <ul style="list-style-type: none"> • the respondent indicated it was first noticed more than 3 months before the reference date of the interview, or • it is a type of condition that ordinarily has a duration of more than 3 months. <p>Examples of conditions that are considered chronic regardless of their time of onset are diabetes, heart conditions, emphysema, and arthritis.</p> <ul style="list-style-type: none"> - An "injury condition" is classified according to the nature-of-injury code numbers (800-999) in the ninth revision of the International Classification of Diseases. In addition to fractures, lacerations, contusions, and burns, which are commonly thought of as injuries, this group of codes includes poisonings and impairments caused by accidents or nonaccidental violence. Unless otherwise specified, the term injury is used to cover all of these. A person may sustain more than one injury, so the number of injury conditions may exceed the number of persons injured. Statistics of acute injury conditions include only Injuries that involved medical attendance or at least a half day of restricted activity. - The NHIS also asks respondents to assess their own or a family member's health status as either excellent, very good, good, fair, or poor (based on a respondent's opinion and not clinical evidence). - Height and weight indicators are also included in the NHIS.
Impairment (disability)	<p>Disability in the NHIS is a general term that refers to any long- or short-term reduction of a person's activity as a result of an acute or chronic condition.</p> <p>Impairment refers to a chronic or permanent defect that results from disease, injury, or congenital malformation. It represents a decrease in or loss of ability to perform various functions, particularly those of the musculoskeletal system and the sense organs. Impairments are grouped according to type of functional impairment and etiology in the special NHIS impairment codes.</p>

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

PERSON SPECIFIC INFORMATION (continued)	
Functional Status	<p>The NHIS relates information on functional status using the following terms:</p> <ul style="list-style-type: none"> • Limitation of activity: a long-term reduction in a person's capacity to perform the average kind or amount of activities associated with his or her age group. • Restriction of activity: particular kinds of behavior usually associated with a reduction in activity due to either long- or short-term conditions. <p>(Thus limitation of activity refers to what a person is generally capable of doing, but restriction of activity ordinarily refers to a relatively short-term reduction in a person's activities below his or her normal capacity.)</p> <p>Restriction of activii is further broken down into bed days, work-loss days, school-loss days, and cut-down days as follows:</p> <ul style="list-style-type: none"> • bed days: one during which a person stayed in bed more than half a day because of illness or injury (all hospital days for Inpatients are considered bed days even if the patient was not in bed more than half a day), • work-loss days: one in which a currently employed person 18 years of age and over missed more than half a day from a job or business, • school-loss days: one in which a student 5-17 years of age missed more than half a day from the school in which he or she was currently enrolled, • cut-down day: a day in which a person cuts down for more than half a day on the things he or she usually does. <p>(Work-loss, school-loss, and cut-down days refer to the short-term effects of illness or injury. However, bed days are a measure of both long- and short- term disability, because a chronically ill bedridden person and a person with a cold could both report having spent more than half a day in bed due to an illness.)</p> <p>The number of restricted-activii days is the number of days a person experienced at least one of the four types of activii restriction just described. In calculating the sum of restricted-activity days, each day is counted only once even if more than one type of activity restriction was involved.</p> <p>Estimates of "cut-down" days are not presented separately but are included in the generic concept of "restricted-activii days." A person may restrict his or her activity on a given day as a result of more than one condition, and these conditions may be acute or chronic. "Restricted activii associated with acute conditions" includes days in which one or more acute conditions caused the activii restriction; it also includes days on which one or more acute conditions, and one or more chronic conditions caused the activii restriction. In the latter case, because the restriction in activity was due to both acute and chronic conditions, the cause cannot be attributed solely to an acute condition. For this reason the words "associated with" rather than "caused by" are used to describe this type of estimate.</p> <ul style="list-style-type: none"> • Limitation of activity because of chronic conditions: persons are classified in terms of the major activity usually associated with their particular age group. The major activities for the age groups are the following: <ul style="list-style-type: none"> - ordinary play for children under 5 years of age, - attending school for those 5-17 years of age, - working or keeping house for persons 18-69 years of age, and - capacity for independent living (e.g., the abilii to bathe, shop, dress, eat, etc., without needing help from another person) for those 70 years of age and over. <p>In regard to these activities, each person is classified into one of four categories:</p> <ul style="list-style-type: none"> • unable to perform the major activity, • able to perform the major activity but limited in the kind or amount of this activity, • not limited in the major activity but limited in the kind or amount of other activities, and, • not limited in any way. <p>Persons are not classified as limited in activity unless one or more chronic conditions are reported as the cause of the activity limitation, If more than one condition is reported, the respondent is asked to identify the condition that is the major cause of the limitation.</p>

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

HEALTH CARE UTILIZATION DATA	
Access to Care (Provider Site)	<p>The NHIS uses the terminology “place of contact” to indicate the type of place at which a physician contact took place. Definitions of the various categories are as follows:</p> <ul style="list-style-type: none"> • telephone: refers to medically related matters discussed in a telephone call with a physician or physician’s assistant. Calls for non-medically related matters (such as for an appointment) are not included, • office: refers to physician offices not located in a hospital, • hospital: involves three types of places in a hospital <ul style="list-style-type: none"> - emergency room, - clinic, and - doctor’s office • other (any place not classified above, including clinics and HMOs not located in hospitals). <p>NHIS does not analyze access to care issues in the core questionnaire.</p>
Providers surveyed	None.
Characteristics of Provider facility	Survey respondents are asked the name and address of hospitals where care was received.
Dates of encounter	Specific dates are not recorded, only the number of contacts or episodes (refer to: “Episodes of Care” in the Health Care Utilization tables).
Types of Medical Service Use	Survey respondents are asked about the following health services: <ul style="list-style-type: none"> • doctor visits, and • hospitalization
Disability Days	Included (refer to: “Functional Status” in the Patient Specific Information tables).
Principal diagnoses rendered by physician	No information is gathered from physicians, but self-reported diagnoses are included (refer to: “Health Status/Diagnostic Indicators” in the Patient Specific Information tables).
Referral status	Not included.
Discharge Destination	Not included.
Prior visit status	Not included.
Diagnostic services/Procedures ordered or provided	Survey respondents are asked to name or describe any surgery or operation performed at a doctor visit or hospitalization.
Prescribed Medicines	Not included.

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

HEALTH CARE UTILIZATION DATA (continued)	
Information about Medical Service Use	<p>Terms. used to gather information relating to physician contacts and hospitalizations include the following:</p> <ul style="list-style-type: none"> • physician contact, <ul style="list-style-type: none"> • place of physician contact (refer to: "Access to Care/Provider Site"), • interval since last physician contact (refer to: "Episodes of Care"), • hospital, <ul style="list-style-type: none"> • short-stay hospital, <ul style="list-style-type: none"> • hospital days during the year, • hospital episode (refer to: "Episodes of Care"), • hospital discharge, <ul style="list-style-type: none"> • length of hospital stay, and • average length of stay <p>A physician contact is defined as consultations with a physician, in person or by telephone, for examination, diagnosis, treatment, or advice. (Physician contacts with hospital inpatients are not included). The contact is considered to be a physician contact if the service is provided directly by the physician or by a nurse or other person acting under a physician's supervision. For the purpose of this definition, "physician" includes doctors of medicine and osteopathic physicians. The term "doctor" is used in the interview rather than "physician" because of popular usage.</p> <ul style="list-style-type: none"> • Physician contacts for services provided on a mass basis are not included in the tabulations. (e.g., obtaining a chest x-ray in a tuberculosis chest x-ray trailer is not included as a physician contact. However, a special chest x-ray given in a physician's office or in an outpatient clinic is considered a physician contact.) • If a physician is called to a house to see more than one person, the call is considered a separate physician contact for each person about whom the physician is consulted. • A physician contact is associated with the person about whom the advice is sought, even if that person does not actually see or consult the physician (e.g., if a mother consults a physician about one of her children, the physician contact is ascribed to the child). <p>A hospital is defined for NHIS as any institution named in the listing of hospitals in the current <u>American Hospital Association Guide to the Health Care Field</u> or found on the Master Facility Inventory List maintained by the NCHS.</p> <p>A short-stay hospital is one in which the type of service provided is either general; maternity; eye, ear, nose, and throat; pediatric; osteopathic; or provided in the hospital department of an institution.</p> <p>A hospital day is a day in which a person is confined to a hospital. It is counted as a hospital day only if the patient stays overnight. Thus a patient who enters the hospital on Monday afternoon and leaves Wednesday noon is considered to have had two hospital days.</p> <p>Hospital days during the year is the total number for all hospital episodes in the 12-month period prior to the interview week. For the purposes of this estimate, episodes overlapping the beginning or end of the 12-month period are subdivided so that only those days falling within the period are included.</p> <p>Hospital discharge is the completion of any continuous period of stay of 1 night or more in a hospital as an inpatient except the period of stay of a well newborn infant. A hospital discharge is recorded whenever a present member of the household is reported to have been discharged from a hospital in the 12-month period prior to the interview week.</p> <p>Length of hospital stay is the duration in days, exclusive of the day of discharge, of a hospitalization.</p> <p>Average length of stay per discharged patient is computed by dividing the total number of hospital days by the total number of discharges.</p>

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

HEALTH CARE UTILIZATION DATA (continued)	
Episodes of Care	<p>The NHIS gathers aggregate data which do not link episodes of care from one provider site to another, or from one year to another. The NHIS does gather information on the overall number of episodes of care related to hospitalization, physician contact, and injuries as defined by the following:</p> <p>A hospital episode - any continuous period of stay of 1 night or more in a hospital as an inpatient except the period of stay of a well newborn infant. A hospital episode is recorded for a family member whenever any part of his or her hospital stay is included in the 12-month period prior to the interview week.</p> <p>Physician contacts: Rate and interval since last contact - includes the number of doctor visits/physician contacts in the past 12 months in addition to the length of time prior to the week of the NHIS interview since a physician was last consulted in person or by telephone for treatment or advice. A physician contact with a hospital inpatient can be counted as the last time a physician was seen even though it is not included in the "physician contact" category. (For physician contact definition refer to: 'Information about Medical Service Use' in Health Care Utilization Data tables).</p> <p>Episodes of persons injured - each time a person is involved in an accident or nonaccidental violence causing injury that results in medical attention or at least a half day of restricted activity, it is counted as a separate episode of a person injured. Therefore, one person may account for more than one episode of a person injured.</p>
Principal reason for visit expressed by patient	<p>Patients are asked to specify medical conditions which have caused the following:</p> <ul style="list-style-type: none"> • limitations of activities, • restrictions of activities, • doctor visits, and • hospitalizations <p>Medical conditions are classified as being caused from an acute illness, a chronic illness or an injury (refer to: "Health Status/Diagnostic Indicators" in the Patient Specific Information tables).</p>

CURRENT BENEFICIARY SURVEY (CBS)

GENERAL SURVEY INFORMATION	
Survey Components	The CBS includes the following components: <ul style="list-style-type: none"> • The household component, and • The nursing home component
Questionnaire Supplements	Beginning with Round 2 or later, the CBS interview will consist of core items, and one or more topical supplements. The content of the supplements will be determined by the research needs of HCFA, the Department, and other interested agencies, including the Physician Payment Review Commission. Topics will include income, assets, and program participation, as well as reprises of the health and functional status measures, and access to care items.
Sponsoring Agency	Health Care Financing Administration.
Frequency	Annual.
Past Years Conducted	The CBS has not been conducted in the past, although from July 1988 until 1980 the Bureau of the Census conducted a continuous nationwide study known as the Current Medicare Survey (CMS). The CMS was designed to collect information on the extent, kinds, and costs of medical services used by Medicare beneficiaries. The CMS was conducted regularly by the Bureau of the Census until terminated in 1980.
Future Years Planned	The CBS is planned to be conducted on a continual basis beginning calendar year 1991.
Data Release	Edited tapes from round 1 are expected to be available October 1, 1992.
Description of Population (Sample Size)	A total sample size of approximately 12,000 is anticipated, with a representation of the following groups: <ul style="list-style-type: none"> • the aged institutionalized, • the aged non-institutionalized, and • those with disabilities
Smallest Area of Analysis	As planned, the CBS will allow analysis by detailed age categories, metropolitan status, and census division.
Response rate	Unknown as the CBS has not been conducted. Based on the response rate from the 1987 NMES survey it is anticipated that the approximate CBS response rate will be as follows: <ul style="list-style-type: none"> • 88 percent for round 1, • 98 percent for each subsequent round, • 83 percent for rounds 1-4 (1 years' worth of data), and • 73 percent for rounds 1-10 (3 years' worth of data).
Description of Survey	The CBS is a continuous, multi-purpose panel survey of Medicare beneficiaries (the aged and those with disabilities) residing in both community and Institutional settings. The CBS will consist of a series of interviews with a representative sample of the Medicare population indicating their patterns of use and cost over time, their sources of coverage and payment, their assets and income, demographic characteristics, health and functional status, health and work history, and family supports. The CBS will focus on issues that are of key concern to HCFA, such as health care use, its determinants, and its cost. This longitudinal survey will be used by all components of HCFA, the Department, and by researchers concerned with Medicare policy and the impact of legislative and programmatic changes on beneficiaries.

