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Development of the National Home and Hospice Care Survey

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The National Home and Hospice Care Survey began operation in 1992. This report presents the development of the survey instruments and survey procedures from a feasibility study in 1990 to the first year of operation of the National Survey.

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Under the legislation establishing the National Health Survey, the Public Health Service is authorized to use, insofar as possible, the services or facilities of other Federal, State, or private agencies.

In accordance with specifications established by the National Center for Health Statistics, the U.S. Bureau of the Census, under a contractual arrangement, participated in collecting the data.

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Symbols

- - -	Data not available
. . .	Category not applicable
–	Quantity zero
0.0	Quantity more than zero but less than 0.05
Z	Quantity more than zero but less than 500 where numbers are rounded to thousands
*	Figure does not meet standard of reliability or precision

Development of the National Home and Hospice Care Survey

by Barbara J. Haupt, D.V.M., Division of Health Care Statistics

Introduction

This report provides a description of the development of the National Home and Hospice Care Survey (NHHCS). The NHHCS is one of a number of surveys conducted by the Division of Health Care Statistics, National Center for Health Statistics (NCHS). The NHHCS was implemented in 1992 and will be conducted annually; data are collected by means of personal interviews with the administrators and staff of a nationally representative sample of hospices and home health agencies.

The legislative mandate 42 USC (Section 306 of the Public Health Service Act) states that one of the duties of NCHS is to "collect statistics on...health resources...[and the] utilization of health care, including utilization of...services of hospitals, extended care facilities, home health agencies, and other institutions...." (see appendix I). Data about the utilization of home health and hospice care services are collected through the NHHCS, which is a part of the National Health Care Survey (NHCS) (1). The NHCS is a program designed by NCHS to collect data on the use of health care providers in the United States. The NHCS is an integrated set of record-based health care provider surveys that has been developed by the Division of Health Care Statistics in response to changes during the 1980's in the delivery of health care.

The National Health Care Survey

The NHCS is composed of five basic components: Long-Term Care, Health Provider Inventory, Patient Follow-on, Hospital and Surgical Care, and Ambulatory Care. This family of surveys is designed to answer questions concerning the utilization of health care services. The surveys generate data that permit analysis of the relationship between the use of health services and health characteristics that can be used to monitor current and changing patterns in health care use.

The Long-Term Care Component of the NHCS includes two surveys: the National Nursing Home Survey and the National Home and Hospice Care Survey. Through this component, data are collected on the services and staff of the facilities and on the personal and health characteristics of current and discharged residents or patients.

The National Health Provider Inventory (NHPI) Component, formerly called the National Master Facility Inventory and the Inventory of Long-Term Care Places, provides a comprehensive national listing of health care facilities such as nursing homes, facilities for the mentally ill and mentally retarded, home health agencies, hospices, and licensed residential care facilities. Data from the NHPI are used to describe the number, distribution, and types of facilities and to select samples of facilities for other component surveys.

The Patient Follow-on Component provides data on outcomes of patient care and subsequent use of health care services through periodic contacts with patients, patients' families, or facilities. Data are available from the 1985 National Nursing Home Survey Followup. A feasibility study is underway to develop, test, and fine-tune the data collection methodology for other provider-based follow-on studies.

The Hospital and Surgical Care Component collects data on the utilization of resources in short-stay hospitals and ambulatory surgical centers. This is done through the National Hospital Discharge Survey, which has been conducted annually since 1965, and the National Survey of Ambulatory Surgery, which will be operational in 1994.

Data on visits to office-based physicians and hospital emergency departments, outpatient departments, and clinics are collected through the National Ambulatory Medical Care Survey and the National Hospital Ambulatory Medical Care Survey. These surveys, which are currently conducted on an annual basis, make up the Ambulatory Care Component of the NHCS.

Purposes of the NHHCS

The purposes of the NHHCS include collection of

- National baseline data on the characteristics of hospices and home health agencies in relationship to patients they serve and the type of staff they employ
- Data on Medicare and Medicaid certification
- Data on charges to patients by hospice and home health agencies
- Information about the source(s) of payment for services from hospices and home health agencies
- Information about patients receiving home and hospice care including functional status and diagnosis
- Information about the categories of people employed by hospices and home health agencies

Data from the NHHCS will be available to analyze relationships that exist between services offered and the populations served by hospices and home health agencies. Such analyses of data on utilization, diagnoses, and services can make important contributions to specific areas of epidemiologic surveillance, particularly chronic disease, injury, and aging.

The data set and procedures for the NHHCS were developed and evaluated in 1990 in the study, *Feasibility of Studying Hospices and Home Health Agencies* (2). Results from this study were refined and pretested in 1991 in preparation for the National Survey. The developmental, testing, and evaluation processes, which resulted in the NHHCS, are presented in this report. Appendix II contains definitions of selected terms used by the NHHCS. Changes will be documented as needed in the Technical Appendix of the NHHCS summary reports (see "Data publication and availability" in the section "The National Home and Hospice Care Survey" in this report).

Feasibility of studying hospices and home health agencies

The first step in the development of the National Home and Hospice Care Survey (NHHCS) was the study, Feasibility of Studying Hospices and Home Health Agencies (Feasibility Study) (2). This study was done under contract in 1990; its purpose was to determine the availability of data and to develop and test data collection plans for the NHHCS and the hospice and home health agency part of the 1991 National Health Provider Inventory (NHPI). Because of this dual purpose, there were two elements of interest in the Feasibility Study: the agency providing the service (the NHPI part) and the client or patient served (the NHHCS part). Although this dual nature is evident throughout the Feasibility Study, this report will concentrate on the NHHCS part of the study.

Sampling frame and sample selection

The sampling frame and sample selection for the Feasibility Study are summarized in table A. The agency sampling frame was a list of hospices and home health agencies developed from lists of agencies provided by States, the Medicare Provider of Service file of the Health Care Financing Administration, and national directories created by trade groups and other organizations. Based on this sampling frame, it was estimated that there were approximately 1,600 hospices and 10,000 home health agencies in the United States. The client sampling frames were lists of current and discharged clients (or patients) that were constructed by the interviewer at the time of the interviewer's visit to the agency. See appendix III for copies of the forms used to construct these patient lists.

The design used to select the sample for the Feasibility Study was a multi-stage design similar to that planned for the NHHCS. The first stage consisted of eight purposively selected areas called primary sampling units (PSU's). These PSU's were geographically dispersed throughout the contiguous United States and included urban and nonurban areas. Within each of the eight PSU's, the frame was sorted by ZIP Code and type of agency (hospice or home health agency). A systematic random sample of 192 agencies was selected from these areas—24 (10 hospices and 14 home health agencies) in each PSU. These agencies were used to test the questionnaires and procedures for the NHPI. Half (96) of these agencies were randomly selected for the NHHCS part of the Feasibility Study. Lists of current clients and of discharges were constructed for these agencies. Client information was obtained from a systematic sample of four current patients and four discharges that were on these lists.

Table A. Sample selection for the Feasibility Study for the National Home and Hospice Care Survey

Sampling frame sources
Agencies:
Lists from States
Medicare Provider of Service File
National directories
Clients:
Lists constructed by interviewer
Sample selection
Primary sampling units (8)
Agencies (192)
Hospices (80)
Home health agencies (112)
Clients—selected from 96 agencies
Current patients (4 per agency)
Discharges (4 per agency)

Data collection instruments

Three questionnaires and two listing forms were used in the Feasibility Study: an Agency Questionnaire, an Administrator's Questionnaire, a Client Questionnaire, a Current Client Listing Form, and a Discharged Client Listing Form. These data collection instruments are shown in appendix III. The questionnaires were used to collect data about the agencies, the clients (or patients) served, and the services provided (table B). The listing forms were used by the interviewers to aid in selecting the samples of current clients and of discharges.

The Agency Questionnaire included the types of agency data that were to be collected primarily through the NHPI. This information included identification, operating status, type of ownership, Medicare and Medicaid certification, and maintenance of clinical records by the agency. Also included were questions on the types of services provided by the agency, the types of personnel providing the services, the types and numbers of clients served, and the number of visits made to clients during the previous year.

Table B. Questionnaires used and information obtained for the Feasibility Study for the National Home and Hospice Care Survey

Agency Questionnaire (NHPI)	Client Questionnaire (NHHCS)
Agency data	Demographic characteristics
Services provided	Administrative data
Personnel	Family and home environment
Client data	Sources of referral
	Health status
Administrator's Questionnaire (NHHCS)	Functional status
	Services provided
Agency data	Payment information
Client data	

The Administrator's Questionnaire was a shortened version of the Agency Questionnaire and included agency data that were to be collected through the NHHCS. This is summarized in table C. Included are identification information, type of ownership of the agency, primary service category of the agency, maintenance of clinical records, and Medicare and Medicaid certification. Questions were also asked about the types and numbers of clients served and discharges that occurred during the previous year.

The Client Questionnaire, which was also to be used in the NHHCS, collected data on current and discharged clients. As shown in table D, this questionnaire obtained information about the client's demographic characteristics; family and home environment, including where and with whom the client was living; services provided to the clients, including number of visits made to the client by agency staff; health and functional status of the clients, including presenting diagnoses; charges and sources of payment for the services provided; sources of referral to the agency; date of enrollment and, for discharged clients, date, status, and reason for discharge. In order to determine data availability, sources of the information used to answer the items on the client questionnaire were collected by asking the respondent if the information was obtained from the client's primary record, from a supplementary record, from the respondent's personal knowledge, or from consultation with another staff member.

The Current and Discharged Client Listing Forms were used to list each client to aid in selecting the client samples. The date of enrollment was listed for each current client and the date of discharge was listed for each discharged client.