CURRENT BENEFICIARY SURVEY (CBS)

GENERAL SURVEY INFORMATION (continued)	
Sample Selection	<p>The CBS household sample will be selected from the Medicare enrollment files, specifically the Health Insurance Master File (HIM) 5% sample. The round one initial sample of approximately 14,000 individuals will include oversampling of selected groups of particular policy interest: the "oldest old" (85+), and those with disabilities. The sample size was chosen to yield 12,000 completed interviews. The oversampling of the oldest old will result in a corresponding oversampling of nursing home residents. The sample will be spread across 107 primary sampling units (PSUs), consisting of metropolitan areas and clusters of non-metropolitan counties. Within these areas, the sample will be concentrated in 1,163 clusters of ZIP code areas (5 digits). After the first year, the sample will be supplemented annually to replenish sample sizes for analytic domains depleted by attrition, to expand coverage of those turning 65 in the prior calendar year, and to expand coverage of the newly disabled.</p>
Groups Oversampled	<p>The oldest-old (age 85 and over), those with disabilities, and the nursing home population will be oversampled.</p>
Data Collection Procedures	<p>The CBS will interview a panel of respondents three times a year in both household and institutional settings. The household interviews will be either the sample person or a knowledgeable proxy. Nursing home interviews will be conducted by proxy without the sample person being interviewed. The nursing home administrator, nursing staff, and administrative staffs will be the respondents.</p> <p>Interviews will be administered to the sample person or a proxy using a computer assisted personal interviewing (CAPI) program on a laptop computer. Each sample person will be given a CBS calendar on which he or she will be encouraged to record health care events. The calendar will also have a pocket to keep medical bills and statements for the next interview. For each sample person in an institution, the interviewer will determine the best staff person to serve as the respondent for the CBS interview. Some administrators will require consent of the sample person or a next of kin before releasing any information.</p>

CURRENT BENEFICIARY SURVEY (CBS)

PERSON SPECIFIC INFORMATION	
Age	Indicated by date of birth.
Sex	Indicated.
Race	Includes the following indicators of race: <ul style="list-style-type: none"> • American Indian, • Asian or Pacific Islander, • Black/African American, • White, and • Other
Ethnicity	Includes probe for hispanic origin without further delineation.
Marital Status	Includes indicators for married, widowed, divorced, separated, and never married.
Family Structure (Living Arrangement)	Respondents are asked to list all individuals who usually live or stay with them, and their relationship.
Social Support (Caregivers)	The CBS collects indicators for community caregivers and family/neighbor support. It is indicated whether home health care is provided through familial or professional support. The CBS will follow sample persons from maintenance in the community through home health care to nursing home admission.
Veteran Status	Veteran status is indicated by period of service and includes the following indicators: <ul style="list-style-type: none"> • Vietnam Era (Aug 1964-May 1975), • Korean Conflict (June 1950-Jan 1955), • World War II (Sept 1940-July 1947), • World War I (1917-1918), and • Peace time (all other times)
Education	Includes indicators for highest grade or year of school completed up to 18 or more years.
Income and Assets	-Respondents are asked whether their total income (including money from jobs, Social Security, Railroad Retirement, and any other retirement income, Supplemental Security Income (SSI), pensions, interest, and any other sources of income) was more or less than \$25,000 in the past 12 months, and if their monthly income was more or less than \$2080. Respondents are also asked what their total pre-tax income for the past 12 months was within \$5,000 increments up to \$50,000 and above. Respondents are not asked about assets. -Questions on income and assets will be included in a supplementary module, planned for round three, and annually thereafter.
Insurance Status	Insurance status is indicated as follows: <ul style="list-style-type: none"> • Medicare, • benefits from the Railroad Retirement Board, • Medicaid, • other public assistance programs (e.g., those which cover prescription drugs), • private insurance, • HMO or any kind of prepaid health plan, • Medigap or Medicare Supplement (other insurance which covers long-term care. or prescription drugs) <p>Additional questions are asked on the insurance coverage period, main person insured (respondent or spouse), and source of insurance (e.g., current employer, former employer, union, family business, or other). If respondent is insured through an employer, additional information is gathered indicating the respondent's job description, business or industry associated with employment, facilities in more than one location, and total number of employees. Information is also gathered on whether insurance plans cover prescribed medicines and nursing home stay, and what the respondent pays for premiums or costs of the insurance.</p>
Disability Benefits	Respondents are asked if they have a disability related to services in the Armed Forces of the United States, and what their current VA disability rating is.
Communication	"Present: Health Status/Diagnostic indicators."

CURRENT BENEFICIARY SURVEY (CBS)

PERSON SPECIFIC INFORMATION (continued)	
Employment Status	Indicated by questions probing for source of private insurance (refer to: "Insurance status").
Health Status (Diagnostic Indicators)	<ul style="list-style-type: none"> • Respondents are asked to rate their health compared to other people their age (as either excellent, very good, good, fair, or poor), and how much time during the past month health problems limited social activities (as either none of the time, some of the time, most of the time, or all of the time). • Respondents are asked if they wear eyeglasses or contact lenses, if they have ever had an operation for cataracts, and if they use a hearing aid. Respondents are also asked to describe their vision and hearing as either having no trouble, little trouble, or a lot of trouble. • Respondents are asked if they have difficulty eating solid foods because of problems with their mouth or teeth. • Respondents are asked their height and weight. • Respondents are asked if they have specific medical conditions, and whether the condition was the original cause of becoming eligible for Medicare. • Respondents are also asked if they have ever smoked cigarettes, cigars, or pipe tobacco, and if they are currently smoking.
Impairment (disability)	(Refer to: " Disability Benefits," "Functional Status," and "Health Status/Diagnostic Indicators").
Functional status	<p>Respondents are asked how difficult on average it is to do certain kinds of activities as follows:</p> <ul style="list-style-type: none"> • stooping, crouching and kneeling, • carrying objects as heavy as 10 pounds, • reaching or extending arms above shoulder level, • writing or handling and grasping small objects, and • walking a quarter of a mile (2 to 3 blocks). <p>Respondents are also asked about activities of daily living, and instrumental activities of daily living (ADLs/IADLs). Respondents are asked if they have any difficulty performing the following activities of daily living:</p> <ul style="list-style-type: none"> • bathing or showering, • dressing, • eating, • getting in and out of chairs, • walking, and • using the toilet <p>If respondents indicate they have difficulty with an ADL, additional questions are asked to indicate if help is received from another person, if a person stays nearby to help, and if special equipment or aids are used.</p> <p>Respondents are also asked if they have difficulty performing the following instrumental activities of daily living:</p> <ul style="list-style-type: none"> • using the telephone, • doing light housework (like washing dishes, straightening up, or light cleaning), • doing heavy housework (like scrubbing floors, or washing windows), • preparing meals, • shopping for personal items (such as toilet items or medicines), and • managing money (like keeping track of expenses or paying bills) <p>If respondents indicate they have difficulty with an IADL, further questions are asked to indicate if the limitation is due to a health or physical problem, and if help is received from another person.</p> <p>Respondents are also asked how often they have lost urinary control during the past 12 months.</p>

CURRENT BENEFICIARY SURVEY (CBS)

HEALTH CARE UTILIZATION DATA	
Access to Care (Provider Site)	<p>-Respondents are asked if they went to a hospital emergency room for medical care since reference date and how many times. Patients are asked more specific questions on the last emergency room visit to indicate medical condition causing the visit, whether they had an appointment, whether medical personnel or a doctor told them to go to the emergency room, the length of time the visit took from arrival to departure, the length of time spent waiting, and whether respondent was admitted to the hospital.</p> <p>-Respondents are also asked how many times they went to a hospital clinic or outpatient department and the main reason for the visit including indicators for the following:</p> <ul style="list-style-type: none"> • medical condition, • diagnosis (including tests) or treatment, • general treatment, • vision exam for glasses, • immunization/flu vaccine, • psychotherapy/mental health counseling, • operation or surgical procedure, and • other <p>respondents are-asked if they had an appointment, whether respondent called for an appointment, how long respondent waited for the appointment, how long the appointment took from arrival to departure, and how much time was spent waiting.</p> <p>-Respondents are asked if they were a patient in a nursing home or any other long-term care facility since the reference date, name of the facili, and date of discharge.</p> <p>-Respondents are asked if they have had trouble getting health care they wanted or needed during the last year, and why. Respondents are also asked if they delayed seeking medical care in the past year because they were worried about the cost, and why.</p> <p>-Respondents are asked how they get to their appointments (e.g., walking, driving, being driven, ambulance or other special vehicle, taxi, public transportation, or other), how long it takes to get there, and who accompanies them.</p> <p>-Respondents are also asked (if they did not see a doctor about a condition) what the main reason was for not seeking care. Indicators include the following:</p> <ul style="list-style-type: none"> • did not think the problem was serious, • thought it would cost too much, • did not have time, • could not get an appointment soon enough, • no doctor was available, • did not have a way to get to the doctor, • could not leave other family member, • felt doctor could not do much about the problem, • was afraid of finding out what was wrong, • doctor charged more than Medicare would pay, • could not find a doctor who would accept Medicare, and • other
Providers surveyed	Providers are surveyed to gather information on the sample which resides in long-term care facilities, Medical records may be reviewed to validate medical expenditure data provided by respondents (upon their approval).
Characteristics of Provider facility	Not included.
Dates of encounter	Included.

CURRENT BENEFICIARY SURVEY (CBS)

HEALTH CARE UTILIZATION (continued)	
Types of Medical Service Use	<p>Respondents are asked if there is a particular medical person or clinic they usually go to for health care or health advice. Questions are asked to indicate if it was a hospital outpatient clinic or other kind of clinic, and include indicators for the following sites of care:</p> <ul style="list-style-type: none"> • doctor's office, • doctor's clinic or HMO, • neighborhood/family health center, • freestanding surgical center, • rural health clinic, • company clinic, • other clinic, • walk-in urgent center, • home visit by doctor, • hospital emergency room, • hospital outpatient department, and • other <p>The name and provider number of the facility, and doctor the respondent usually sees are indicated, as well as the doctor's specialty. (For additional information refer to: "Information about medical service use").</p>
Disability Days	Not included.
Principal diagnoses rendered by physician	Indicated by respondent.
Referral status	Respondents are asked if the doctor they normally see was referred by another doctor.
Discharge Destination	Not included.
Prior visit status	Not included.
Principal reason for visit expressed by patient	Indicated.
Diagnostic services/Procedures ordered or provided	Included, (refer to: " Information about medical service use.")