Data collection methods

The data collection methods for the Feasibility Study are summarized in figure 1. The Feasibility Study was done in two phases. In Phase I (the NHPI part) the Agency Questionnaire was mailed to all of the 192 sampled agencies. Half of these agencies were randomly selected to receive a prenotification letter. This was sent out 1 week before the main mailing, that consisted of a letter from NCHS explaining the survey, an Agency Questionnaire, and letters of endorsement from the National Hospice Organization and the National Association of Home Care. (Copies of the letters used are shown in appendix III.) Agencies not responding to the first mailout

Table C. Information collected through the Administrator's Questionnaire for the Feasibility Study for the National Home and Hospice Care Survey

Agency data

- Identification information
  - Agency name, address, and telephone number
    - Mailing and location
  - Administrator's name, title, and telephone number
- Ownership
  - Independent agency
  - Part of chain
  - Owned/operated by:
    - Hospital
    - Nursing home
    - Federal, state, or local health department or agency
  - Other
- Primary service category
  - Hospice
  - Home health care
  - Hospice and home health care equal
  - Other
- Clinical records
  - Maintained by agency?
  - Where kept (at this location or at another location)
    - For current/active clients
    - For discharges
- Certification
  - Medicare
  - Medicaid

Client data

- Active clients served during 1989
  - Number of hospice-only clients
  - Number of home health care-only clients
  - Number of clients that were both home health care and hospice clients
- Discharges during 1989
  - Number of hospice discharges
  - Number of home health care discharges

Table D. Information collected through the Client Questionnaire for the Feasibility Study for the National Home and Hospice Care Survey

- Demographic characteristics
  - Date of birth
  - Sex
  - Race
    - White
    - Black
    - American Indian, Eskimo, Aleut
    - Asian, Pacific Islander
    - Other
  - Hispanic origin
  - Marital status
    - Married
    - Widowed
    - Divorced
    - Separated
    - Never married
- Family and home environment
  - Living children present
  - Family involved in providing care
  - Primary caregiver present
    - Relationship to client
      - Spouse
      - Parent
      - Child
      - Other relative
      - Neighbor
      - Friend
      - Volunteer group
      - Other
  - Where client living
    - Private residence
    - Rented room, boarding house
    - Retirement home
    - Health facility
    - Other
  - With whom living
    - Alone
    - With others (family, nonfamily)
  - Safety assessment done of home
- Sources of referral
  - Self or family
  - Nursing home
  - Hospital
  - Physician
  - Health department
  - Other
- Functional status
  - Vision
  - Hearing
  - Activities of daily living
    - Bathing
    - Dressing
    - Eating
    - Transferring
    - Walking
    - Using toilet room
  - Instrumental activities of daily living
    - Doing light housework
    - Handling money
    - Shopping for groceries/clothes
    - Using telephone
    - Preparing meals
    - Taking medication
- Administrative data
  - Date of enrollment
  - For discharges only:
    - Date of discharge
    - Discharge status
      - Alive
      - Deceased
    - Reason for discharge (narrative)
  - Social Security Number
- Payment information
  - Sources and amount billed
    - Private insurance
    - Own income, family support, etc.
    - Medicare
    - Medicaid
    - Religious organizations, foundations, volunteer agencies
    - No charge
    - Other
  - Care paid by Medicare or private insurance hospice benefit
- Services provided
  - Services provided to family?
  - Number of visits made to client
  - Days of respite care provided
  - Services to client:
    - Personal care
    - Nursing services
    - Physician services
    - Other medical services
    - Mental health services
    - Social services
    - Physical therapy
    - Occupational therapy
    - Speech and hearing therapy
    - Vocational rehabilitation
    - Special education
    - Nutritionist services
    - Sheltered employment
    - Homemaker-household services
    - Transportation
    - Meals on wheels
    - Recreational services
    - Housing services
    - Protective overnight services
    - Medication
    - Other services
- Health status
  - Diagnosis at enrollment
    - Primary
    - Secondary (up to six)
  - Bladder and bowel status
    - Catheter/ostomy
    - Continence
  - Mental status
    - Behavioral problems
    - Disorientation/memory impairment
    - Psychiatric symptoms affecting daily functioning

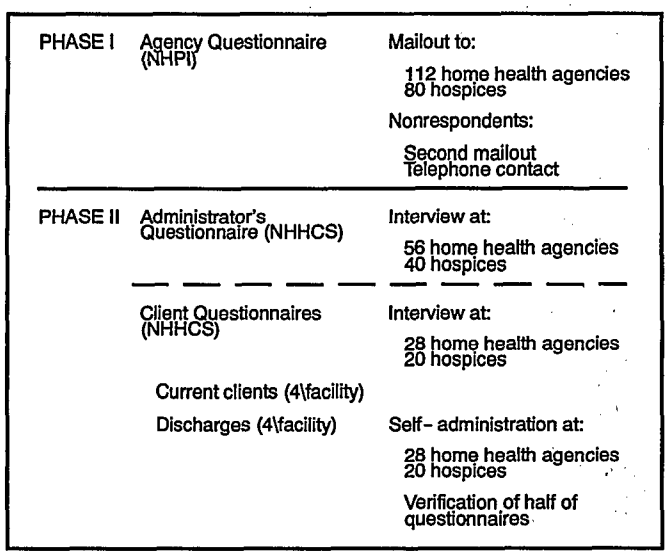

Figure 1. Data collection methods for the Feasibility Study for the National Home and Hospice Care Survey.

received a second mailed questionnaire with a reminder letter. If no response was received to the second mailout, a telephone contact was made with the agency. An interview was then conducted by telephone in which the information on the Agency Questionnaire was obtained. Half (96) of the agencies selected for Phase I were randomly selected to participate in Phase II (the NHHCS part). Seven home health agencies and five hospices were selected in each of the eight PSU's. These 96 agencies were then randomly assigned to 1 of 2 groups. Interviewers contacted both groups by telephone to gain their participation and to set up an appointment with the agency administrator.

At the appointed time, the interviewer met with the agency administrator to conduct the interview using the Administrator's Questionnaire. With the cooperation of the agency staff, the interviewer constructed two client sampling lists: one of current clients and one of discharges. The Current Client Listing Form and the Discharged Client Listing Form were used for this process. Current clients were those clients who were on the rolls of the agency on the calendar day immediately preceding the day that the interviewer visited the agency. The discharges that were listed were those that occurred between January 1, 1989, and December 31, 1989. If a person was discharged more than once during the year, each discharge was listed separately. However, persons who were admitted and discharged on the *same day* were *not* included in the list of discharges. In agencies selected as home health agencies only home health clients were listed; only hospice clients were listed in agencies that were selected for the sample as hospices. Using a programmable calculator, the interviewer drew a systematic random sample of four current clients and four discharges. In the agencies assigned to the first group, the interviewer obtained the information on the Client Questionnaire for each of the sampled clients by interviewing a member of the agency staff designated by the administrator. In the agencies assigned to the second group, the interviewer trained a designated staff member how to complete the Client Questionnaire. The questionnaires were then left for self-administration. In both groups the staff member providing the information was to refer to each client's medical record when answering the questionnaires. When the interviewer returned to the second group of agencies to collect the completed Client Questionnaires, the interviewer verified the information reported in half of the questionnaires by interviewing the staff member who completed them or by abstracting the data from the patient's medical records.

Results of the Feasibility Study

Results of the Feasibility Study are summarized in table E. The most important finding was that data about hospices, home health agencies, and the patients they serve are available and can be collected through a national survey. Of the 96 agencies that were selected for Phase II, all were able to complete the Administrator's Questionnaire. Moreover, 82 agencies (85 percent) completed the sampling lists and client questionnaires. Some changes were made for the NHHCS based on the experiences gained from the Feasibility Study—both to the questionnaires and to the procedures used for the survey.

The changes that were made to the data collection instruments are shown in detail in table F. A shortened version of the Administrator's Questionnaire, referred to as the "Facility Questionnaire," would be used to collect the information needed about the sampled agencies. Clients of the agencies would more correctly be referred to as "patients." Since results of the Feasibility Study indicated that using only one questionnaire for the two different types of patients (current and discharged) was confusing, two questionnaires (one for current patients and one for discharges) would be used to collect patient information. The Current and Discharged Client Listing Forms were renamed the Current Patient Sampling List and the Discharged Patient Sampling List. Since the date of enrollment of current patients was not needed, and was not always readily available at the listing stage, this item was deleted from the Current Patient Sampling List. However, the date of discharge was retained on the Discharged Patient

Table E. Results of the Feasibility Study for the National Home and Hospice Care Survey

Data about hospices and home health agencies are available and can be collected through a National survey
Changes in data collection instruments
One Facility Questionnaire, two Patient Questionnaires, two sampling lists to be used
Facility Questionnaire:
Less patient information collected
Additional information to be collected on services and staff
Patient Questionnaires:
Rewording of questions to allow for infants, children, comatose and very debilitated patients
Revision of many questions
Additional information collected
Changes in procedures
Entire survey will be interviewer-administered
All hospice and home health patients eligible
Reference period for discharges changed
Patient sampling done using sampling lists and table of random numbers

Table F. Changes made in the data collection instruments for the National Home and Hospice Care Survey as a result of the Feasibility Study

Data collection instruments used	Feasibility Study: Agency Questionnaire Administrator's Questionnaire Current Client Listing Form Discharged Client Listing Form Client Questionnaire Changed to: Facility Questionnaire Current Patient Sampling List Discharged Patient Sampling List Current Patient Questionnaire Discharged Patient Questionnaire
Information collected	"Clients" (Feasibility Study) will be referred to as "patients"
Facility information questionnaire	Questions on clinical records dropped Question about number of discharges dropped Reference time period for current (active) patients changed Ownership categories revised Questions on selected services added Questions on facility staff added
Patient Sampling Lists	Date of enrollment for current clients (patients) dropped
Patient information questionnaires	Demographic characteristics: Age of patient asked if date of birth not available Administrative data: Discharge status included in reason for discharge question Reason for discharge question modified Category about assessment only added Family and home environment: Question on family involvement in providing care dropped Question about safety assessment dropped Relationship of primary caregiver to patient categories revised Where patient living categories revised Question about primary caregiver living with patient added Questions on next of kin added Sources of referral categories revised Payment information: Amount billed not collected for each source of payment Sources of payment categories revised Question on primary source of payment added Services provided: Question on services provided to family dropped Services provided categories revised Health status: Questions on mental status dropped Questions on bladder and bowel status revised Question on current (or discharge) diagnosis added Question on special aids added Question on types of staff that provided services added

Sampling List since it would be used in determining which discharges are eligible for the sample.

Several changes were made in the content of the questionnaires. The Facility Questionnaire would collect only agency information needed for the survey; therefore, the questions on clinical records were dropped since they had served their purpose for the Feasibility Study. Less patient information would be collected on the Facility Questionnaire—only the information needed to determine if the agency was eligible to participate in the survey would be necessary. The questions about agency ownership and operation were revised and questions about selected services and the agency staff were added.

Many of the items on the patient questionnaires were re-worded to allow for the fact that hospices and home health agencies serve a wider variety of patients (for example, a wider age group) than are usually served by more traditional long-term care facilities. Some items were revised in order to collect better or more complete data. Some questions were dropped; others were added. Additional information to be collected include the identification of "assessment only" patients, the collection of current or discharge diagnoses (in addition to diagnoses at admission), information on special aids used by each patient, the types of staff that provided services to each patient, and information on each patient's next of kin. "Assessment only" patients were those who had been admitted by the hospice or home health agency for an assessment or determination of eligibility for services but were not actually provided services by the agency (for example, they may not have met the requirements of the agency for provision of services or they may have elected not to receive services from the agency). The next of kin information was added as a Pretest item to determine the availability of this sort of information for use in future follow-up studies. Procedural changes and changes made in data collection methods are detailed in table G. In the Feasibility Study, patient information was collected through two different methods: personal interviewer and self-administered questionnaires. Although *participation* in the Feasibility Study did not differ significantly between the two groups, the *completeness* of the questionnaires was significantly higher for the interviewer-administered group (96 percent) than for the self-administered

Table G. Changes made in the procedures for the National Home and Hospice Care Survey as a result of the Feasibility Study

All questionnaires would be completed by personal interview: Better completion rate More uniformity of data Less respondent burden
All hospice and home health patients admitted to and served by an agency would be eligible for the survey regardless of how the agency was categorized (hospice or home health agency)
Changes in reference period for discharges: Discharges during a 12-month period ending at midnight of the day immediately preceding the day of the interviewer's visit to the agency Discharges for an episode of care of less than one day would be included
Changes in patient sampling: Number of current patients and of discharges sampled increased from four to five Total number of patients listed on sampling lists used in selecting sample (rather than numbers reported on Agency Questionnaire) Sample Selection Table used rather than a programmable calculator to select sample patients and discharges

group (91 percent) (2). Other advantages of an interviewer-administered survey over a self-administered survey included the higher motivation of the interviewers to obtain quality data, a more thorough and uniform training of the interviewers than was possible with agency staff, less respondent burden since the interviewer would handle all of the paperwork necessary for the survey, and no need for the interviewers to return to the agencies to pick up the completed questionnaires (or to rely on the agency personnel to mail them in). It was, therefore, decided that the National Survey would be entirely interviewer-administered.

Another change that was made as a result of the Feasibility Study concerned the type of patient that was eligible for the survey. In the Feasibility Study, only home health patients were selected from facilities that were selected as home health agencies and only hospice patients were selected from facilities that were selected as hospices. However, it was found that many agencies served both types of patients. In addition, the Feasibility Study showed that agencies often changed or expanded the focus of their service. For example, agencies that previously served only hospice patients may expand their focus to also serve home health patients (or even change their focus to *only* serve home health patients). Therefore, it was decided that *all* hospice and home health patients admitted to and served by an agency would be eligible for the National Survey.

The reference period for discharges was also changed. For the Feasibility Study, all discharges that occurred during the previous calendar year (January 1, 1989–December 31, 1989) were in scope for the survey. This was changed to all discharges that occurred during a 12-month period ending at midnight of the day immediately preceding the day of the interviewer's visit to the agency. For example, if the interviewer would visit the agency on September 11, 1991, the reference period for the discharges from that agency would be September 11, 1990–September 10, 1991. Many agencies did not have discharge information readily available if the discharges had occurred more than a year before the interviewer's visit. By changing the reference period in this way, it was felt that more complete and more current discharge data would be obtained.

Another change that was made regarding discharges was accepting discharges for an episode of care that lasted less than one full day. This change would give more accurate information about services provided by these agencies, especially by hospices, since, for example, some patients admitted to a hospice could die (and thus be discharged) on the same day as they were admitted.

Changes were also made to the sampling procedures at the patient level. For the Feasibility Study, a systematic sample of four current patients and four discharges was selected from each agency. This was increased to five current patients and five discharges. Since the sampling interval for the Feasibility Study was determined by means of a programmable calculator, the total numbers of current patients and of discharges were needed in order to program the calculators. For the Feasibility Study, these numbers were obtained from the Agency Questionnaire (that had been completed *before* the interviewer's visit) for each agency. If the numbers used in the program differed by more than 50 percent from the actual number (obtained from the current patient and discharged patient listings), the interviewer had to stop the interviewing process and call the home office for instructions on how to get the correct sampling interval. This problem occurred in over 25 percent of the cases during the Feasibility Study (2). Therefore, a Sample Selection Table, determined from random numbers, was created for use in sampling patients. The total number of current patients and/or discharges was determined from the respective listing and a space was added to record this number on each listing form. Using this number, the interviewer then referred to the Sample Selection Table to determine which current patients and discharges should be included in the sample.

Pretest for the National Home and Hospice Care Survey

The Pretest, the "dress rehearsal" for the NHHCS, was conducted in 1991 by the U.S. Bureau of the Census as the data collection agent. The purpose of the Pretest was to evaluate all aspects of the data collection plans that were to be used in conducting the National Survey, including the methods, procedures, interviewer training materials, data collection instruments, and other survey materials.

Sampling frame and sample selection

The sampling frame and sample selection for the Pretest are summarized in table H. The facility sampling frame was the mailing list for the 1991 National Health Provider Inventory (NHPI) and a list compiled from State directories representing those places that opened for business after the NHPI list was completed. A total of 100 agencies was selected for the Pretest. The patient sampling frames were lists of current and discharged patients that were constructed by the interviewer at the time of the interviewer's visit to the agency.

The ultimate sampling unit for the Pretest was the patient served by each agency. The design used to select the patients was a multi-stage design similar to that used in the Feasibility Study. The first stage consisted of five purposively selected areas or primary sampling units (PSU's) that were geographically dispersed throughout the contiguous United States and that included agencies in urban and nonurban locations. The second stage consisted of a systematic selection of 20 agencies (8 hospices and 12 home health agencies) within each area. The third stage of sample selection consisted of a systematic probability sample of five current patients and five discharges. This was done using a sample selection table and lists of current patients and discharges that were prepared by the interviewer during the visit to the agency.

Table H. Sample selection for the Pretest for the National Home and Hospice Care Survey

Sampling frame sources
Agencies:
Mailing list for 1991 National Health Provider Inventory
State directories
Patients
Lists constructed by interviewer
Sample selection
Primary sampling units (5)
Agencies (100)
Hospices (40)
Home health agencies (60)
Patients
Current patients (5 per agency)
Discharges (5 per agency)

Data collection instruments

Three questionnaires and two sampling lists were used in the Pretest: a Facility Questionnaire, a Current Patient Questionnaire, a Discharged Patient Questionnaire, a Current Patient Sampling List, and a Discharged Patient Sampling List. These data collection instruments are shown in appendix IV. The questionnaires were used to collect data about the agencies, the patients served, and the services provided (see table J). All of the questionnaires in the Pretest were completed by personal interview. The sampling lists were used as worksheets by the interviewers to aid in selecting the samples of current patients and of discharges.

Agency data were collected through the Facility Questionnaire and included identification information, type of ownership, and Medicare and Medicaid certification. The Facility Questionnaire also included a few questions on the types of services provided and the types of personnel providing the services. This is summarized in table K.

The Current and Discharged Patient Questionnaires were very similar. Two separate questionnaires were used, however, because results of the Feasibility Study indicated that using only one questionnaire for the two different types of patients was confusing. The information collected through these questionnaires is shown in table L. Data were collected about each patient's demographic characteristics, including where and

Table J. Questionnaires used and information obtained for the Pretest for the National Home and Hospice Care Survey

Facility Questionnaire
Agency data
Patient data
Staffing data
Patient Questionnaires
Current Patient Questionnaire and
Discharged Patient Questionnaire:
Demographic characteristics
Administrative data
Family and home environment
Sources of referral
Health status
Functional status
Services provided
Service providers
Payment information

Table K. Information collected through the Facility Questionnaire for the Pretest for the National Home and Hospice Care Survey

Agency data

- Identification information
  - Agency name, address, and telephone number
  - Administrator's name, title, and telephone number
- Ownership/operation
  - Ownership
    - For profit
    - Nonprofit
    - State or local government
    - Federal Government
    - Other
  - Operated by hospital
  - Operated by nursing home
  - Part of a group of facilities
- Primary service category
  - Hospice
  - Home health agency
  - Hospice/home health care equal
  - Other
- Services provided
  - Bereavement care
  - Pastoral care
- Number of volunteers
- Certification
  - Medicare
  - Medicaid

Patient data

- Number of patients served during past 30 days
  - Hospice patients
  - Home health care patients

Staffing data

- Information obtained about each type of staff (listed below)
  - Number of full-time staff
    - On payroll
    - Budgeted positions that are vacant
  - Number of part-time staff
    - On payroll
    - Budgeted positions that are vacant
  - Hours worked in last 7 days
    - By all payroll staff
    - By nonpayroll staff
  - Visits made in last 7 days by all staff
- Type of staff
  - Physicians
  - Registered nurses
  - Licensed practical or vocational nurses
  - Nursing aides and attendants
  - Home health aides
  - Homemakers/personal caretakers
  - Dieticians/nutritionists
  - Occupational therapists
  - Speech pathologists and audiologists
  - Physical therapists
  - Social workers
  - Health educators
  - Other health care providers

Table L. Information collected through the Patient Questionnaires for the Pretest for the National Home and Hospice Care Survey