CURRENT BENEFICIARY SURVEY (CBS)

HEALTH CARE UTILIZATION DATA (continued)	
Episodes of Care	Included. Survey is longitudinal and gathers information on dates care was received and medical conditions for which health care was sought.
Information about Medical Service Use	<p>Dental utilization and events: Respondents are asked if they went to a dentist or other person for dental care since reference date. Indicators for dental procedures include the following:</p> <ul style="list-style-type: none"> . nothing else/x-rays only, • cleaning teeth, • examination, • fillings, • extractions, • root canals, • crowns, • bridges, • dentures, • repair of bridges, dentures, relinings, etc., • orthodontia (bite adjustment, braces, retainers, other), and • other <p>Hospital utilization and events: Respondents are asked if they went to a hospital since the reference date, Indicators for hospital utilization include the emergency room, outpatient department or clinic, or inpatient stay. (See medical provider utilization and events for individuals responding that they used an outpatient department or clinic). Patients are also asked to list any operations or surgical procedures performed during a hospital stay.</p> <p>Institutional utilization: Respondents are asked if they were a patient in a nursing home, a nursing home unit of a hospital, a convalescent home, or any other similar place providing long-term care. The names of all long-term care facilities respondent has been a patient in since reference date are recorded.</p> <p>Home health utilization and events: Respondents are asked if they have been visited at home by any health professionals such as a nurse, social worker, therapist, and hospice worker since reference date. Information is gathered on type of place or organization health care professional is affiliated with, such as visiting nurse association, home health agency, hospital, private physician/group practice, hospice, other medical Institution, local government organization, church or community organization, or other. Questions are asked to gather information on the kind of care received, or help received with ADLs or IADLs.</p> <p>Medical Provider Utilization and Events: Respondents are asked if they have seen a medical doctor since reference date, and where the visit took place. Indicators include the following:</p> <ul style="list-style-type: none"> • doctors office or group practice, • doctor's clinic or HMO, • neighborhood/family health center, • free standing surgical center, • rural health clinic, • company clinic, • other clinic, • laboratory, • walk-in urgent center, • at home, • hospital emergency room, • hospital outpatient department, • hospital inpatient, and • other <p>Indicators for the main reason for the visit include the following:</p> <ul style="list-style-type: none"> • diagnosis (including tests) or treatment, . general check-up, . vision exam for glasses, • immunizations/flu vaccine, • psychotherapy/mental health counseling, • operation or surgical procedure, and • other <p>Respondents are asked to name all the providers from which they received care since the-reference date.</p>

CURRENT BENEFICIARY SURVEY (CBS)

HEALTH CARE EXPENDITURES DATA	
Health Care Charge per Service	included.
Charges per practitioner	included.
Source of Payment	Included.
Prescribed medicines	Respondents are asked if they have bought, obtained, or refilled any medicine prescribed by a doctor, the name of the medicine, the condition for which the medication was prescribed, and the number of times the medication was obtained since the reference date.
Other medical expenses	<p>Respondents are asked if they bought, replaced, rented or repaired medical equipment or supplies since the reference date. Equipment and supply indicators include the following:</p> <ul style="list-style-type: none"> • eyeglasses or contact lenses, • orthopedic items, <ul style="list-style-type: none"> -braces or supports, -cane, -corrective shoes, -crutches, -walker, -wheelchair, and -other (and for what condition the items are used), • hearing aid, amplifier for a telephone, or similar device to help them hear or speak, • diabetic equipment or supplies, • ambulance or rescue squad service, • prostheses, • kidney dialysis equipment or supplies, • oxygen, and • other equipment and supplies <ul style="list-style-type: none"> -diapers, -hospital bed, -ostomy supplies, -portable commode, -other <p>Respondents are also asked if they altered or modified the inside or outside of their house or car because of some illness or injury. indicators for alterations or modifications include the following:</p> <ul style="list-style-type: none"> • elevator, • handrails (other than tub), • raised toilet seat, • ramps, • tub handrails, • tub seat, and • other <p>Respondents are asked to list the condition for which the alteration or modification was made.</p>
Out-of-Pocket Expenses	included.
Financial assistance from someone outside household	included.

NATIONAL HEALTH CARE SURVEY (NHCS) *

GENERAL SURVEY INFORMATION	
Survey Components	<ul style="list-style-type: none"> • The National Health Provider Inventory Component (NHPI) is based on the National Master Facility Inventory. The inventory provides national data on facilities and is the sampling frame for the National Hospital Discharge Survey (NHDS) and the National Nursing Home Survey (NNHS). Future expansions will add providers of acute ambulatory care and community-based long-term care to the NHPI. • The Hospital and Surgical Care Component is based on the National Hospital Discharge Survey (NHDS). This component is being expanded to include ambulatory surgical centers (hospital based and freestanding). • The Ambulatory Care Component has as its base the National Ambulatory Medical Care Survey (NAMCS). This component is being expanded initially to include medical care provided in hospital emergency and outpatient departments and clinics. When fully implemented, this component will also cover ambulatory care provided in other settings such as neighborhood health clinics, • The Long-Term Care Component is based on the National Nursing Home Survey (NNHS) and is being restructured and expanded to include long-term care provided through home health agencies and hospices. • The Patient Follow-up Component is being developed to collect information from the patient or patient's family about the outcomes of patient care in hospital, ambulatory, and LTC settings, including subsequent use of medical care and morbidity; hospital readmissions; and changes in health status. The dimensions could change to address emerging issues and special topics. Follow-up with nursing home residents has been conducted; other patient follow-up studies are being developed. The Patient Follow-up Component will be conducted as resources permit.
Questionnaire Supplements	<ul style="list-style-type: none"> • Long-Term Care Component: Next-of-Kin telephone follow-up (1985 only; release pending).
Sponsoring Agency	The National Center for Health Statistics (NCHS).
Frequency	It is anticipated that the first four components of the NHCS will be conducted annually by 1994.
Past Years Conducted	<p>As a major initiative in the FY 1938 Public Health Service Planning Process, NCHS developed a plan to restructure the Center's surveys of health care providers into a National Health Care Survey. Four existing surveys of health care providers, which had been used as early as the mid-1960s, were modified into the major components (listed above) that now constitute the NHCS. These four surveys and the past years in which they were conducted are:</p> <ul style="list-style-type: none"> • National Master Facility inventory (NMFI): conducted on a periodic basis since 1933, with the latest update in 1989, as part of the inventory of Long-Term Care Places. • National Hospital Discharge Survey (NHDS): conducted annually since 1965. • National Ambulatory Medical Care Survey (NAMCS): conducted annually from 1973 through 1981, in 1985, and annually again beginning in 1989. • National Nursing Home Survey (NNHS): conducted on a periodic basis since 1973, with the latest update in 1985.

The National Nursing Home Survey (NNHS), a component of the NHCS, is described in detail on pages **E43-E50**.

NATIONAL HEALTH CARE SURVEY (NHCS)

GENERAL SURVEY INFORMATION (continued)	
Future Years Planned	<p>It is planned that all components of the NHCS will be conducted operational by 1994. The status or planned date for administering each of the components of the NHCS is summarized below:</p> <ul style="list-style-type: none"> • National Health Provider Inventory Component: 1991 • Hospital and Surgical Care Component: in field • Ambulatory Care Component: in field • Long-Term Care Component: 1994 • Patient Follow-up Survey (Nursing Home Residents): 1990 • Patient Follow-up Survey (Other Patients): 1994
Data Release	<ul style="list-style-type: none"> • National Health Provider Inventory Component: 12 months after data collected • Hospital and Surgical Care Component (NHDS): nine months after data collected • Ambulatory Care Component (NAMCS): 12 months after data collected • Long-Term Care Component (NNHS): 12 months after data collected • Patient Follow-up Survey: nine to 12 months after data collected
Description of Population (Sample Size)	<ul style="list-style-type: none"> • Hospital and Surgical Care Component: 542 hospitals • Ambulatory Care Component: 2,500 office-based physicians • Long-Term Care Component: 5,238 current residents; 6,017 discharges; 1,078 facilities; 2,760 staff.
Smallest Area of Analysis	Census regions, SMSA indicator, and DHHS administrative region; some local area information is also available.
Response rate	<ul style="list-style-type: none"> • National Health Provider Inventory Component: The response rate for the 1986 Inventory of Long Term Care Places was 90 percent. • Hospital and Surgical Care Component (NHDS): The hospital response rate was 78 percent in 1989. • Ambulatory Care Component (NAMCS): Physician response rate from 1985 was 70.2 percent, providing data concerning a random sample of about 71,594 patient visits. • Long-Term Care Component (NNHS): Response rates were 93 percent for facilities, 68 percent for expenses, 80 percent for registered nurses, 97 percent for residents, 95 percent for discharges, and 90 percent for next of kin.
Description of Survey	<p>As a major initiative in the FY 1968 Public Health Service Planning Process, NCHS examined the changes occurring in the health care delivery system, the impact of these changes, and the implications of these changes for the types of surveys of health care that are needed. This examination resulted in a plan for restructuring of the Center's current surveys of health care utilization into a National Health Care Survey that is expected to provide a more comprehensive picture of the medical care provided in the United States. The Center's four existing surveys of health care providers (the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, the National Nursing Home Survey, and the National Master Facility Inventory) are being modified into components of the NHCS. The scope of these surveys is being expanded to include alternative sites of care, and greater continuity is being achieved by moving periodic surveys to an annual basis. In part, this is being accomplished by reducing historical sample sizes for health care providers covered in existing surveys and reducing or modifying the content of each provider component. The capability-to conduct routine and specialized patient follow-up studies is being instituted through a patient follow-up component to address outcome and quality of care issues. Greater analytic utility is expected through the use of an integrated cluster sample approach.</p>

NATIONAL HEALTH CARE SURVEY (NHCS)

GENERAL SURVEY INFORMATION (continued)

<p>Sample Selection</p>	<p>All components involving sample surveys will utilize a cluster sample design based on the geographic areas used for the National Health Interview Survey (NHIS)¹</p> <ul style="list-style-type: none"> • National Health Provider Inventory Component: Complete enumeration of selected health care providers. • Hospital and Surgical Care Component: Stratified sample used (by bed size and geographic location): current and complete listing of short-stay non-federal hospitals with six or more beds. The probability of selection of a hospital decreases as the bed size of the hospital decreases. Within each sample hospital, a systematic random sample of discharges varies inversely with the probability of selection of the hospital, so that the overall probability of selecting a discharge is approximately the same in each bed-size class. • Ambulatory Care Component: A multi-stage probability design is employed. The first stage sample consists of 112 primary sample units (PSUs) selected from about 1,999 such units in the United States. In each sample PSU, a sample of practicing physicians is selected. The final stage involves selection within a randomly-assigned 7-day reporting period of samples of patient visits during that period. • Long-term Care Component: The sample of 1,229 nursing homes including personal care and domiciliary care homes, was selected from a sample frame of 29,479 nursing and related-care homes. The frame consisted of all homes in the 1982 NMFI, homes identified in the 1982 Complement Survey of the NMFI as missing from the 1982 NMFI, facilities that opened for business between 1982 and June 1984, and hospital-based nursing homes obtained from HCFA. Data were sampled using a stratified two-stage probability design, the first stage being a selection of facilities, and the second being a selection of residents and employees of sample facilities. In 1985, only registered nurses were sampled from the list of all staff members including those employed on contract. The sampling frame for residents was the total number of residents on the register of the facility on the evening prior to the day of the survey. • Patient Follow-on (Nursing home residents): Residents from the NNHS sampled facilities are contacted for follow-up on the use of nursing homes and hospitals since the last contact.
<p>Groups Oversampled</p>	<p>The PSUs with predominately black populations were oversampled to increase the precision of estimates for that population.</p>

¹The sampling plan of the NHIS follows a multistage probability design that permits continuous sampling of the civilian **noninstitutionalized** population residing the **United** States. The survey is designed in such a way that the sample scheduled for each week is representative of the target population, and weekly samples are addiive over time. The response rate has been around 96 percent in recent years.

NATIONAL HEALTH CARE SURVEY (NHCS)

GENERAL SURVEY INFORMATION (continued)

Data Collection Procedures

- National Health **Provider Inventory** Component: Mailing lists of facilities for the 1991 National Health Provider Inventory are currently being prepared, and in early **1991** the **NHPI** will be fielded. This mail survey will concentrate on compiling current and complete listings of hospitals, home health care agencies, hospices, nursing homes, personal care homes, and licensed residential care facilities. The **NMFI** is kept current by the periodic addition of names and addresses obtained from State licensing and other agencies for all newly-established inpatient facilities. In addition, annual surveys of hospitals and periodic surveys of nursing homes and other facilities are conducted to update name and location, type of business, number of beds, and number of residents or patients in the facilities, and to identify those facilities that have gone out of business.
- Hospital and Surgical Care Component: The National Hospital Discharge Survey was redesigned based on the integrated cluster sample design and fielded in 1988. The redesigned **NHDS** sample contains **542** hospitals and emphasizes the purchase of discharge data from hospital abstract services as a method of data collection. Approximately 75 percent of the sampled discharges for the 1988 **NHDS** were collected via hospital abstract services. Imbedded in the design is a nationally representative subsample of 128 hospitals which provide data via hard copy abstracts. This feature reduces the dependence on abstract services and provides narrative, as opposed to **precoded**, diagnoses and procedures for special studies.
- Ambulatory Care Component: The 1989 **NAMCS** was redesigned based on the integrated cluster sample design (**NHIS PSUs**) and data collection began in March 1989. The 1989 and 1990 **NAMCS** samples include approximately **2,500** office-based physicians. Data items can be aggregated to produce approximately the same level of detail as in 1986 when 5,600 physicians were sampled. Induction interview questions about in-office laboratories, health maintenance organizations and other prepaid practice arrangements have been incorporated into the **1989-90** **NAMCS**.
- Long-Term Care Component: Data on facilities were collected by personal interviews with administrators; facility accountants completed questionnaires on expenditures. Resident data were collected by personal interviews with a nurse familiar with the care provided to the resident. The nurse relied on the medical record and personal knowledge of the resident. Employees completed self-administered questionnaires. Discharge data were based on information recorded in the medical record. Additional data about the current and discharged residents were obtained by telephone interviews with next of kin.
- Patient Follow-up Component: The 1985 **NNHS** included a survey of the current and discharged residents' "**next of kin**." This survey provided experience in obtaining release of information to identify the patient and in contacting the "**next of kin**" in order to collect **longitudinal** information not readily available in the medical record. This included information on the resident's health and functional status prior to admission, the reason for admission, and a history of previous nursing home admissions. Three follow-up cycles have been conducted to determine residents' current functional status, living arrangements, use of medical care, and sources of payment since the last contact. The interviews are conducted using computer-assisted telephone interviewing, and the questionnaire includes questions concerning vital status, nursing home and hospital utilization since the last contact, current living arrangements, and source of payment.

NATIONAL HEALTH CARE SURVEY (NHCS)

PERSON SPECIFIC INFORMATION	
Age	<ul style="list-style-type: none"> • National Health Provider Inventory Component: indicated by number of residents by category: age 21 or younger, 22-64, 65-84, 85 and older • Hospital and Surgical Care Component: indicated by date of birth and age recode • Ambulatory Care Component: indicated by date of birth • Long-Term Care Component: date of birth and age recode
Sex	<ul style="list-style-type: none"> • National Health Provider Inventory Component (NHPI) indicated • Hospital and Surgical Care Component: indicated • Ambulatory Care Component: indicated • Long-Term Care Component: indicated
Race	<ul style="list-style-type: none"> • National Health Provider Inventory Component (NHPI): indicated by white, black, American Indian/Alaskan Native, Asian/Pacific Islander • Hospital and Surgical Care Component: indicated by white, black, American Indian/Eskimo/Aleut, Asian/Pacific Islander • Ambulatory Care Component: indicated by white, black, Asian/Pacific Islander, American Indian/Eskimo/Aleut • Long-Term Care Component: indicated by white, black, American Indian or Alaskan Native, Asian or Pacific Islander
Ethnicity	<ul style="list-style-type: none"> • National Health Provider Inventory Component (NHPI): indicated by Hispanic • Hospital and Surgical Care Component: Indicated by Hispanic • Ambulatory Care Component: indicated by Hispanic • Long-Term Care Component: indicated by Hispanic
Marital Status	<ul style="list-style-type: none"> • Hospital and Surgical Care Component: indicated by married, single, widowed, divorce, separated • Long-Term Care Component: indicated by married, widowed, divorced, separated, never married -- information at admission, discharge (for discharges) and current (for current residents)
Family Structure (Living Arrangement)	<ul style="list-style-type: none"> • Long-Term Care Component: Indicated prior to admission (for current residents and discharges) and at discharge (for discharges) and includes the following: private residence, rented room or boarding house, retirement home, another health care facility other arrangements. Types of health facilities reported include domiciliary or personal care facility, ICF, SNF, facility for the mentally retarded, short-term non-psych hospital, short-term hospital psych unit, VA hospital, mental health center, resident facility group.
Social Support (Caregivers)	<ul style="list-style-type: none"> • Long-Term Care Component: Any living children
Veteran Status	Not indicated.
Education	<ul style="list-style-type: none"> • Long-Term Care: Not Indicated in survey.
Income and Assets	<ul style="list-style-type: none"> • Long-Term Care Component: Limited information available from the Next of kin Followup
Insurance Status	<ul style="list-style-type: none"> • Long-Term Care Component: Not Indicated in survey.
Disability Benefits	<ul style="list-style-type: none"> • Long-Term Care Component: Not Indicated in survey.
Communication	<ul style="list-style-type: none"> • Long-Term Care Component: Not Indicated in survey.
Mental Status	<ul style="list-style-type: none"> • Long-Term Care Component: Available for current residents.

NATIONAL HEALTH CARE SURVEY (NHCS)

PERSON SPECIFIC INFORMATION (continued)	
Health Status (Diagnosis Indicators)	<ul style="list-style-type: none"> • Long-Term Care Component: Health and mental health rating (excellent, good, fair, poor) for current residents and ICD-9s for admission, any hospital use and currently for current residents and discharges.
Employment Status	<ul style="list-style-type: none"> • Long-Term Care Component: Implicitly not employed.
Functional Status	<ul style="list-style-type: none"> • Long-Term Care Component: Includes the following indicators for current residents at time of interview: <ul style="list-style-type: none"> • Activities of Daily Living and Instrumental Activities of Daily Living (ADLs/IADLs) - (bathing, dressing, eating, bedfast, chairfast, transferring, toileting, walking, getting around outside, incontinence, care of possessions, handling money, and using telephone), • Types of behavior (exposure, screaming, physical abuse, stealing, getting lost, lack of caution), • Basic activities (ability to remember dates and location, recall important events, make judgments), and • Mood indicators (depression, anxiety, fearfulness or worry) for current residents at time of interview.

NATIONAL HEALTH CARE SURVEY (NHCS)

HEALTH CARE UTILIZATION DATA	
Access to Care (Provider Site)	<ul style="list-style-type: none"> • National Health Provider Inventory Component: Specific location of the facility indicated (including mailing address, telephone number, and county) • Long-Term Care Component: General location (geographic region and MSA/non-MSA) of nursing home available, but no indication in relation to permanent residence.
Providers Surveyed	<ul style="list-style-type: none"> • National Health Provider Inventory Component: Category of the home or facility indicated, including: licensed nursing home, skilled nursing long-term care unit of hospital, a board and care home, a home for mentally retarded or developmentally disabled, home for the mentally ill, a halfway or quarter-way house for alcohol or drug abusers, home health agencies and hospices. • Long-Term Care Component: Nursing homes, personal care homes (with and without nursing), and domiciliary homes sampled.
Characteristics of Provider Facility	<ul style="list-style-type: none"> • National Health Provider Inventory Component includes the following: <ul style="list-style-type: none"> - Ownership (proprietary, other) - Number of beds - Certification status (Medicare and Medicaid, Medicare only, Medicaid only, neither) - Services offered to residents (protective oversight; supervision over medications that may be self-administered; help with bathing; help with dressing; help with walking or getting about; help with managing money; help with doing laundry; training or therapy according to a written program plan or an agreement with a government agency; transportation - Category or type of facility (see Providers Surveyed, above). In the case of nursing homes, more detailed questions are asked: type of nursing home facility (includes: nursing facility certified under Medicare or Medicaid, ICF/MR, nursing home unit of a retirement center, or other type of nursing home) - Type of resident primarily served (includes: mentally ill, mentally retarded or developmentally disabled, otherwise physically or cognitively impaired, alcohol or drug abusers, some other type) or no primary type - Number of beds currently set up and staffed for use - Number of beds certified by Medicare or Medicaid - Number of respite care beds - Number and characteristics of residents served the previous night (includes sex, age groups, race and ethnicity; see patient characteristics, above) - Number and types of employees (includes: physicians, nurses, licensed practical or vocational nurses, nursing assistants, home health aides, homemakers, dietitians and dietetic technicians, occupational therapists, occupational therapy assistants, speech pathologists and audiologists, clinical psychologists, podiatrists, physical therapists, and social workers. Each type of employee is asked the number of hours worked the previous week.

NATIONAL HEALTH CARE SURVEY (NHCS)

HEALTH CARE UTILIZATION DATA (continued)	
<p>Characteristics of Provider Facility (con't)</p>	<ul style="list-style-type: none"> • Long-Term Care Component includes the following: <ul style="list-style-type: none"> - Ownership (proprietary, other) - Number of beds - Certification status (Medicare and Medicaid, Medicare only, Medicaid only, neither) - Per diem rates (categorical ranges for each certification) - Admissions and resident days in 1994 - Services offered to residents (medical, other medical, nursing, mental health, physical, speech or hearing, and occupational therapy, special education, personal care, social services, nutrition services, hospice services, sheltered employment, vocational rehabilitation, transportation, prescribed/non-prescribed medicines, equipment or devices, other) - Services offered to non-residents (day care, physical therapy, home health, social services, other) - Physician service arrangements (on premises at all times, daytime hours every weekday and on call, scheduled times no less than once a month and on-call, on call only, other) - Full- and part-time staff, part-time staff hours, nursing staff hours, volunteer staff
<p>Dates of Encounter</p>	<ul style="list-style-type: none"> • Hospital and Surgical Care Component: Date of admission and date of discharge • Ambulatory Care Component: Date and time of visit; duration of the visit (Le., time actually spent with physician) • Long-Term Care Component: Date of admission for current residents, calculated length of stay, date of admission and discharge for discharges, calculated length of stay
<p>Types of Medical Service Use</p>	<ul style="list-style-type: none"> • National Health Provider Inventory Component: Indicated by services offered to residents and Includes the following: protective oversight; supervision over medications that may be self-administered; help with bathing; help with dressing; help with walking or getting about; help with managing money; help with doing laundry; training or therapy according to a written program plan or an agreement with a government agency; transportation. • Hospital and Surgical Care Component: Principal and other surgical and diagnostic procedures are listed
<p>Disability Days</p>	<ul style="list-style-type: none"> • Long-Term Care Component: Not Indicated in survey.
<p>Prescribed Medicines</p>	<ul style="list-style-type: none"> • Ambulatory Care Component: Medication therapy listed, including the brand name or generic name of the prescribed medication, whether it was a new or continued medication. • Long-Term Care Component: Not Indicated in survey.
<p>Principal Reason for Visit Expressed by Patient</p>	<ul style="list-style-type: none"> • Ambulatory Care Component: Patient's complaints, symptoms, or other reasons for the visit (including most important, other) • Long-Term Care Component: Not Indicated in survey.
<p>Principal Diagnosis Rendered by Physician</p>	<ul style="list-style-type: none"> • Hospital and Surgical Care Component: Principal and other diagnoses reported; ICD-9-CM Nos. may be provided, but optional • Ambulatory Care Component: Physician's diagnoses listed, including principal diagnosis problem associated with the patient's complaint and other significant current diagnoses • Long-Term Care Component: Principal and numerous secondary conditions reported

NATIONAL HEALTH CARE SURVEY (NHCS)

HEALTH CARE UTILIZATION DATA (continued)	
Prior Visit Status	<ul style="list-style-type: none"> • Ambulatory Care Component: Asks whether the physician has seen the patient before and if so, for the same condition • Long-Term Care Component: Includes previous nursing home stays and all hospital visits during current nursing home stay
Referral Status	<ul style="list-style-type: none"> • Ambulatory Care Component: Asks whether the patient was referred for this visit by another physician • Long-Term Care Component: Not Indicated in survey.
Diagnostic Services or Procedures Ordered or Provided	<ul style="list-style-type: none"> • Hospital and Surgical Care Component: Principal and other surgical and diagnostic procedures are listed • Ambulatory Care Component: indicates diagnostic/screening services, counseling advice, non-medication therapy, and medication therapy provided. Diagnostic/screening services listed are extensive (e.g., pap test, pelvic exam, breast palpation, and many others). Counseling advice includes weight reduction, cholesterol reduction, smoking cessation, HIV transmission, breast self-exam. Non-medication therapy includes psychotherapy, corrective lenses, ambulatory surgery and physiotherapy. • Long-Term Care Component: indicates whether diagnostic procedures were performed during a hospital stay
Discharge Destination	<ul style="list-style-type: none"> • Hospital and Surgical Care Component: Status or disposition of patient is listed (alive, died, or status not stated); for living patients the following dispositions are listed: routine discharge/discharged home; left against medical advice; discharged, transferred to another short-term hospital; discharged, transferred to long-term care institution; other dispositions/not stated. • Ambulatory Care Component: The disposition of the visit is indicated, including: no follow-up planned; return at specified time; return if needed; telephone follow-up planned, referred to other physician; returned to referring physician; admit to hospital. • Long-Term Care Component: Available for discharges -- alive/dead distinction and for those discharged alive residents (private residence, rented room or boarding house, retirement home, another health care facility and type of facility, other arrangements)
Episodes of Care	<ul style="list-style-type: none"> • Long-Term Care Component: Length of stay for nursing home episodes can be constructed from the discharge file using previous stay information

NATIONAL HEALTH CARE SURVEY (NHCS)

HEALTH CARE EXPENDITURES DATA

Health Care Charge per Service	<ul style="list-style-type: none"> • Long-Term Care Component: Last months charges for current residents
Charges per Practitioner	Not included.
Source of Payment	<ul style="list-style-type: none"> • Hospital and Surgical Care Component: Expected sources of payment are listed, including the following: <ul style="list-style-type: none"> • government sources, including workers' compensation, Medicare, Medicaid, Title V, and other government payments; • private sources, including Blue Cross, other private or commercial insurance; and • other sources, including self pay, no charge, and other. • Long-Term Care Component: Payment indicators are asked (at admission for both the current resident and discharge samples and at discharge for discharges and currently for current residents) for the following sources: <ul style="list-style-type: none"> • own or families resources or health insurance, • Medicare, • Medicaid, • state indigent programs, • other government sources, • charii, and • Veteran's Administration (VA). • Ambulatory Care Component: Expected sources of payment are listed, including the following: <ul style="list-style-type: none"> • self pay, • Medicare, • Medicaid • BC/BS, • other commercial insurance, • prepaid health plan, • no charge, and • other.
Prescribed Medicines	Not included.
Other Medical Expenses	Not included.
Out-of Pocket Expenses	<ul style="list-style-type: none"> • Long-Term Care Component: Payment made from own or family resources or health insurance available for current residents
Financial Assistance from Someone Outside Household	Not included.