- Demographic characteristics
  - Date of birth (or age)
  - Sex
  - Race
    - White
    - Black
    - American Indian, Eskimo, Aleut
    - Asian, Pacific Islander
    - Other
  - Hispanic origin
  - Marital status
    - Married
    - Widowed
    - Divorced
    - Separated
    - Never married
- Family and home environment
  - Living children present
  - Primary caregiver present
    - Relationship to patient
      - Spouse
      - Parent
      - Child
      - Daughter/son-in-law
      - Other relative
      - Neighbor
      - Friend
      - Volunteer group
      - Other
    - Living with patient?
  - Where patient living
    - Private residence
    - Rented room, boarding house
    - Retirement home
    - Board and care or residential care facility
    - Hospice inpatient
    - Other health facility
    - Other
  - With whom living
    - Alone
    - With others (family, nonfamily)
  - Next of kin information
- Functional status
  - Vision
  - Hearing
  - Activities of daily living
    - Bathing
    - Dressing
    - Eating
    - Transferring
    - Walking
    - Using toilet room
  - Instrumental activities of daily living
    - Doing light housework
    - Handling money
    - Shopping for groceries/clothes
    - Using telephone
    - Preparing meals
    - Taking medication
- Health status
  - Admission diagnosis
    - Primary
    - Secondary (up to five)
  - Current or discharge diagnosis
    - Primary
    - Secondary (up to five)
  - Bladder and bowel status
    - Catheter/ostomy
    - Continence
  - Special aids used:
    - Eye glasses
    - Dentures
    - Hearing aid
    - Wheelchair
    - Cane
    - Walker
    - Crutches
    - Brace
    - Other
- Administrative data
  - Date of admission
  - Assessment only done
  - For discharges only:
    - Date of discharge
    - Reason for discharge
      - Recovered
      - Stabilized
      - Moved out of district
      - Deceased
      - Admitted to hospital inpatient service
      - Admitted to nursing home
      - Other
  - Social Security Number
- Payment information
  - Amount billed (including none)
  - Sources of payment (primary, all)
    - Private insurance
    - Own income, family support, etc.
    - Supplemental Security Income
    - Medicare
    - Medicaid
    - Other government assistance or welfare
    - Religious organizations, foundations, agencies
    - Veterans' Administration compensation
    - Not yet determined
    - Other
- Sources of referral
  - Self/family
  - Nursing home
  - Hospital
  - Physician
  - Health department
  - Social service agency
  - Other
- Services provided
  - Number of visits made
  - Services:
    - Dietary/nutritional services
    - Occupational/vocational therapy
    - Speech therapy/audiology
    - Homemaker/companion services
    - Meals on wheels
    - Transportation
    - Enterostomal therapy
    - Counseling
    - Medications
    - Respite care
    - High-tech care
    - Referral services
    - Personal care
    - Skilled nursing services
    - Physician services
    - Social services
    - Physical therapy
    - Other services
- Service providers
  - Physicians
  - Registered nurses
  - Licensed practical or vocational nurses
  - Nursing aides and attendants
  - Home health aides
  - Homemakers/personal caretakers
  - Occupational therapists
  - Speech pathologists, audiologists
  - Physical therapists
  - Social workers
  - Health educators
  - Other providers

with whom they lived; services provided to the patients and the types of personnel that provided the services; health and functional status of the patients, including admitting and current or discharge diagnoses; charges and sources of payment for the services provided; sources of referral to the agency; date of admission and, for discharged patients, date and reason for discharge.

The Current and Discharged Patient Sampling Lists were used to list each patient to aid in selecting the patient samples. After each list was constructed, the total number of current or discharged patients was determined. Using these lists and the sample selection table (shown in appendix IV), the interviewer was able to determine which current patients and discharges to select for the sample.

Data collection methods

The Pretest began with the mailing of a letter to the administrators of the sampled agencies to inform them of the survey (see appendix IV). About a week after the letters were mailed an interviewer contacted each agency by telephone to check that the letter was received, discuss the survey, and to set up an appointment with the agency administrator.

At the appointed time, the interviewer met with the agency administrator to conduct the interview using the Facility Questionnaire. Since the staffing information was quite

extensive, a separate worksheet was available that the administrator or other agency staff member could complete while the interviewer continued with the rest of the survey. This worksheet was to be collected by the interviewer before leaving the agency.

After the Facility Questionnaire was completed, the interviewer, with the cooperation of agency staff designated by the administrator, constructed two lists: one of current patients and one of discharges. The Current Patient Sampling List (CPSL) and the Discharged Patient Sampling List (DPSL) were available for this purpose. These lists are shown in appendix IV. Current patients were those patients who were on the rolls of the agency on the evening before the day of the survey. The discharges listed were those that occurred during the 12 months before the day of the survey.

Some agencies already had lists available that the interviewer could use. Other agencies, especially those with computer capabilities, offered to generate computer lists for the interviewer. In these cases, the interviewer used the agency lists rather than creating the lists by hand. After the lists were completed (whether they were interviewer-generated or agency-generated), the interviewer checked them for completeness and accuracy. If the lists were not complete, the interviewer added any patients (or discharges) that were missing. Similarly, the interviewer deleted any patients (discharges) that were on the lists but were out of scope for the Pretest. The interviewer completed Step 3 of each sampling list that asked for the total number of patients or discharges listed. Then, using a sample selection table, the interviewer drew a systematic sample of five current patients and five discharges. In agencies with fewer than five current patients (or discharges), all patients (discharges) were selected for the respective sample.

The interviewer then obtained the information on the Current and Discharged Patient Questionnaires for each of the sampled patients by interviewing a member of the agency staff. The staff member was to refer to each patient's medical record to obtain the information in the questionnaires. At no time were the patients themselves contacted. The interviewers were instructed to complete as much of the interviewing procedure as possible in one visit; return visits were discouraged since one purpose of the Pretest was to determine how much information could be obtained in only one visit to the agency.

When all the interviews were completed, the interviewer returned to the administrator to collect the Facility Staff Worksheet (if applicable) and to leave a thank-you letter, thanking the administrator for his or her time and cooperation. A copy of this letter is in appendix IV.

Results of the Pretest

Very few changes were made as a result of the Pretest for the National Home and Hospice Care Survey. Changes made to the data collection instruments and to the procedures are summarized in table M.

The item in the Facility Questionnaire asking for the primary service category of the agency was deleted. Instead, the agency administrator would be asked a series of questions to determine if the agency currently provides home health and/or hospice care services, if the agency provided these types of services to patients during the 12 months before the interview, and if the agency currently had any active home health or hospice care patients. If the answers to all three of these questions were "No," the agency would be out of scope for the survey and the interview would be terminated.

Table M. Changes made in the data collection instruments and procedures for the National Home and Hospice Care Survey as a result of the Pretest

	Changes to data collection instruments
Facility Questionnaire	Question on primary service category dropped Questions on services provided added Questions on certification revised Questions on patients served revised Staffing data: Reference time period changed Staff categories revised
Patient Sampling Lists	Line number and patient identifier listed for sampled patients Discharged Patient Sampling List: Dates of reference period added Dates of partial listing added (if applicable)
Patient Questionnaires	Question on type of care received added Family and home environment: Question on living children dropped Questions on next of kin dropped Where patient living categories revised Special aids categories revised Services provided categories reordered Types of staff that provided services revised and reordered
	Changes to procedures
Number of current patients and of discharges sampled increased from five to six	
Return visits made to agency if necessary to obtain complete data	
Facility staffing worksheet could be mailed to interviewer	
Changes in reference period for discharges:	
Discharges during a 12-month period ending the last day of the month before the interviewer's visit to the agency	
Listing of discharges for part of a 12-month period accepted	

The questions on certification status of the agency were expanded to get more specific information. For the Pretest, only certification status (Medicare and/or Medicaid) was ascertained. Additional questions would be asked in the National Survey to determine if an agency is certified as a hospice, a home health agency, both, or neither.

More information would be obtained on the Facility Questionnaire about the numbers and types of patients served. The Pretest asked for the numbers of hospice and of home health care patients served during the past 30 days. The National Survey, on the other hand, would ask about the numbers of current patients and of patients served during the past 12 months. Separate numbers would be asked for those served only as hospice patients, only as home health care patients, and as both hospice and home health care patients.

The question about the agency's staff would also be modified slightly. The reference time period would be changed from the past 7 days to the most recent pay period since personnel information by pay period was found to be more readily available. In addition, the categories of type of staff would be expanded to include additional types of service staff and administrative staff.

Very few changes would be made to the Patient Sampling Lists. The interviewer would list the line numbers and the identifier of the sample patients on the front of the form in order to make it easier for the agency personnel to pull the medical records for the sample patients. Space would be added to the Discharged Patient Sampling List for the dates of the reference period and, if applicable, the dates of partial listings (see the following paragraph on procedural changes for more information).

Some changes would also be made to the Patient Questionnaires as a result of the Pretest. In order to identify the numbers of patients receiving hospice or home health care, an item would be added to the Patient Questionnaires asking for the type of care the patient received from the agency (hospice, home health, or other). The questions about living children and the next of kin item would be deleted from the Patient Questionnaires. The next-of-kin questions were included in the Pretest to determine whether this type of information could be obtained through the NHHCS. The Pretest results indicated that it is indeed possible to obtain this type of information; however, it will not be collected by the NHHCS until follow-up studies will be done. Some questions on the Patient Questionnaires were revised, mainly by adding additional categories that were found to be needed based on the results of the Pretest. Finally, some rewording and reordering of data items were done to the questionnaires as a result of the Pretest.

The Pretest also indicated the need for some procedural changes in order to get more complete and valid data. A sample of six current patients and six discharges would be selected for the National Survey (compared to five each for the Pretest). The interviewers would be instructed to make return visits to the agencies (if necessary) in order to obtain the information requested. The agencies would be able to mail in the staffing information collected on the Facility Questionnaire if additional time was needed to respond to that item. The reference period for discharges would be changed to the last 12 months as of the *last day of the month* before the interview rather than as of the *day* before the interview. For example, if the interview were conducted on September 9, 1992, the reference period for discharges would be September 1, 1991–August 31, 1992 (rather than September 9, 1991–September 8, 1992, as was done in the Pretest). A list of discharges for less than a 12-month period would be accepted for sampling as long as the available time period could be identified and it falls within the 12-month reference period of the NHHCS.

The National Home and Hospice Care Survey

The National Home and Hospice Care Survey (NHHCS) began operation in September 1992. This survey is conducted annually and collects baseline data on the characteristics of hospices and home health agencies, the patients they serve, and the types of staff they employ.

Sampling frame and sample selection

The sampling frame and sample selection for the 1992 NHHCS are summarized in tables N and O. The agency sampling frame is the hospice and home health agency part of the 1991 NHPI and all agencies that opened for business after the 1991 NHPI and before June 30, 1992, as identified through the Agency Reporting System (ARS) (3). A representative sample of 1,500 agencies was selected. The patient sampling frames are lists of current patients and discharges that are constructed by the interviewer at the time of the interviewer's visit to the agency. See appendix V for copies of the forms used to construct these patient lists.

The elementary sampling unit of the NHHCS is the patient served by the agency. The sampling design used to select the sample patients is a three-stage design. The first stage consists of the selection of 198 primary sampling units, or PSU's. These PSU's are the same ones used in the 1985–94 NCHS National Health Interview Survey (NHIS), a survey of the civilian noninstitutionalized population of the United States (4). The PSU's are counties, groups of counties, county equivalents (such as parishes or independent cities), or towns and townships (for some PSU's in New England).