1985 NATIONAL NURSING HOME SURVEY (NNHS)

GENERAL SURVEY INFORMATION													
Survey Components	The 1985 NNHS components include the following: <ul style="list-style-type: none"> • Discharge Sample • Resident Sample • Facility and Staff Characteristics • Next of kin Telephone Follow-up (1985 only). 												
Questionnaire Supplements (Topics Covered)	The 1985 NNHS questionnaire supplements include the following: <ul style="list-style-type: none"> • Facility Questionnaire • Expense Questionnaire and Definition Booklet • Nursing Staff Sampling List • Nursing Staff Questionnaire • Current Resident Sampling List • Current Resident Questionnaire • Discharged Resident Sampling List • Discharged Resident Questionnaire • Next of kin Questionnaire 												
Sponsoring Agency	National Center for Health Statistics (NCHS).												
Frequency	Variable.												
Past Years Conducted	The NNHS has been conducted August 1973 through April 1974, May through December 1977, and August 1985 through January 1988.												
Future Years Planned	To be incorporated into the National Health Care Survey in 1992-1993 and conducted on a continual basis afterwards.												
Data Release	Approximately two years; longer for Next of kin component (approximately 5 years).												
Description of Population (Sample Size)	<ul style="list-style-type: none"> • 5,238 current residents • 6,017 discharges • 1,078 facilities • 2,780 staff 												
Smallest Area of Analysis	Census region, SMSA indicator, and DHHS administrative region are available; also state level estimates are available for California, Illinois, Massachusetts, New York, and Texas												
Response Rate	The response rate for the 1985 NNHS questionnaires are as follows: <table> <tr> <td>Facility</td> <td>100 percent</td> </tr> <tr> <td>Expense</td> <td>88 percent</td> </tr> <tr> <td>Current Resident</td> <td>97 percent</td> </tr> <tr> <td>Discharged Resident</td> <td>95 percent</td> </tr> <tr> <td>Nursing Staff</td> <td>80 percent</td> </tr> <tr> <td>Next of kin</td> <td>90 percent</td> </tr> </table>	Facility	100 percent	Expense	88 percent	Current Resident	97 percent	Discharged Resident	95 percent	Nursing Staff	80 percent	Next of kin	90 percent
Facility	100 percent												
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Next of kin	90 percent												

1995 NATIONAL NURSING HOME SURVEY (NNHS)

GENERAL SURVEY INFORMATION (continued)	
Description of Survey	<p>A series of national sample surveys of nursing homes, their residents, and their staff. The survey collects data on characteristics of the facility and its finances, residents, discharges, and staff as follows:</p> <p><u>Facility:</u> Size, ownership, Medicare and Medicaid certified, staffing patterns, and services offered.</p> <p><u>Financial Characteristics:</u> Total expenses and major components of operation.</p> <p><u>Residents:</u> Demographic characteristics, living arrangements prior to admission, diagnosis and conditions, functional status, receipt of services (medical, nursing, and therapeutic), cost of care, and source of payment.</p> <p><u>Discharges:</u> A subset of items are collected for current residents from medical records.</p> <p><u>Staff:</u> Data varies with surveys. The 1985 survey included characteristics of registered nurse services such as work schedule, experience, activities in facility, demographic characteristics, and salary.</p> <p><u>Next of kin:</u> Information is gathered about residents' and discharges' living arrangements, health and functional status prior to nursing home admission, lifetime use of nursing home care, and Medicaid spend-down.</p>

1985 NATIONAL NURSING HOME SURVEY (NNHS)

GENERAL SURVEY INFORMATION (continued)																			
Sample Selection	Data were sampled using a stratified two-stage probability design, the first stage being a selection of facilities, and the second being a selection of residents and employees of sample facilities. In 1985, only registered nurses were sampled from the list of all staff members including those employed on contract. The sampling frame for residents was the total number of residents on the register of the facility on the evening prior to the day of the survey.																		
Groups Oversampled	No minority groups were oversampled in this survey.																		
Data Collection Procedures	<p>Survey data were collected using a combination of personal interviews and self-enumerated forms according to the following:</p> <table border="0" style="width: 100%;"> <tr> <td style="padding-left: 20px;"><u>Facility Questionnaire:</u></td> <td>Interview of administrator</td> </tr> <tr> <td style="padding-left: 20px;"><u>Expense Questionnaire:</u></td> <td>Self-enumerated by administrator, owner, accountant, or bookkeeper</td> </tr> <tr> <td style="padding-left: 20px;"><u>Nursing Staff Sampling List:</u></td> <td>informal interview of staff members</td> </tr> <tr> <td style="padding-left: 20px;"><u>Nursing Staff Questionnaire:</u></td> <td>Self-enumerated by sampled registered nurses</td> </tr> <tr> <td style="padding-left: 20px;"><u>Current Resident Sampling List:</u></td> <td>Interview with staff member who refers to current resident census or copied from records.</td> </tr> <tr> <td style="padding-left: 20px;"><u>Current Resident Questionnaire:</u></td> <td>Interview with nurse who refers to medical records</td> </tr> <tr> <td style="padding-left: 20px;"><u>Discharged Resident Sampling List:</u></td> <td>Informal interview with staff member who refers to discharge records</td> </tr> <tr> <td style="padding-left: 20px;"><u>Discharged Resident Questionnaire:</u></td> <td>Interview with nurse who refers to discharge records</td> </tr> <tr> <td style="padding-left: 20px;"><u>Next of kin Questionnaire:</u></td> <td>Telephone interview with relatives, guardians, or anyone familiar with the sampled person.</td> </tr> </table>	<u>Facility Questionnaire:</u>	Interview of administrator	<u>Expense Questionnaire:</u>	Self-enumerated by administrator, owner, accountant, or bookkeeper	<u>Nursing Staff Sampling List:</u>	informal interview of staff members	<u>Nursing Staff Questionnaire:</u>	Self-enumerated by sampled registered nurses	<u>Current Resident Sampling List:</u>	Interview with staff member who refers to current resident census or copied from records.	<u>Current Resident Questionnaire:</u>	Interview with nurse who refers to medical records	<u>Discharged Resident Sampling List:</u>	Informal interview with staff member who refers to discharge records	<u>Discharged Resident Questionnaire:</u>	Interview with nurse who refers to discharge records	<u>Next of kin Questionnaire:</u>	Telephone interview with relatives, guardians, or anyone familiar with the sampled person.
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1995 NATIONAL NURSING HOME SURVEY (NNHS)

	PERSON SPECIFIC INFORMATION
Age	Includes date of birth and age recode.
Sex	Indicated.
Race	Indicated by: <ul style="list-style-type: none"> • White, • Black, • American Indian or Alaskan Native, • Asian or Pacific Islander
Ethnicity	Includes Hispanic indicator.
Marital Status	Indicated as follows: <ul style="list-style-type: none"> • Married, • Widowed, • Divorced, • Separated, • Never married -- Information gathered at admission, discharge (for discharges), and current (for current residents)
Family Structure (Living Arrangement)	<ul style="list-style-type: none"> • Questions on family structure are asked prior to admission (for current residents and discharges) and at discharge (for discharges) and include the following indicators: <ul style="list-style-type: none"> • private residence, • rented room or boarding house, • retirement home, • another health care facility, • other arrangements • Types of health facilities reported include: <ul style="list-style-type: none"> • domiciliary or personal care facility, • intermediate care facility (ICF), • skilled nursing facility (SNF), • facility for the mentally retarded, • short-term non-psych hospital, • short-term hospital psych unit, • VA hospital, • mental health center, • resident facility group home, • state mental hospital, • private mental hospital, • chronic disease, rehab, • geriatric or other hospital, • hospice, • home health agency, • other
Social Support (Caregivers Used)	Includes indicators for any living children.
Education	Not included.
Income and Assets	Limited information available from the Next of kin Followback.
Insurance Status	Not included.
Disability Benefits	Not included.

1985 NATIONAL NURSING HOME SURVEY (NNHS)

PERSON SPECIFIC INFORMATION (continued)	
Knowledge of Government Programs	Not included.
Employment Status	Implicitly not employed.
Veteran Status	Not included.
Functional Status	<p>Functional status includes indicators for the following:</p> <ul style="list-style-type: none"> • ADLs and IADLs (bathing, dressing, eating, bedfast, chairfast, transferring, toileting, walking, getting around outside, incontinence, care of possessions, handling money, using telephone), • types of behavior (exposure, screaming, physical abuse, stealing, getting lost, lack of caution), basic activities (ability to remember dates and location, recall important events, make judgements), and • mood Indicators (depression, anxiety, fearfulness or worry) for current residents at time of interview; mobility and incontinence indicators at discharge for discharges.
Communication	Not included.
Mental Status	Available for current residents.
Health Status (Diagnostic Indicators)	A health and mental health rating (excellent, good, fair, poor) is used for current residents and ICD-9s are used for admissions. Hospital use is asked for current residents and discharges.

1985 NATIONAL NURSING HOME SURVEY (NNHS)

HEALTH CARE UTILIZATION DATA	
Access to Care (Provider Site)	General location (geographic region and MSA/non-MSA) of nursing home is available, but no indication of relation to permanent residence.
Providers/Facilities Surveyed	Nursing homes, personal care homes (with and without nursing), and domiciliary homes are sampled.
Characteristics of Provider Facility	Includes the following indicators: <ul style="list-style-type: none"> • Ownership (proprietary, other) • Number of beds • Certification status (Medicare and Medicaid, Medicare only, Medicaid only, neither) • Per diem rates (categorical ranges for each certification) • Admissions and resident days in 1984 • Services offered to residents (medical, other medical, nursing, mental health, physical, speech or hearing, and occupational therapy, special education, personal care, social services, nutrition services, hospice services, sheltered employment, vocational rehabilitation, transportation, prescribed/non-prescribed medicines, equipment or devices, other) • Services offered to non-residents (day care, physical therapy, home health, social services, other) • Physician service arrangements (on premises at all times, daytime hours every weekday and on call, scheduled times no less than once a month and on-call, on call only, other) • Full- and part-time staff • Part-time staff hours • Nursing staff hours • Volunteer staff
Dates of Encounter	Includes the following: <ul style="list-style-type: none"> • Date of admission for current residents and calculated length of stay • Date of admission and discharge for discharges and calculated length of stay
Hospital Stay	Indicates short-term hospital stays prior to admission to nursing home and any during nursing home stay,
Hospital Outpatient Department Visit	Not Included.
Disability Days	Not Included.
Nursing Home Use	Includes dates for sample stay and up to eight prior admissions and discharges for both current resident and discharge sample.

1985 NATIONAL NURSING HOME SURVEY (NNHS)

HEALTH CARE UTILIZATION DATA (continued)	
Principal Reason for Visit Expressed by Patient	Not included.
Principal Diagnoses Rendered by Physician	Principal and numerous secondary conditions are reported.
Prior Visit Status	Includes previous nursing home stays, and all hospital visits during current nursing home stay.
Referral Status	Not included.
Diagnostic Services/Procedures ordered or Provided	Indicates whether diagnostic procedures were performed during a hospital stay.
Discharge Destination	Available for discharges -- alive/dead distinction, and for those discharged alive residences (private residence, rented room or boarding house, retirement home, another health care facility and type of facility, other arrangements).
Episodes of Care	Length of stay for nursing home episodes can be constructed from the discharge file using previous stay information.