The second sampling stage involves the selection of agencies within six primary strata. These strata, which are shown in figure 2, were formed in the 1992 sampling frame on the basis of type of agency, type of PSU, and metropolitan statistical area (MSA) status of the PSU. Type of agency was determined from information collected through the NHPI and the ARS. Four types of agencies were considered for selection and were placed into one of two groups: (1) hospices and (2) home health agencies, mixed agencies (those that provide both types of care), and unknown type of agency (this second group will be referred to as home health and other agencies). Type of PSU refers to those PSU's that are self-representing (SR) in contrast to those that are non-self-representing (NSR). SR PSU's are the largest PSU's in the United States and were selected in the NHIS sample with certainty (probability of 1). NSR PSU's are those that were not selected with certainty (4). NSR PSU's are further subdivided into MSA and non-MSA status. MSA is a metropolitan statistical area defined by the U.S. Office of Management and Budget on the basis of the 1980 Census.

Within these six sampling strata, agencies were arrayed by one or more of the following characteristics: region (Northeast, Midwest, South, and West), type of ownership (for profit, nonprofit, State or local government, Federal Government, and other), certification status (certified by Medicare and/or Medicaid and not certified), and agency size (number of patients

Table N. Sample selection for the National Home and Hospice Care Survey

Sampling frame sources
Agencies:
1991 National Health Provider Inventory
Agency Reporting System
Patients
Lists constructed by interviewer
Sample selection
Primary sampling units (198)
Agencies (1,500)
Hospices (384)
Home health and other agencies (1,116)
Patients
Current patients (6 per agency)
Discharges (6 per agency)

Table O. Distribution of hospices and home health agencies in the 1992 National Home and Hospice Care Survey universe (sampling frame), National Health Interview Survey primary sampling units, and 1992 survey sample by primary strata and region

	Hospices			*Home health and other agencies*		
Agency	*Universe*	*NHIS PSU's*	*Survey sample*	*Universe*	*NHIS PSU's*	*Survey sample*
	Number of agencies					
All agencies	1,014	472	384	7,845	4,055	1,116
Primary strata						
Self-representing	368	351	263	3,226	3,112	568
Non-self-representing						
MSA	213	76	76	1,701	710	315
Non-MSA	433	45	45	2,918	233	233
Region						
Northeast	169	108	89	1,767	1,327	340
Midwest	310	111	85	2,195	877	249
South	335	155	132	2,867	1,294	372
West	200	98	78	1,016	557	155

NOTE: PSU is primary sampling unit.

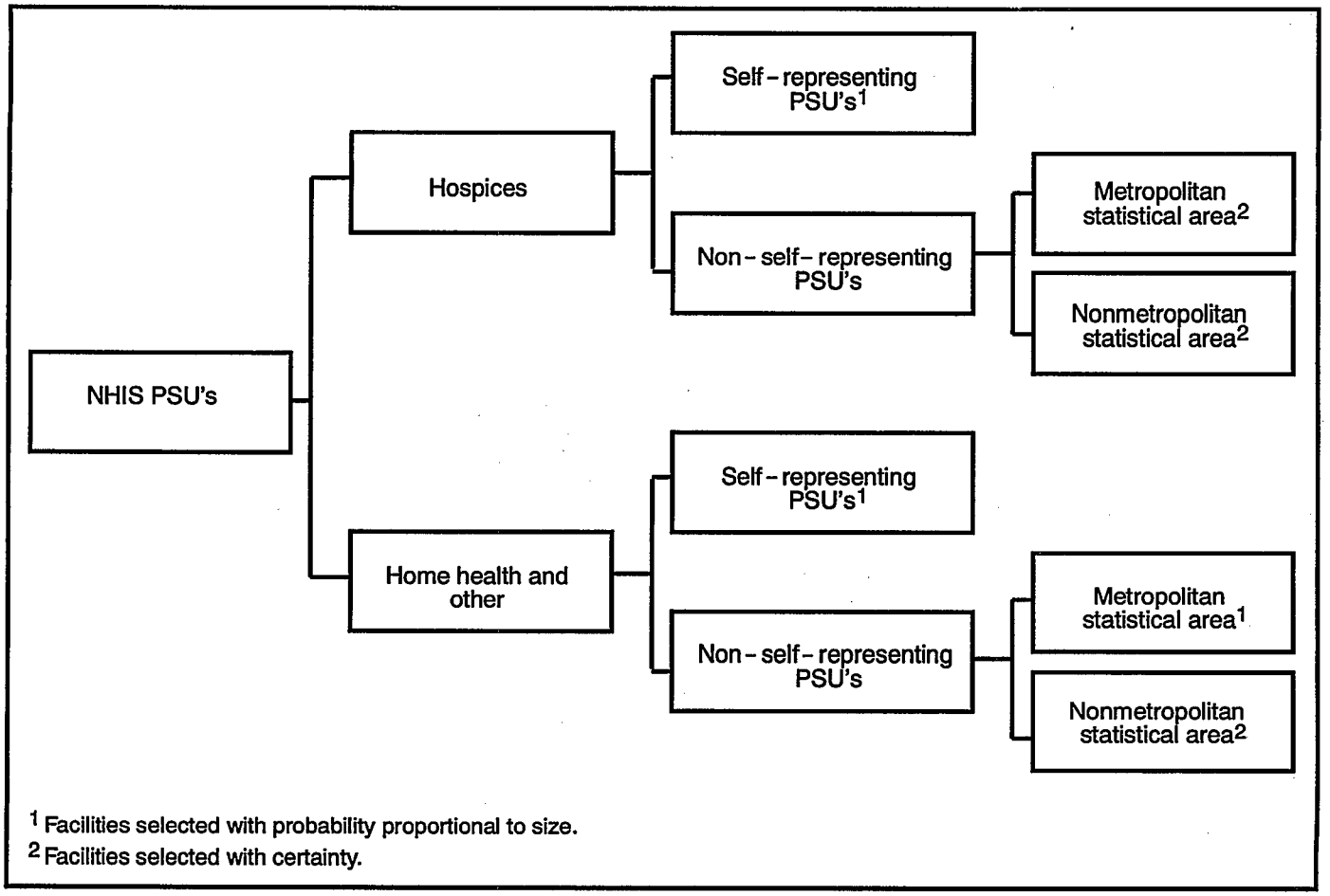

Figure 2. Second stage of sample selection for the National Home and Hospice Care Survey.

currently being served by the agency). These categories are based on information from the NHPI and the ARS. The number of agencies selected from each sampling stratum, shown in table O, was based primarily on the distribution of agencies in the universe and other research results leading to the best sample design for the 1992 NHHCS. As shown in figure 2, hospices in the NSR PSU's (MSA and non-MSA) and home health and other agencies in the non-MSA NSR PSU's were selected with certainty. Hospices in the SR PSU's and home health and other agencies in the MSA NSR PSU's, and the SR PSU's were selected with probability proportional to the agency size (5).

The third stage of sample selection, sampling of six current patients and six discharges within each agency, is done using a sample selection table to obtain systematic probability samples of current patients and of discharges. The patients and discharges are selected from sampling lists that the interviewers construct for each agency. Current patients are those patients who are on the rolls of the agency on the evening before the day of the survey. The discharges that are listed were those that occurred during the last complete 12-month period before the month the survey was completed.

The agencies selected for the 1992 NHHCS sample will be retained for the 1993 and 1994 surveys. The agency sample will be updated when the ARS reports a significant number of new agencies. The sample patients and discharges will be drawn from sampling lists created each year in each sample agency as part of the survey procedures.

Table P. Questionnaires used and information obtained for the National Home and Hospice Care Survey

	Facility Questionnaire	Patient Questionnaires
Agency data		
Patient data		
Staffing data		
Current Patient Questionnaire and Discharged Patient Questionnaire:		
Demographic characteristics		
Administrative data		
Family and home environment		
Payment information		
Sources of referral		
Functional status		
Health status		
Services provided		
Services providers		

Data collection instruments

Three questionnaires and two sampling lists are used in the NHHCS: a Facility Questionnaire, a Current Patient Questionnaire, a Discharged Patient Questionnaire, a Current Patient

Sampling List, and a Discharged Patient Sampling List. The data collection instruments used for the 1992 NHHCS are shown in appendix V. Copies of the instruments used for subsequent years of the survey will be included in the appropriate reports. All of the questionnaires are completed by personal interview. The questionnaires are used to collect data about the agencies, the patients served, and the services provided (see table P). The sampling lists are used as worksheets by the interviewers to aid in selecting the samples of current patients and of discharges.

Agency data are collected through the Facility Questionnaire and include identification information, type of ownership, and Medicare and Medicaid certification. The Facility Questionnaire also includes questions on the numbers and types of patients served, a few questions on the types of services provided, and the types of personnel providing the services. This is summarized in table Q.