1985 NATIONAL NURSING HOME SURVEY (NNHS)

HEALTH CARE EXPENDITURES DATA	
Health Care Charge per Service	Last months charges for current residents.
Source of Payment	<p>Payment indicators are used at admission for both the current resident and discharge sample, at discharge for discharges, and currently for current residents from the following sources:</p> <ul style="list-style-type: none"> . own or families resources or health insurance, . Medicare, . Medicaid, . state indigent programs, . other government, . charity, . VA <p>Includes primary source of payment.</p> <p>Amounts from each source are asked for current resident sample.</p>
Prescribed Medicines	Not included.
Other medical expenses	Not included.
Out-of-Pocket Expenses	Payment made from own or family resources, or health insurance available for current residents
Financial assistance from someone outside household	Not included.

1984 NATIONAL LONG-TERM CARE SURVEY (NLTC)

GENERAL SURVEY INFORMATION	
Survey Components	The 1984 NLTC includes the following components: <ul style="list-style-type: none"> . Screener Sample . Community Disabled Sample . Institutional Sample . Decedent Sample
Questionnaire Supplements (Topics Covered)	There is a 1982 Caregiver Supplement which is also matched to Medicare billing records.
Sponsoring Agency	National Institute on Aging (NIA), Health Care Financing Administration (HCFA), Office of the Assistant Secretary for Planning and Evaluation (ASPE).
Frequency	Variable.
Past Years Conducted	1982, 1964, and 1989 .
Future Years Planned	The NLTC is likely to be conducted again in 1992. The intent of the NIA is to conduct the survey every four years.
Time Lag	Data are available two to three years after the survey is conducted.
Description of Population (Sample Size)	<ul style="list-style-type: none"> . 14,146 screened (representative sample of Medicare eligible) . 5,934 community disabled (impaired in ADLs or IADLs) . 1,696 institutionalized . 2,475 decedents (those who died between 1982 and 1964)
Smallest Area of Analysis	State, SSA county code, census region and DHHS administrative region are available; type of area (open country/not farm, farm, city/town/village (under 50,000), city (50,000-250,000) , suburb of large city , large city (over 250,000)).
Response Rate	Response rates averaged 96 percent for the 1982 and 1964 survey.
Description of Survey	A longitudinal and cross-sectional national representative sample of Medicare beneficiaries with chronic disabilities which reports information on level of disability , social supports, housing and neighborhood characteristics, financial resources, and medical service use for those living in the community.

1984 NATIONAL LONG TERM CARE SURVEY (NLTC)

GENERAL SURVEY INFORMATION (continued)	
Sample Selection	<ul style="list-style-type: none">• The sample was drawn using a two-stage procedure. In 1982, 35,789 names were drawn from the Medicare Health Insurance Skeleton Eligibility Write-Off (HISKEW) file. These persons were screened for chronic ADL or IADL impairments. Detailed household interviews were conducted with persons living in the community with a chronic impairment.• In 1984, persons who reported chronic disability on the 1982 screener or who were not screened due to being institutionalized on April 1, 1982, and who survived to 1984 were given a detailed household interview regardless of their 1984 functional status. Of the 25,541 persons who did not report functional impairments in 1982 (and who were not institutionalized), a random sample of 47% was drawn and subjected to the same screening procedure as in 1982. A sample of persons who became 65 between 1982 and 1984 (4,916) were also screened so that, in addition to having a longitudinal sample from 1982 to 1984, a full cross-section of persons age 66 and over in 1984 would be included. Persons in institutions in 1984 also were surveyed. "Next of kin" of persons who died between 1982 and 1984 were also interviewed.
Groups Oversampled	No minority groups are oversampled .
Data Collection Procedures	Screeners were performed by telephone or personal visit. Other survey components were conducted in person.

1994 NATIONAL LONG TERM CARE SURVEY (NLTC)

PERSON SPECIFIC INFORMATION	
Age	Indicated. Provides data in five year age intervals up to age 95.
Sex	Indicated.
Race	Indicated for the community and institutional components as follows: <ul style="list-style-type: none"> • White, • Black, • American Indian, Alaskan Native, or Aleut, • Asian or Pacific Islander
Ethnicity	The community sample includes indicators for the following: German, Italian, Irish, French, Polish, Russian, English, Scottish, Welsh, Mexican American, Chicano, Mexican, Puerto Rican, Cuban, Central or South American, Other Spanish, Afro-American (Black or Negro), other groups The Institutionalized and Deceased sample include a Hispanic indicator.
Marital Status	Marital status for the Community and deceased sample are indicated as follows: <ul style="list-style-type: none"> • Married, • Widowed, • Divorced, • Separated, • Never married
Family Structure (Living Arrangement)	Family structure are indicated as follows: <ul style="list-style-type: none"> • Community sample: constructed from information for each household member, including relationship to sample person • Institutionalized sample: type of residence prior to admission (house, apartment, or mobile home; rented room; retirement or rest home, foster care, personal care or residential care home; nursing or convalescent home; hospital; other) • Decedent sample: location of death and place of residence prior to death
Social Support (Caregivers Used)	<ul style="list-style-type: none"> • Indicated by source of care provided and includes the following probes: someone living with sample person, someone outside of household, and paid or unpaid status. • Number of living children are calculated, and has indicator for how far away (in terms of time) children live
Education	Indicated by kindergarten or less; 1-12th grade or equivalent; 1, 2, 3, and 4 years of college or equivalent; 1 year of graduate school; 2 or more years of graduate school
Income and Assets	Includes the following: <ul style="list-style-type: none"> • Total combined income before deductions for all members of the family and husband and wife only (categorical variable) • Home ownership, categorical variable for value of home and amount remaining of mortgage • Estimate of total financial assets and ownership of various financial asset holdings
Insurance Status	For community sample: Medicare, Medicaid, CHAMPUS/VA , and private health insurance coverage For institutionalized sample: CHAMPUS/VA and private health insurance For deceased sample: Family Income.

1984 NATIONAL LONG TERM CARE SURVEY (NLTC)

	PERSON SPECIFIC INFORMATION (continued)
Disability Benefits	Not included.
Knowledge of Government Programs	Not included.
Employment Status	Sample persons are either institutionalized or ADL or IADL impaired. Employment status of other household members is recorded.
Veteran Status	Indicated by active duty during WWI, WWII, Vietnam, post-Vietnam, all other periods; VA disability rating is also recorded.
Functional Status	<ul style="list-style-type: none"> • Includes the following Activities of Daily Living (ADLs) indicators for the community and institutional sample: bathing, dressing, eating, getting in or out of bed, getting around inside, toileting. • Includes the following Instrumental Activities of Daily Living (IADLs) for the community sample only: heavy housework, light housework, laundry, prepare own meals, grocery shop, get around outside, money management, taking medication, using telephone. • The community sample also includes an indicator of chronicity for medical conditions (less than 3 months, 3-6 months, 6-12 months, 1-5 years, 5 or more years) and behavioral problems (lose temper, throw, kick, shout, destroy things; loses way; stealing; forgets important events).
Communication	Includes probes for understandability of sample person's speech and ability of sample person to hear and understand.
Mental Status	A Short Portable Mental Status Questionnaire is included for the community and institutional sample with indicators for mental retardation, senility, and other mental conditions.
Health Status (Diagnostic Indicators)	<ul style="list-style-type: none"> • Includes a health rating indicator of excellent, good, fair, and poor, and probes for the Community Sample, and probes for the following conditions: rheumatism or arthritis; paralysis; permanent numbness or stiffness; multiple sclerosis; cerebral palsy; epilepsy; Parkinson's Disease; glaucoma; diabetes; cancer; arteriosclerosis; and other conditions. • Diagnostic indicators are gotten from Medicare billing records for the institutional and deceased samples.

1984 NATIONAL LONG TERM CARE SURVEY (NLTC)

HEALTH CARE UTILIZATION DATA	
Access to Care (Provider Site)	includes indicators for unmet needs for the community sample, such as would have liked to have seen a doctor but did not; indicators for reasons include: financial, time, availability of doctor, not free to leave, problem not serious, afraid to find out what's wrong, weather, other.
Providers/Facilities Surveyed	Not included.
Characteristics of Provider Facility	Information for institutionalized reports includes: number of beds, Medicare SNF, Medicaid SNF, Medicaid ICF certification, and number of beds for each.
Dates of encounter	Available for the following selected services: Number of times seen by the following professionals during the last month: <ul style="list-style-type: none"> • therapist (physical; occupational; speech or hearing), • mental health professional, • chiropractor, • dentist, • foot doctor, • optometrist, and • doctor
Hospital Stay	<ul style="list-style-type: none"> • The community sample includes month and year of last three hospital admissions, length of hospital stay, and emergency room or hospital clinic visits in the last month. • The institutional sample includes month and year of last three hospital admissions. • The decedent sample Includes month and year if died in a hospital, or if it was a prior residence.
Hospital Outpatient Department Visit	Not included.
Disability Days	Not included.
Nursing Home Use	For community sample: Number of admissions, month/year of three previous admissions, and length of stay For institutional sample: Month/year of current admission For decedent sample: Month/year if died in a hospital, or if it was a prior residence, also month/year of last three stays.
Principal Reason for Visit Expressed by Patient	Not included.
Principal Diagnoses Rendered by Physician	Diagnostic codes (ICD-9) are obtained from Medicare billing data.
Prior Visit Status	Includes indication of length of stay for previous nursing home and hospital stays.
Referral Status	Not included.

1984 NATIONAL LONG TERM CARE SURVEY (NLTC)

HEALTH CARE UTILIZATION DATA (continued)

Diagnostic services/Procedures Ordered or Provided	Surgical codes are obtained from Medicare billing data.
Discharge Destination	Not included.
Episodes of Care	Can be constructed from Medicare billing data to a limited extent.

1984 NATIONAL LONG TERM CARE SURVEY (NLTC)

HEALTH CARE EXPENDITURES DATA	
Health Care Charge per Service	Available for community sample for physical therapy, occupational therapy, speech therapy, hearing therapy, and mental health professionals. Data on Medicare Part A and Pan B charges can be obtained from the Medicare billing records.
Source of Payment	<ul style="list-style-type: none"> • For the community sample: physical therapy, occupational therapy, speech therapy, hearing therapy, and mental health professionals. Payment sources are categorized by the following: insurance, Medicare, Medicaid, household members, and non-household members (children, father, mother, son-in-law, daughter-in-law, brother, sister, other relative, and friends). • For the Institutional sample: includes sources of payment at admission and currently. Payment sources are categorized by the following: sample person, spouse, children, other relatives, non-relatives, private insurance, Medicare, Medicaid, other public assistance, VA/CHAMPUS, other; if receiving Medicaid payments records month/year began paying. • For the Decedent sample: includes sources of payment if person died in a nursing home and how long Medicaid paid for care.
Prescribed Medicines	Includes percent paid out-of-pocket for prescription drugs for the community sample only.
Other medical expenses	For the community sample, assistance from persons outside the household can be determined for therapy visits and mental health professional visits. Can be determined for nursing home care for institutionalized.
Out-of-Pocket Expenses	Can be obtained for therapy, mental health professionals, and prescriptions for the community sample.
Financial Assistance from Someone Outside Household	Indicated for services described above.

SURVEY OF INCOME & PROGRAM PARTICIPATION (SIPP)*

GENERAL SURVEY INFORMATION

<p>survey Components</p>	<p>SIPP employs two data collection instruments, a control card and a questionnaire. The control card serves as a basic source of information for updating over successive interviews: the core card is filled out at the initial interview and updated as needed. The primary survey document is the questionnaire. The questionnaire is subdivided into modules for the core information. The core information consists of responses to questions asked at every interview, and includes five major sections:</p> <ul style="list-style-type: none"> . Labor Force and Reciprocity . Earnings and Employment . Amounts of income received . A short set of program questions (Information asked only of the householder) . Missing wave (collects previous wave data for persons who missed the preceding interview) <p>Additional modules are added when topical data are collected.</p>
<p>Questionnaire Supplement (Topics Covered)</p>	<p>The topical modules asked In addition to the core questionnaire are:</p> <ul style="list-style-type: none"> . Health & Disability . Long-term care . Education and Work History . Assets and Liabilities . Housing Costs and Energy Usage . Child Care . Welfare History . Reasons for Not Working . Support for Nonhousehold Members . Annual Earnings and Benefits . Property Income and Taxes . Education Financing and Enrollment . Household Relationships . Migration History . Marital History . Fertility History . Personal History -- began in 1988 and incorporates the following: <ul style="list-style-type: none"> - Reciprocity History - Employment History - Work Disability History - Education and Training History - Family Background - Migration History - Fertility History - Marital History - Household Relationships
<p>Sponsoring Agency</p>	<p>U.S. Dept. of Commerce, Bureau of the Census.</p>
<p>Frequency</p>	<p>Ongoing. A new panel is started every year. Each panel lasts 2 1/2 years, so the panels overlap.</p>
<p>Past Years Conducted</p>	<p>Panel 1 (the 1984 panel) was started in October 1983. Subsequent panels were begun in February of every year starting in 1985.</p>
<p>Future Years Planned</p>	<p>Continuous.</p>

Health care expenditure data not included.