The Current and Discharged Patient Questionnaires are very similar to each other and to the questionnaires used in the Pretest. Based on results of the Pretest, the ordering of some questions was changed, additional response categories were added to some items, and an item identifying the type of care

Table Q. Information collected through the Facility Questionnaire for the National Home and Hospice Care Survey

Agency data

- Identification information
  - Agency name, address, and telephone number
  - Administrator's name, title, and telephone number
- Ownership/operation
  - Ownership
    - For profit
    - Nonprofit
    - State or local government
    - Federal Government
    - Other
  - Operated by hospital
  - Operated by nursing home
  - Part of a group of facilities
- Services provided
  - Home health or hospice care
    - Currently
    - During last 12 months
  - Bereavement care
  - Pastoral care
- Number of volunteers
- Certification
  - Medicare
    - As home health agency
    - As hospice
  - Medicaid
    - As home health agency
    - As hospice

Patient data

- Number of patients served during past 12 months
  - Home health only
  - Hospice only
  - Both hospice and home health
- Number of patients currently being served
  - Home health only
  - Hospice only
  - Both hospice and home health

Staffing data

- Information obtained about each type of staff (listed below)
  - Number of full-time staff
    - On payroll
    - Budgeted positions that are vacant
  - Number of part-time staff
    - On payroll
    - Budgeted positions that are vacant
  - Hours worked during last pay period
    - By all payroll staff
    - By nonpayroll staff
  - Visits made during last pay period by all staff
- Type of staff
  - Physicians
  - Registered nurses
  - Licensed practical or vocational nurses
  - Nursing aides and attendants
  - Home health aides
  - Homemakers/personal caretakers
  - Dieticians/nutritionists
  - Occupational therapists
  - Speech pathologists and audiologists
  - Physical therapists
  - Social workers
  - Health educators
  - Pastoral/bereavement staff
  - Administrator/director
  - Case manager/coordinator
  - Secretarial/clerical
  - Other health personnel
  - Other personnel

Table R. Information collected through the Patient Questionnaires for the National Home and Hospice Care Survey

- Demographic characteristics
  - Date of birth (or age)
  - Sex
  - Race
    - White
    - Black
    - American Indian, Eskimo, Aleut
    - Asian, Pacific Islander
    - Other
  - Hispanic origin
  - Marital status
    - Married
    - Widowed
    - Divorced
    - Separated
    - Never married
- Family and home environment
  - Primary caregiver present
    - Relationship to patient
      - Spouse
      - Parent
      - Child
      - Daughter/son-in-law
      - Other relative
      - Neighbor
      - Friend
      - Volunteer group
      - Other
    - Living with patient?
  - Where patient living
    - Private residence
    - Rented room, boarding house
    - Retirement home
    - Board and care or residential care facility
    - Health facility
    - Other
  - With whom living
    - Alone
    - With others (family and nonfamily)
- Functional status
  - Vision
  - Hearing
  - Activities of daily living
    - Bathing
    - Dressing
    - Eating
    - Transferring
    - Walking
    - Using toilet room
  - Instrumental activities of daily living
    - Doing light housework
    - Handling money
    - Shopping for groceries/clothes
    - Using telephone
    - Preparing meals
    - Taking medication
- Health status
  - Admission diagnosis
    - Primary
    - Secondary (up to five)
  - Current or discharge diagnosis
    - Primary
    - Secondary (up to five)
  - Bladder and bowel status
    - Catheter/ostomy
    - Continence
  - Special aids used:
    - Eye glasses
    - Dentures
    - Hearing aid
    - Wheelchair
    - Cane
    - Walker
    - Crutches
    - Brace
    - Oxygen
    - Hospital bed
    - Commode
    - Other
- Administrative data
  - Date of admission
  - Assessment only done
  - For discharges only:
    - Date of discharge
    - Reason for discharge
      - Recovered
      - Stabilized
      - Moved out of district
      - Deceased
      - Admitted to hospital inpatient service
      - Admitted to nursing home
      - Other
  - Social Security Number
  - Type of care received
    - Home health care
    - Hospice care
    - Other
- Payment information
  - Amount billed (including none)
  - Sources of payment (primary, all)
    - Private insurance
    - Own income, family support, etc.
    - Supplemental Security Income
    - Medicare
    - Medicaid
    - Other government assistance or welfare
    - Religious organizations, foundations, and agencies
    - Veterans' Administration compensation
    - Not yet determined
    - Other
- Sources of referral
  - Self/family
  - Nursing home
  - Hospital
  - Physician
  - Health department
  - Social service agency
  - Other
- Services provided
  - Number of visits made
  - Services:
    - Skilled nursing services
    - Personal care
    - Social services
    - Counseling
    - Medications
    - Physical therapy
    - Homemaker/companion services
    - Respite care
    - Referral services
    - Dietary/nutritional services
    - Physician services
    - High-tech care
    - Occupational/vocational therapy
    - Speech therapy/audiology
    - Transportation
    - Enterostomal therapy
    - Meals on wheels
    - Other services
- Service providers
  - Registered nurses
  - Licensed practical or vocational nurses
  - Nursing aides and attendants
  - Home health aides
  - Homemakers/personal caretakers
  - Social workers
  - Physical therapists
  - Physicians
  - Occupational therapists
  - Speech pathologists/audiologists
  - Dieticians/nutritionists
  - Health educators
  - Volunteers
  - Other providers

provided to the patient (home health, hospice, or other) was added. The information collected through these questionnaires is shown in table R. Data are collected about each patient's demographic characteristics, including where and with whom they lived; services provided to the patients and the types of personnel that provided the services; health and functional status of the patients, including admitting and current or discharge diagnoses; charges and sources of payment for the services provided; sources of referral to the agency; date of admission; and for discharged patients, date and reason for discharge.

The Current and Discharged Patient Sampling Lists are used to list each patient to aid in selecting the patient samples. After each list is constructed, the total number of current or discharged patients is determined. Using these lists and the sample selection table (shown in appendix V), the interviewer is able to determine which current patients and discharges to select for the sample.

Data collection methods

Although the NHHCS is an annual survey, it is not operated continuously throughout the year. The NHHCS is conducted once a year during a 3- to 4-month period, with the U.S. Bureau of the Census acting as the data collection agent for NCHS. Before each survey the interviewers undergo extensive training in survey procedures, using self-study materials and classroom training. In addition, each interviewer is given a manual that contains detailed instructions and information that can be used to answer respondent questions, provide detailed definitions of items, and ensure accurate entries on the data collection forms.

Training for the NHHCS is done by the U.S. Bureau of the Census and consists of a supervisors' conference, a self-study session, and a classroom training session. The supervisors' conference is held centrally and is attended by supervisors from the 12 Census regional offices. During the conference the questionnaires and listing procedures are reviewed, and field and office procedures are discussed.

The self-study sessions are done by each of the interviewers (referred to as field representatives or FR's). These sessions consist of written material that the FR's review and an audio tape. The self-study includes information about the survey objectives, the forms that are used in the survey, confidentiality procedures, and information on contacting agency administrators and on resolving problems with the sample or participation. The audio tape includes examples of calls to agency administrators; listening to the tape enables the FR's to get some practice in calling the administrators and setting up an appointment.

The classroom sessions are conducted by the Census supervisors that attended the supervisors' conference. These sessions are held in the regional offices. To assure uniformity of training, each supervisor follows a written script that was prepared by Census headquarters staff. During the classroom sessions the FR's conduct several mock interviews, completing several facility and patient questionnaires. The FR's also complete several patient listing and sampling exercises. Role-playing exercises, during which the FR's respond to respondent questions about the survey, are also part of the classroom sessions.

Each year the survey begins with the mailing of a letter from the Director, NCHS, to the administrators of the sampled agencies. The purposes of the letter are to enlist the cooperation of each administrator and to inform the administrator of the authorizing legislation, purpose and content of the survey, and its voluntary nature and confidentiality provisions. Letters endorsing the NHHCS are also enclosed. For the 1992 Survey an endorsement letter was received from the National Association of Home Care (see appendix V). About a week after the letters are sent, the interviewers contact each agency by telephone to check that the letter was received and to gain the participation of the agency. Each interviewer also sets up an appointment with the agency administrator at this time.

At the appointed time, the interviewer meets with the agency administrator to conduct the interview using the Facility Questionnaire. Since the staffing information is quite extensive, a separate worksheet is available that the administrator or other agency staff member could complete while the interviewer continued with the rest of the survey. This worksheet is either mailed back to the interviewer's supervisor at the regional office (a self-addressed stamped envelope is given to the agency administrator for this purpose) or is collected by the interviewer before leaving the agency.

After the Facility Questionnaire is completed, the interviewer, with the cooperation of agency staff appointed by the administrator, constructs two sampling lists: one of current patients and one of discharges. The Current Patient Sampling List (CPSL) and the Discharged Patient Sampling List (DPSL) are available for this purpose. These lists are shown in appendix V. Current patients are those patients who are on the rolls of the agency on the evening before the day of the survey. The discharges that are listed are those that occurred during the last complete 12-month period—that is, during the 12 months ending the last day of the month before the survey. For example, if the interview is conducted on September 9, 1992, the reference period for discharges will be September 1, 1991–August 31, 1992.

Some agencies may already have lists available for the interviewer to use. Other agencies, especially those with computer capabilities, may offer to generate computer lists for the interviewer. In these cases, the interviewer may use the agency lists rather than having to create the lists by hand. After the lists are completed (whether they are interviewer-generated or agency-generated), the interviewer checks them for completeness and accuracy. If the lists are not complete, the interviewer adds any patients (or discharges) that are missing. Similarly, the interviewer deletes any patients (discharges) that are on the lists but are out of scope for the Survey. Step 3 of each sampling list, which asks for the total number of patients or discharges listed, is completed. Then, using the sample selection table, the interviewer draws a systematic sample of six current patients and six discharges. In agencies with fewer than six current patients (or discharges), all patients (discharges) are selected for the respective sample.

Steps 6 (number of patients or discharges selected) and 7 (the sampled patients or discharges) are answered last.

The interviewer then completes the Current and Discharged Patient Questionnaires for each of the sampled patients by interviewing a member of the agency staff. The staff person is instructed to refer to each patient's medical record to obtain the information in the questionnaires. As in the Pretest, the patients themselves are not contacted. If necessary, the interviewers will return to the agency to obtain all of the necessary information.

When all the interviews are completed, the interviewer returns to the administrator to collect the Facility Staff Worksheet (if applicable) and leaves a thank-you letter, thanking the administrator for his or her time and cooperation. A copy of this letter is in appendix V.

All completed survey materials are reviewed by the interviewers in the field before being submitted for processing. Attempts are made at that time to retrieve missing data or to correct inconsistent data. Quality control is also maintained through standardized procedures of supervisor observation of interviews, review of completed questionnaires, and feedback to interviewers.

Data processing and estimation

After the entire interview process is completed for an agency, the interviewer sends all forms for that agency to the supervisor at the regional office where the forms are checked in and reviewed for completeness. Any Facility Staff Worksheets that the regional office receives are attached to the appropriate Facility Questionnaires. The forms are then sent to the NCHS data-processing facility in Research Triangle Park, North Carolina.

Manual editing and coding of data are done centrally by trained NCHS staff. Diagnoses are coded according to the *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM) (6). Up to 12 diagnostic codes are assigned for each sample patient (a maximum of six at admission and a maximum of six at the time of the survey or discharge). After keying, extensive editing is conducted by computer to assure that all responses are accurate, consistent, logical, and complete. When necessary, records are reviewed manually to resolve inconsistencies. In some cases, missing data are imputed. All imputed data are identified as such on the data tapes to enable the analyst to distinguish between imputed data and reported data. After the editing is completed, the computer is used to calculate and assign weights, ratio adjustments, recodes, and other related procedures necessary to produce national estimates from the sample data.