SURVEY OF INCOME & PROGRAM PARTICIPATION (SIPP)

GENERAL SURVEY INFORMATION (continued)	
Data Release	Cross-sectional data for every four-month wave is released 1 to 2 years after the wave is completed. Clean longitudinal data is still not available in public form and must be developed by users.
Response Rate	Approximately 95 percent
Description of Population (Sample Size)	SIPP's population is a nationally representative sample of adults 15 years and older from households in the civilian non-institutional population. The first panel, begun in 1984, interviewed adults in 19,878 households. This number dropped in subsequent panels approximately 11,000 to 14,000 households due to budgetary considerations.
Smallest Area of Analysis	SIPP data can be disaggregated by state of residence and census region,
Description of Survey	<p>SIPP is a multi-panel longitudinal survey of adults, measuring their economic and demographic characteristics over a period of 2 1/2 years. The adults followed in each panel of the survey are obtained from a multi-stage stratified sample of the non-institutional resident population of the U.S. it is a multi-panel survey with a new sample (panel) introduced at the beginning of each calendar year. The primary focus of SIPP is adults in the initial sample; they are followed over the life of the panel, even if they move from the original housing unit. Thus, SIPP provides cross-sectional views of respondent's lives at discrete points in time, as well as a longitudinal history of changes in economic circumstances and household relationships. The major goals of SIPP include the following:</p> <ul style="list-style-type: none"> • To improve accuracy in reporting and classifying income sources. • To obtain subannual information on income reciprocity and program participation. • To examine interactions among transfer programs, labor force participation, and living arrangements. • To obtain sufficient information to improve the simulation of eligibility under the major means-tested cash and in-kind transfer programs. • To obtain improved measures of assets and liabilities.
Sample Selection	The SIPP universe is the civilian non-institutional resident population living in the U.S. , who are at least 15 years old. The 1984 SIPP sample is located in 174 areas, called Primary Sampling Units (PSUs), comprising 450 counties and independent cities. Usually a group of counties rather than a single county is used as a PSU. The PSUs are combined into strata, and one PSU is selected from each stratum. The PSUs with the largest populations are treated as separate strata and included in the sample with certainty; they are called self-representing (SR). The remaining 129 PSUs are called nonself-representing (NSR) and are selected with probability proportional to size. The sample consists mostly of clusters of two to four living quarters, called segments. The bulk of the segments are systematically selected from lists of addresses prepared for the 1970 decennial census. The sample is updated to reflect new construction since 1970. The sample for the 1985 Panel and subsequent panels is in 230 PSUs of which 86 are self-representing and 144 are nonself-representing. The PSUs are selected so that each state has a sample area with certainty. The sample design involves multiple stages of selection. The main sampling frame for selecting living quarters, from 1985 on, is the 1980 decennial census address list, which is updated for new construction. The overall probability of selection for all living quarters in the SIPP sample is not the same, but the probabilities are very close. To select an efficient sample, a systematic sample of segments of living quarters is selected within each sample PSU. The 1985 and subsequent panels had a smaller initial sample than the 1984 panel due to budgetary constraints: 17,800 housing units from which 13,300 households were interviewed versus 26,000 housing units from which 19,878 households were interviewed.
Groups Oversampled	None.

SURVEY OF INCOME & PROGRAM PARTICIPATION (SIPP)

GENERAL SURVEY INFORMATION (continued)	
Data Collection Procedures	Data are collected through personal interviews, although follow ups may be done by telephone. Persons in the SIPP sample are interviewed once every four months for 2% years. This sample composes a panel. Each panel is divided into four random subsamples which are considered rotation groups. Each rotation group is interviewed in a separate month. A wave is considered one cycle of interviewing for the entire panel which takes four months to complete.

SURVEY OF INCOME & PROGRAM PARTICIPATION (SIPP)

PERSON SPECIFIC INFORMATION	
Age	Included; Date of birth is recorded so that age can be computed for any subsequent interview or reference month.
Sex	Indicated.
Race	Indicated as follows: <ul style="list-style-type: none"> • White • Black • American Indian, Eskimo, and Aleut • Asian and Pacific Islander • Other
Ethnicity	Ethnicity includes 23 categories, including seven categories of Spanish origin.
Marital Status	Indicated as follows: <ul style="list-style-type: none"> • Married -- spouse present • Married -- spouse absent • Widowed • Divorced • Separated • Never Married
Family Structure (Living Arrangement)	Included; the family is defined as two or more persons who are living together and are related by blood, marriage, or adoption. SIPP summarizes economic and demographic data for each primary and unrelated subfamily unit and each unrelated individual. A primary family is the family containing the household reference person; an unrelated subfamily is a family which does not contain the reference person or anyone related to the reference person. Family membership and relationships to the reference person are noted for each person in the survey on the control card. The household relationship module more fully develops relationships.
Social Support (Caregivers Used)	Included; Long-term care Module documents up to two helpers for persons needing aid with daily living activities.
Education	Included; highest grade attended and whether or not respondent finished that grade.

SURVEY OF INCOME & PROGRAM PARTICIPATION (SIPP)

PERSON SPECIFIC INFORMATION (continued)

income and Assets

Included; Data gathered on type of employment: wage and salary, or self. Total pay from up to two jobs is determined (ii the respondent works more than two jobs, full information is collected for the two in which he/she worked the most hours, and earnings from other jobs are Included in other cash income.) **Self-**employment earnings are defined as the income received each month by each person involved with the business. Reciprocity and amounts are recorded for the following types of income:

- . Wage or Salary Income
 - Income from Job **#1**
 - Income from Job **#2**
- . Self-Employment Income
 - Income from Business **#1**
 - Income from Business **#2**
- . Program and Miscellaneous Income
 - Social Security
 - US. Government Railroad Retirement pay
 - Federal SSI
 - *- State SSI
 - State unemployment compensation
 - Supplemental Unemployment **Benefits**
 - Other unemployment compensation
 - Veteran's compensation or pensions
 - *- Black lung payments
 - Worker's compensation
 - *- State temporary sickness or disability benefits
 - Employer or union temporary sickness policy
 - Payments from personal insurance policy
 - AFDC
 - General assistance or General relief
 - *- Indian, Cuban, or Refugee Assistance
 - Foster **child** care payments
 - Other Welfare
 - **WIC**
 - Food Stamps
 - Child support payments
 - Alimony payments
 - Pension from company or union
 - Federal employee pensions
 - U.S. Military retirement pay
 - *- National Guard or Reserve Forces retirement
 - State government pensions
 - Local government pensions
 - Income from paid-up life insurance policies or annuities
 - Estates and trusts
 - Other payments for retirement, disability, or survivor
 - G.I. **Bill/VEAP** education **benefits**
 - Income assistance from a **charitable** group
 - **Money from** relatives or friends
 - Lump sum payments
 - Income from roomers or boarders
 - National guard or reserve pay
 - Incidental or casual earnings
 - Other cash income not included elsewhere

* These five types of **benefits** are combined into a single category on the public files to avoid increasing the **risk of individual exposure.**

SURVEY OF INCOME & PROGRAM PARTICIPATION (SIPP)

PERSON SPECIFIC INFORMATION (continued)

<p>income and Assets (Con't)</p>	<ul style="list-style-type: none"> • Asset Income <ul style="list-style-type: none"> - Regular/passbook savings accounts - Money Market deposit accounts - Certificates of Deposit or other savings certificates - NOW, Super NOW, or other interest earning checking accounts - Money market funds - U.S. Government securities - Municipal or Corporate bonds - Other interest earning assets - Stocks or mutual fund shares - Rental property - Mortgages - Royalties - Other financial investments • Noncash Benefits (other than WIC and Food Stamps) <ul style="list-style-type: none"> - Medicare - Medicaid - Public housing occupancy - Rent subsidies - Energy assistance - Subsidized school lunches or breakfasts <p>SIPP also administers a topical module on assets and liabilities which examines the amount of assets held by persons: their net worth. Some of the major types of assets covered are:</p> <ul style="list-style-type: none"> • Savings accounts • Stocks • Mutual funds • bonds • Keogh plans • IRA accounts <p>Also covered are unsecured liabilities:</p> <ul style="list-style-type: none"> • Loans • Credit cards • Medical bills <p>The net worth of home and automobiles are also collected.</p>
<p>Insurance Status</p>	<p>Includes indicators for health insurance (private, Medicare, CHAMPUS, or Medicaid), and life insurance.</p>
<p>Disability Benefits</p>	<p>Included (refer to "Income and Assets" in Patient Specific Information tables).</p>
<p>Utilization of Government Proarams</p>	<p>Included; SIPP includes data on whether or not person receives aid from government programs but does not test respondents knowledge of such programs.</p>

SURVEY OF INCOME & PROGRAM PARTICIPATION (SIPP)

PERSON SPECIFIC INFORMATION (continued)

Employment Status	<p>includes the following:</p> <ul style="list-style-type: none"> • Wage employment • Self-employment • Laid off • Looking for a job • Not in labor force <p>There is also a topical module which details why persons are not in the work force and what conditions might attract them back into the work force.</p>
Veteran Status	included.
Functional Status	included; (refer to "Health Status").
impairment Disabilities	included; (refer to "Health Status").
Communication	included; (refer to "Health Status").
Mental Status	included (refer to " Health Status").
Health Status (Diagnostic indicators)	SIPP administers a topical module on Health Status and Utilization of Health Care Services and a topical module on long-term care starting with the 1985 panel which provides data on persons' health status. in 1984, there was an extensive supplement on disability and functional limitations.

SURVEY OF INCOME & PROGRAM PARTICIPATION (SIPP)

HEALTH CARE UTILIZATION DATA	
Access to Care (Provider Site)	included; Number of times respondent has seen a doctor in the past twelve months. Providers are differentiated as follows: <ul style="list-style-type: none"> • Doctor's office (or HMO) • VA hospital • Military Hospital • Hospital outpatient clinic (not VA or Military) • Hospital emergency room • Company or industry clinic • Health center (neighborhood health center or free or low-cost clinic) • Other
Providers Surveyed	Not included.
Characteristics of Provider Facility	Not included.
Dates of Encounter	Not included.
Hospital Stay	indicated as follows: <ul style="list-style-type: none"> • Number of times respondent was in the hospital in the last twelve months • Total number of nights spent in the hospital in the past twelve months • Number of these nights spent in a VA or Military hospital • Number of these nights that were in the past four months.
Hospital Outpatient Department Visit	Not included.
Disability Days	indicated by number of days in the past four months that injury or illness kept respondent in bed more than half of the day.
Nursing Home Use	Not included.
Use of Long-Term Care Facility	Not included.
Principal Reason for Visit Expressed by Patient	Not included.
Principal Diagnoses Rendered by Physician	Not included.
Prior Visit Status	Not included.
Referral Status	Not included.
Diagnostic Services/Procedures Ordered or Provided	Not included.
Discharge Destination	Not included.
Episodes of Care	Not included.

CURRENT POPULATION SURVEY (CPS)*

GENERAL SURVEY INFORMATION	
Survey Components	Not included.
Supplements (Topics Covered)	<ul style="list-style-type: none"> • Health • Education • Income • Work Experience • Noncash Benefits • Migration
Sponsoring Agency	Conducted by U.S. Dept. of Commerce, Bureau of the Census for the Bureau of Labor Statistics.
Frequency	Monthly.
Past Years Conducted	Every year since 1848.
Future Years Planned	Continued on a monthly basis.
Data Release	Approximately 1 year from the time the survey is completed.
Description of Population (Sample Size)	Civilian noninstitutional population of the U.S. and members of the Armed Forces living in civilian housing units on a military base or in a household not on a military base . (56,000 households containing 115,000 persons 15 years old and older plus 33,600 children 0-14 years old and 660 Armed Forces members every month.) In March, supplemental data are collected on Armed Forces members, and additional Spanish households are sampled (2,600).
Smallest Area of Analysis	State of residence, census geographic division and region, the 113 largest Consolidated Metropolitan Statistical Areas (CMSAs) or Metropolitan Statistical Areas (MSAs), an additional 88 selected MSAs , 66 selected Primary Metropolitan Statistical Areas (PMSAs), and 30 central cities in multi-central city MSAs or PMSAs are uniquely identified. Within confidentiality restrictions indicators are provided for MSA-PMSA/non-MSA-PMSA , central city/noncentral city, farm/nonfarm , and MSA/CMSA size.
Response Rate	Approximately 81 percent.
Description of Survey	Main Purpose: Employment and Unemployment statistics Secondary Purpose: Demographic characteristics of the population
Sample Selection	The CPS sample is based on the civilian non-institutional population of the U.S. The sample is located in 728 sample areas comprising 1,973 counties and independent cities with coverage in every state and in the District of Columbia. In all, some 70,800 housing units or other living quarters are assigned for interview each month. Approximately 13,600 noninterview households are present each month. In March each year supplemental data are collected for the Armed Forces. In addition since 1976 the March CPS is supplemented with a sample of Spanish households identified the previous November. This results in the addition of 2,500 households in the March CPS.
Groups Oversampled	In March an additional 2,600 households with at least one Hispanic member are sampled.
Data Collection Procedures	Personal Interview.

The CPS does not include health care utilization and expenditure data.

CURRENT POPULATION SURVEY (CPS)

PERSON SPECIFIC INFORMATION	
Age	included; adult population is persons 15 years old and over.
Sex	indicated.
Race	Race is indicated as follows: <ul style="list-style-type: none"> • White • Black • American Indian/Aleut/Eskimo • Asian or Pacific Islander • Other Races
Ethnicity	Ethnicity includes the following indicators: <ul style="list-style-type: none"> • Mexican American • Chicano • Mexican (Mexicano) • Puerto Rican • Cuban • Central or South American • Other Spanish • All Other
Marriial Status	Marital status is indicated as follows: <ul style="list-style-type: none"> • Married - civilian spouse present • Married - Armed Forces (AF) spouse present • Married - spouse absent • Widowed • Divorced • Separated • Never Married
Family Structure (Living Arrangement)	Included; Households are broken down into primary and subfamilies. Relationships between all members of a household to the reference person are included.
Social Support (Caregivers Used)	Not included.
Education	Indicated by highest grade obtained.
Income and Assets	Included; for each person 15 years and older amount of income for the preceding calendar year is determined for the following: <ul style="list-style-type: none"> • Wages or salary • Net income from nonfarm self-employment • Net income from farm self-employment • Social Security or railroad retirement • Supplemental Securii Income • Public assistance or welfare payments • Interest • Dividends, income from estates or trusts, and net rental income • Veteran's payment or unemployment and workman's compensation • Private pensions or government employee pensions • Alimony, child support, regular contributions from persons not living in the household, and other periodic income

CURRENT POPULATION SURVEY (CPS)

PERSON SPECIFIC INFORMATION (continued)	
Insurance Status	Included in the March supplement only. Indicators include the following: Medicaid, Medicare, Champus , VA or military health care, or through group health insurance plans provided by a current or former employer or union, Retirees coverage under continuing employer-sponsored insurance is also determined.
Disability Benefits	Includes source of disability income as determined by one of the following: <ul style="list-style-type: none"> . Worker's compensation . Company or union disability . Federal government disability . U.S. military retirement disability . State or local government employee disability . U.S. Railroad Retirement Disability . Accident or disability insurance . Other
Utilization of Government Programs	Includes questions on whether the following types of assistance were received during the previous calendar year: <ul style="list-style-type: none"> . Medicare . Medicaid . Food Stamps • Federal School Lunch Program • Public housing assistance • Energy assistance • SSI . AFDC • VA payments • Social Security <p>Data on how long the assistance is received and how much is received for some types of assistance is included.</p>
Employment Status	includes detailed information on employment. Adults are classified as either employed unemployed, or not in the labor force. The unemployed are broken down into job leavers, job losers, new job entrants, and job re-entrants. The income supplement includes information on wages and salaries. Various data on employment such as type of job or length of employment, and unemployment such as why and how long unemployed, are gathered.
Veteran Status	Includes information on veteran status, and VA benefits received, i.e. disability, survivor, pension, education assistance, and other benefits .
Impairment Disabilities	Respondents are not asked specific questions about limitations in performing activities of daily living or instrumental activities of daily living (ADLs/IADLS).
Functional Status	Included; respondents are asked whether any health problems or disability prevents or limits their work. They are also asked if they retired from or left a job for health reasons.
Communication	Not included.
Mental Status	Not Included.
Health Status (Diagnostic Indicators)	Not Included.

NEW BENEFICIARY SURVEY (NBS)*

GENERAL SURVEY INFORMATION	
Survey Components	<p>Survey components include the following:</p> <ul style="list-style-type: none"> • Retired workers • Disabled workers • Spouses <ul style="list-style-type: none"> - Wives - Widows - Divorced wives - Surviving divorced wives • Nonretired category (Medicare-only) • for comparison with retired beneficiaries only; cannot be combined with the new beneficiaries.
Questionnaire Supplements (Topics Covered)	<ol style="list-style-type: none"> 1. Household composition 2. Employment history 3. Job characteristics, including pension status of the current job (ii employed), the last job (ii not currently employed or the current job if relatively recent), and the longest job (ii different from the current or last job) 4. Other employment not covered by Social Security 5. Health 6. Topics 2 through 5 above for the respondent's spouse (ii married) 7. Sources of income and amount of income received in the last three months (asked separately for unmarried respondents and for married respondents and their spouses) 8. Asset holdings and income from assets (asked jointly for married respondents and their spouses) 9. Marital history 10. Child care
Sponsoring Agency	U.S. Dept. of Health & Human Resources, Social Security Administration, Office of Policy, Office of Research, Statistics, and International Policy.
Frequency	Twice; Includes a follow-up survey of surviving respondents and/or spouses in 1990-1991 .
Past Years Conducted	October-December 1982.
Future Years Planned	Unknown.
Data Release	1982 Survey available January 1986.

The NBS does not include health care utilization and expenditure data.

NEW BENEFICIARY SURVEY (NBS)

GENERAL SURVEY INFORMATION (continued)

Description of Population (Sample Size)	<p>Population represents living non-institutionalized persons in late 1982 who had begun receiving retirement or disability benefits under the Social Security program for the time period between mid-1980 and mid-1981. The NBS separately sampled from the following strata:</p> <ul style="list-style-type: none"> • Retired-worker men aged 62 (1,673) aged 63-64 (1,698) aged 65 (1,651), and aged 66 or older (1,265) • Retired-worker women aged 62 (1,538) aged 63-64 (1,275) aged 65 (1,283) and aged 66 or older (1,009) • Disabled-worker men (4,376) • Disabled-worker women (1,936) • Woman first receiving cash benefits solely as: <ul style="list-style-type: none"> - Wives (1,243) - Widows (1,188) - Divorced wives (246) - Surviving divorced wives (258) • Insured workers entitled to Medicare but not receiving benefits by July 1982 were eligible for sample selection (1,795) <p>(The total number interviewed was 22,434)</p>
Response Rate	Response rates ranged from 80 to 89 percent.
Smallest Area of Analysis	National.
Description of Survey	<ul style="list-style-type: none"> • The NBS is a nationally representative, cross-sectional, household survey using samples randomly selected from the SSA's Master Beneficiary Record (MBR). The NBS represents new beneficiaries and nonbeneficiaries as individual respondents. The NBS uses a cluster sampling method. • The goal of the new beneficiary portion of the NBS is to represent the situations of living non-institutionalized persons in late 1982 (Oct.-Dec.) who had begun receiving retirement or disability benefits under the Social Security program for the time period between mid-1980 and mid-1981. The goal of the non-beneficiary portion of the survey is to provide comparable information about persons in late 1982 who were at least age 65, but who had not retired.
Sample Selection	<p>The NBS uses a clustered sample; the time and expense of travel between interviews prohibited using a simple random sample design. Given that a cluster sample was desired, the NBS used the Institute for Survey Research/Mathematica Policy Research (ISWMPR) National Sample of Primary Sampling Units, based on the 1980 Census. This sampling frame is representative of the populations of the 48 continental states and the District of Columbia. The sampling strategy was to adapt the NBS sample to the ISR/MPR frame by selecting beneficiaries only within the 100 sampling points of the ISR/MPR national sample. However, before this took place, the 100 sampling points were modified to correspond to clusters of zip code areas encompassing the primary areas. This allowed the subselection of beneficiaries on the basis of the zip code number associated with their address on the universe tape. The sampling proceeded in two stages; selection of the ISR/MPR primary sampling units (PSU's) and selection of respondents within the ISR/MPR sample of PSU's using the MBR.</p>
Groups Oversampled	None.
Data Collection	Personal interview

NEW BENEFICIARY SURVEY (NBS)

	PERSON SPECIFIC INFORMATION
Age	Includes age of respondent and all members of his/her household.
Sex	indicates sex of respondent and all members of his/her household.
Race	Race is indicated as follows: <ul style="list-style-type: none">• White• Black or Negro• American Indian or Alaskan Native• Asian or Pacific Islander• Other Races
Ethnicity	Ethnicity is indicated by questions to determine if respondent has a Hispanic background.
Marital Status	Indicated as follows: <ul style="list-style-type: none">• Married• Widow/widower• Separated,• Divorced• Never married
Family Structure (Living Arrangement)	Includes names of all members of the respondents household and their relationship to the respondent. Also, separate data on the respondent's spouse are gathered if the respondent is married.
Social Support (Caregivers Used)	Not included.
Education	Includes highest grade completed.

NEW BENEFICIARY SURVEY (NBS)

PERSON SPECIFIC INFORMATION (continued)

Income and Assets	<p>Included; Recipency and amounts are determined for the following income types:</p> <ul style="list-style-type: none"> • Social Securii • Supplemental Security Income • Railroad Retirement • Black Lung • Veteran's Benefits • Welfare • Earnings • State/Local Pension • Military Pension • Federal Pension • Private Pension • Annuities • Worker's Compensation • Unemployment Compensation • Alimony • Estate/Trust/Royalties • Household Transfer • Interhousehold Transfer • Food stamps <p>Holdings, amounts and income are determined for the following assets:</p> <ul style="list-style-type: none"> • Money Market • Certificate of Deposit • Savings • Credit Union • Checking • Bonds • Stocks • Respondent IRA • Spouse IRA • Own Home • Other Property • Business Equity • Professional Practice • Farm Equity
Insurance Status	<p>Included; Respondent's coverage under Medicaid, Medical Assistance/MediCal, California Medicaid, Champus, VA, military health care, or other health insurance is ascertained.</p>
Disability Benefits	<p>Included; Disabled strata already receiving Social Securii disability. Others asked if they. have ever applied for Social Securii disability assistance. Respondents are quizzed on their knowledge of the Social Security disability benefits program including trial work periods.</p>

NEW BENEFICIARY SURVEY (NBS)

PERSON SPECIFIC INFORMATION (continued)	
Utilization of Government Programs	Includes questions on whether the following types of assistance were received by the respondent after becoming disabled before receiving their first Social Security disability check: <ul style="list-style-type: none"> . Supplemental Security Income (SSI) . Aid to Families with Dependent Children (AFDC) . Veteran's Payments . State cash sickness or temporary disability . Worker's Compensation . Unemployment Compensation . Earnings of spouse . Earnings of family member other than spouse . Company, union, or employer pension plans . Insurance plans . Investments or annuities . Other sources
Employment Status	Included; Data are collected on respondent's current job (if presently employed), last employment, and longest employment (if different from the previous two) and include the following: <ul style="list-style-type: none"> . Employed/self-employed . Hours worked per week . Weeks worked per year . Salary . Keogh account . Employment status . F.I.C.A. deducted . Retirement plan . Receiving retirement benefits . Covered by pension plan . Receiving payments from plan
Veteran Status	Includes information on Veteran status, VA disability, and VA disability benefits.
Functional Status	Included; respondents are asked whether or not they have any health problem or a disability which prevents or limits his/her work. Effect of disability on work is ascertained. Also asked if the disability is work related. The respondent is asked how much help they need looking after their personal needs.
Impairment Disabilities	(refer to: 'Health Status').
Communication	(refer to: 'Health Status').
Mental Status	(refer to: "Health Status').
Health Status (Diagnostic Indicators)	Included; Respondents are questioned on the incidence of specific medical conditions.
Disability Days	Includes the number of days illness or injury kept the respondent in bed all or most of the day in the past 12 months.