Because the NHHCS is designed to produce national estimates on the use of home health and hospice care services, the data must have weights to inflate the sample numbers to the national estimates. Each record on the final data tapes has a weight for this purpose. By aggregating these weights, estimated counts for national data can be obtained. The weights used to inflate sample data have three principal components: inflation by the reciprocals of the probabilities of sample selection, adjustment for nonresponse, and ratio adjustment to fixed totals (7).

Inflation by the reciprocals of the probabilities of sample selection—There is one probability for each stage of sampling: (a) the probability of selecting the PSU, (b) the probability of selecting the agency, and (c) the probability of selecting the patient or discharge within the agency. For example, the probability of selecting a current patient within an agency is the number of current patients selected divided by the total number of current patients on the agency's roster as of the night before the survey. The overall probability of selection is the product of the probabilities at each stage. The inverse of the overall selection probability is the basic inflation weight.

Adjustment for nonresponse—NHHCS data are adjusted for three types of nonresponse. The first type of nonresponse occurs when an in-scope (NHHCS eligible) sample agency does not respond. This adjustment is a multiplicative factor that has as its numerator the number of in-scope sample agencies within each PSU and as its denominator the number of in-scope agencies that completed an agency questionnaire in that same PSU. The second type of nonresponse occurs when an agency does not complete the sampling lists used to select the patient or discharge samples. This adjustment is a multiplicative factor that has as its numerator the number of eligible current patients (discharges) from in-scope sample agencies regardless of whether they completed a current patient (discharge) questionnaire within each PSU and as its denominator the number of eligible patients for in-scope agencies that completed at least one in-scope sample current patient (discharge) questionnaire in that same PSU. The third type of nonresponse occurs when the agency does not complete the questionnaire for a sample patient or discharge. This adjustment is a multiplicative factor that has as its numerator the number of in-scope sample current patients (discharges) within each agency and as its denominator the number of in-scope current patients (discharges) that had a completed questionnaire in that same agency. The nonresponse adjustment brings estimates based only on the responding cases up to the level that would be achieved if all eligible cases respond.

Ratio adjustment to fixed totals—The purpose of ratio adjustment is to take into account all relevant information in the estimation process, thereby reducing the variability of the estimate. Adjustments are made within each of eight groups defined by region (Northeast, Midwest, South, and West) and type of agency (hospice or home health and other agencies) to adjust for over or undersampling of agencies reported in the sampling frame. This adjustment is a multiplicative factor that has as its numerator the number of agencies in the sampling frame within each region-type of agency group and as its denominator the estimated number of agencies for that same group.

Because the statistics produced from the NHHCS are based on a sample, they will differ somewhat from figures that would have been obtained if a complete census had been taken using the same schedules, instructions, and procedures. As in any sample survey, the results are subject to sampling and

nonsampling errors. Nonsampling errors include errors due to response bias, questionnaire and item nonresponse, recording, and processing errors. To the extent possible, the latter types of errors are kept to a minimum by methods built into survey procedures. Such methods include standardized interviewer training, observation of interviews, manual and computer editing, verification of keypunching, and other quality checks. Because survey results are subject to both sampling and nonsampling errors, the total error is larger than errors due to sampling variability alone.

The standard error is primarily a measure of the variability that occurs by chance because only a sample, rather than the entire universe, is surveyed. The standard error also reflects part of the measurement error, but it does not measure any systematic biases in the data. It is inversely proportional to the square root of the number of observations in the sample. As the sample size increases, the standard error generally decreases.

The chances are about 68 in 100 that an estimate from the sample differs by less than the standard error from the value that would be obtained from a complete census. The chances are about 95 in 100 that the difference is less than twice the standard error and about 99 in 100 that it is less than 2½ times as large.

The standard errors used by NCHS for published data from the NHHCS are computed using SUDAAN software. SUDAAN computes standard errors by using a first-order Taylor approximation of the derivation of estimates from their expected values. A description of the software and the approach it uses has been published (8).

Data publication and availability

This report presents a description of the NHHCS through its first year of operation (1992). Preliminary data from the 1992 NHHCS has been published (9,10,11) and a report presenting final data will be available soon (12). Both of these reports will be done for each year of the NHHCS. In addition, more analytical reports, concentrating on special topics, are planned. These will be published by the National Center for Health Statistics *Vital and Health Statistics*, series 1, 2, and 13, and in *Advance Data from Vital and Health Statistics*. Information will also be made available in journal articles and in papers presented at professional meetings.

Data from the NHHCS will also be available in the form of public- use computer data tapes. Three tapes were produced for the 1992 NHHCS: one containing agency information, one containing current patient information, and one containing discharged patient information. Comparable data tapes will be produced for subsequent years of the Survey.

For general information on the NCHS data tape program, computer products currently available, schedule of release of upcoming data files, or published information, contact:

Data Dissemination Branch (DDB)
National Center for Health Statistics
Centers for Disease Control and Prevention
6525 Belcrest Road, Room 1064
Hyattsville, MD 20782
(301) 436-8500

Data tapes and other computer products are sold by the National Technical Information Service (NTIS) and are not available from NCHS. To purchase computer products from NTIS, contact:

National Technical Information Service
5285 Port Royal Road
Springfield, VA 22161
(703) 487-4650

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Appendix I
NCHS authorizing legislation

NATIONAL CENTER FOR HEALTH STATISTICS

Sec. 306. [242k] (a) There is established in the Department of Health and Human Services the National Center for Health Statistics (hereinafter in this section referred to as the "Center") which shall be under the direction of a Director who shall be appointed by the Secretary and supervised by the Assistant Secretary for Health (or such officer of the Department as may be designated by the Secretary as the principal adviser to him for health programs).

(b) In carrying out section 304(a), the Secretary, acting through the Center -

(1) shall collect statistics on-

(A) the extent and nature of illness and disability of the population of the United States (or any groupings of people included in the population), including life expectancy, the incidence of various acute and chronic illnesses, and infant and maternal morbidity and mortality,

(B) the impact of illness and disability of the population on the economy of the United States and on other aspects of the well-being of its population (or of such groupings),

(C) environmental, social, and other health hazards,

(D) determinants of health,

(E) health resources, including physicians, dentists, nurses, and other health professionals by specialty and type of practice and supply of services by hospitals, extended care facilities, home health agencies, and other health institutions,

(F) utilization of health care, including utilization of (i) ambulatory health services by specialties and type of practice of health professionals providing such service, and (ii) services of hospitals, extended care facilities, home health agencies, and other institutions,

(G) health care costs and financing, including the trends in health care prices and costs, the sources of payments for health care services, and Federal, State, and local governmental expenditures for health care services, and

(H) family formation, growth, and dissolution;

(2) shall undertake and support (by grant or contract) research, demonstrations, and evaluations respecting new or improved methods for obtaining current data on the matters referred to in a paragraph (1);

(3) may undertake and support (by grant or contract) epidemiologic research, demonstrations, and evaluations on the matters referred to in paragraph (1); and ...."

(4) may collect, furnish, tabulate, and analyze statistics, and prepare studies, on matters referred to in paragraph (1) upon request of public and nonprofit entities under arrangements under which the entities will pay the cost of the service provided.

Amounts appropriated to the Secretary from payments made under arrangements made under paragraph (4) shall be available to the Secretary for obligation until expended.

Appendix II
Definitions of selected terms used by the National Home and Hospice Care Survey

Terms relating to agencies

Hospice and Home Health Agency—Hospices and home health agencies are usually defined in terms of the type of care that they provide. They may be free-standing health facilities or units of larger organizations, such as a hospital or nursing home.

Home health care—Home health care is provided to individuals and families in their places of residence for the purpose of promoting, maintaining, or restoring health or for maximizing the level of independence while minimizing the effects of disability and illness, including terminal illness.

Hospice care—Hospice care is a program of palliative and supportive care services providing physical, psychological, social, and spiritual care for dying persons, their families, and other loved ones. Hospice services are available in the home and inpatient settings. Home hospice care is provided on part-time, intermittent, regularly scheduled, and around-the-clock basis. Bereavement services and other types of counseling are available to the family and significant others.

Certification—Refers to agency certification by Medicare and/or Medicaid. Both programs can certify home health agencies and hospices as meeting agency criteria for participation.

Medicare—The medical assistance provided in title XVIII of the Social Security Act. Medicare is a health insurance program administered by the Social Security Administration for persons 65 years of age and over and for disabled persons who are eligible for benefits.

Medicaid—The medical assistance provided in title XIX of the Social Security Act. Medicaid is a Federal or State administered program for the medically indigent.

Geographic region—Agencies are classified by location in one of the four geographic regions of the United States that correspond to those used by the U.S. Bureau of the Census.

Region	*States included*
Northeast	Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut, New York, New Jersey, and Pennsylvania
Midwest	Michigan, Ohio, Illinois, Indiana, Wisconsin, Minnesota, Iowa, Missouri, North Dakota, South Dakota, Nebraska, and Kansas
South	Delaware, Maryland, District of Columbia, Virginia, West Virginia, North Carolina, South Carolina, Georgia, Florida, Kentucky, Tennessee, Alabama, Mississippi, Arkansas, Louisiana, Oklahoma, and Texas
West	Montana, Idaho, Wyoming, Colorado, New Mexico, Arizona, Utah, Nevada, Washington, Oregon, California, Hawaii, and Alaska

Metropolitan statistical area—The definition and titles of MSA's are established by the U.S. Office of Management and Budget with advice of the Federal Committee on Metropolitan Statistical Areas. Generally speaking, an MSA consists of a county or group of counties containing at least one city (or twin cities) having a population of 50,000 or more plus adjacent counties that are metropolitan in character and are economically and socially integrated with the central city. In New England, towns and cities rather than counties are the units used in defining MSA's. There is no limit to the number of adjacent counties included in the MSA as long as they are integrated with the central city, nor is an MSA limited to a single State; boundaries may cross State lines. The metropolitan population in this report is based on MSA's as defined in the 1980 census and does not include any subsequent additions or changes.

Ownership—The type of organization that controls and operates the home health agency or hospice.

For profit—Operated under private commercial ownership, including individual or private ownership, partnerships, or corporations.

Voluntary nonprofit—Operated under voluntary or nonprofit auspices, including church-related and nonprofit corporations.

State or local government—Operated under State, county, city, city-county, and hospital district or authority.

Federal Government—Includes USPHS, Armed Forces, and Veterans Administration.

Terms relating to patients and discharges

Current patient—A patient on the agency's roster as of midnight of the night before the survey.

Discharge—A patient formally discharged from care by the home health agency or hospice. Live and dead discharges are included. A patient can be counted more than once if the patient was discharged more than once during the reference period.

Activities of daily living—Refers to six activities (bathing, dressing, transferring, walking, using the toilet room, and eating) that reflect the patient's capacity for self-care. The patient's need for assistance with these activities refers to personal help received from agency staff at the time of the survey (for current patients) or at the time of discharge or immediately before discharge (for discharges).

Instrumental activities of daily living—Refers to six daily tasks (light housework, preparing meals, taking medications, shopping for groceries or clothes, using the telephone, and managing money) that enable the patient to live independently in the community. The patient's need for assistance with these activities refers to personal help received from agency staff at the time of the survey.

Primary source of payment—The one payment source that paid the greatest amount of the patient's charge during the billing period indicated.

Private insurance—Includes private health insurance. Excludes unemployment insurance.

Own income or family support—Includes retirement funds, family income, and social security.

Supplemental Security Income—Includes money from Social Security's Supplemental Security Income.

Medicare—Money received under the Medicare program for home health or hospice care.

Medicaid—Money received under the Medicaid program for community-based care.

Other government assistance or welfare—Sources of government aid (Federal, State, or local) other than Medicare or Medicaid. Includes funds available under the Older Americans Act (Title III) and Social Service Block Grants (Title XX).

All other sources—Includes religious organizations, foundations, volunteer agencies, Veterans Administration pensions or compensation, miscellaneous sources, no-charge arrangements, and unknown arrangements.

Appendix III
Letters and data collection instruments for the Feasibility Study for the National Home and Hospice Care Survey

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control

National Center for Health Statistics
3700 East-West Highway
Hyattsville, MD 20782

Dear Administrator:

The National Center for Health Statistics (NCHS) of the Centers for Disease Control collects and provides information on the health of the Nation and the utilization of its health resources. As part of this continuing program, NCHS is conducting "The Study of the Feasibility of Surveying Hospices and Home Health Agencies." This survey is authorized under section 306 (42 USC 242K) of the Public Health Service Act.

The purpose of this study is to develop and test the methodology and data collection instruments to be used in conducting a National Survey of Hospices and Home Health Agencies. The ultimate goal of the larger survey is to provide a more complete information base on available long-term care services and the utilization of those services.

The Feasibility Study includes a small sample of Hospices and Home Health Agencies. Agency information will be collected through a mail questionnaire. Although your participation is voluntary and there are no penalties for refusing to answer any question, it is essential that we obtain data from all sampled Hospices and Home Health Agencies to meet the survey goals.

Within the next week, you will receive a short questionnaire from Westat, Inc., the company selected by NCHS to help conduct the Feasibility Study. The questionnaire contains items about your agency location and ownership, services provided, and agency size and certification.

Please return your completed questionnaire to Westat. If you have any questions, please call Susan Englehart at 1-800-937-8285.

Sincerely yours,

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

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Center for Health Statistics
Centers for Disease Control
3700 East-West Highway
Hyattsville, MD 20782

January 22, 1990

Dear Administrator:

The National Center for Health Statistics (NCHS) of the Centers for Disease Control collects and provides information on the health of the Nation and the utilization of its health resources. As part of this continuing program, NCHS is conducting "The Study of the Feasibility of Surveying Hospices and Home Health Agencies." This survey is authorized under section 306 (42 USC 242K) of the Public Health Service Act.

The purpose of this study is to develop and test the methodology and data collection instruments to be used in conducting a National Survey of Hospices and Home Health Agencies. The ultimate goal of the larger survey is to provide a more complete information base on available long-term care services and the utilization of those services.

The Feasibility Study includes a small sample of Hospices and Home Health Agencies. Information about your agency will be collected through the enclosed mail questionnaire which should take 20 minutes to complete. Additionally, for a small subset of agencies, time involving some of your staff will be required to complete interviews concerning a small sample of clients. No clients will be contacted at any time. Although your participation is voluntary and there are no penalties for refusing to answer any question, it is essential that we obtain data from all sampled agencies to evaluate the data collection procedures and questionnaires. Copies of letters of endorsement from organizations which represent Hospices and Home Health Agencies are enclosed.

I want to emphasize that the information you and your staff supply will be used only by the National Center for Health Statistics. In accordance with Section 308(d) (42 USC 424m) of the Public Health Service Act. no information collected in this survey may be used for any purpose other than the purpose for which it was collected. Such information may not be published or released in any form if the individual or establishment is identifiable unless the individual or establishment has consented to its release.

Please complete the enclosed questionnaire and return it within two weeks to Westat, Inc., the firm selected to help NCHS conduct the Feasibility Study. A postage paid return envelope is included for your convenience. If you have any further questions, please call Susan Englehart at 1-800-937-8285.

Sincerely yours,

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

National Hospice Organization

January 5, 1990

Dear Hospice Administrator:

Enclosed is survey material being sent to you from the National Center for Health Statistics (NCHS). The prompt, accurate and thorough completion of the survey questionnaire is important to the conduct of a national survey of long term care services and utilization of those services, including hospices.

Your cooperation can only help NCHS in its efforts to include hospices in its National Survey of Long Term Care Facilities, for developing policies which promote efficient allocation of health care resources, and for supporting research directed at finding effective means for treatment of long-term health problems.

The National Hospice Organization requests your assistance in this most important matter.

Sincerely,

John J. Mahoney

John J. Mahoney
President

Suite 901 • 1901 North Moore Street • Arlington, Virginia 22209 • (703) 243-5900

HOMECARE™

NATIONAL ASSOCIATION FOR HOME CARE
519 C STREET, N.E., STANTON PARK
WASHINGTON, D.C. 20002-5809
Telephone: (202) 547-7424, FAX: (202) 547-3540

January 5, 1990

Dear Colleague:

The enclosed survey material is being sent to you from the National Center for Health Statistics. It represents an important first step in the development of a minimum data set for home care agencies and their patients and the expansion of the National Survey of Long-Term Care Facilities to include our industry.

The National Association for Home Care supports these objectives and requests your cooperation.

Sincerely,

Val

Val J. Halamandaris
President

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Center for Health Statistics
Centers for Disease Control
3700 East-West Highway
Hyattsville, MD 20782

February 7, 1990

Dear Administrator:

You were recently asked to complete a questionnaire for "The Study of the Feasibility of Surveying Hospices and Home Health Agencies." The survey is being conducted by the National Center for Health Statistics (NCHS) of the Centers for Disease Control.

I want to emphasize that the information you supply will be used solely for statistical research and reporting purposes. No information collected under the authority of Section 306(d) (42 USC 242K) of the Public Health Service Act may be used for any purpose other than the purpose for which it was collected. Such information may not be published or released in any form if the individual or establishment is identifiable unless the individual or establishment has consented to such release.

The data from this study will be used to test the methodology and data collection instruments to be used in conducting a National Survey of Hospices and Home Health Agencies. The ultimate goal of the longer study is to provide a more complete information base on available long-term care services and the utilization of these services. It is important that hospice and home health agencies be part of this information set. Although your participation is voluntary, it is essential that all those surveyed respond so that the estimates are as accurate as possible.

Since we have not received your completed questionnaire, another copy of the questionnaire and a postage-paid business reply envelope are enclosed. We would greatly appreciate your cooperation in completing and returning your questionnaire within five working days. The questionnaire takes only 20 minutes to complete, and your answers are totally confidential. If you have any questions, you may call Susan Englehart at 1-800-937-8285 for answers.

Sincerely yours,

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

OMB #: 0920-0236
Expires: 01/01/92

(Place label here)

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control
National Center for Health Statistics

FEASIBILITY OF SURVEYING HOSPICES AND HOME HEALTH AGENCIES

AGENCY QUESTIONNAIRE

Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

Conducted by:

WESTAT, INC.

SECTION I: AGENCY LOCATION AND OWNERSHIP

1. If your agency's name, mailing address or telephone number is not printed correctly on the label above, please make any necessary changes in the spaces provided below. If the label information is correct, skip this item and go on to Question 2.

Agency name:_____

Agency mailing address:_____

City:_____ State:_____ Zip:_____

Agency phone number: |__|__|__| |__|__|__| |__|__|__|__|

2. If your agency's location address is different than it's mailing address, please write the location address in the spaces provided below. If the agency mailing address is the same as the location address, skip this item and go on to Question 3.

Agency location address:_____

_____

City:_____ State:_____ Zip:_____

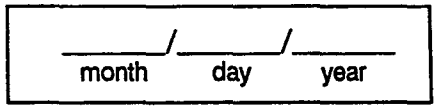
Agency's phone number: |__|__|__| |__|__|__| |__|__|__|__|

3. What is this agency's operating status?

[CIRCLE ONE]

1 Agency currently provides hospice care and/or home care.

2 Agency does not yet provide hospice and/or home care, but plans to do so in the future. [SPECIFY EXPECTED OPERATIONAL DATE BELOW]



3 Agency is in operation but no longer provides hospice or home care.

4 Agency is no longer in operation.

5 Agency never provided hospice or home care.

6 Other [PLEASE EXPLAIN]_____

_____

_____

IF YOU CIRCLED 2, 3, 4, 5, OR 6 IN QUESTION 3, PLEASE SKIP TO QUESTION 27 ON PAGE 9.

4. What is the name, title and telephone number of the person who has day-to-day responsibility for administering or directing this agency?

Administrator's name: _____

Administrator's title: _____

Administrator's phone number: |__|__|__| |__|__|__| |__|__|__|__|

5. What is the type of ownership of this agency?

[CIRCLE ONE]

1 For profit (includes individual or private, partnership, corporation)

2 Nonprofit (includes church-related, nonprofit corporation, other nonprofit ownership)

3 State or local government (includes state, county, city, city-county, hospital district or authority)

4 Federal government (includes USPHS, armed forces, Veterans Administration)

5 Other [SPECIFY] _____

_____

6. Is this agency....

[CIRCLE ONE]

1 an independent organization?

2 a branch of a parent agency or part of a chain?

3 owned or operated by a hospital?

4 owned or operated by a nursing home?

5 owned or operated by a federal, state or local health department or agency?

6 Other [SPECIFY]? _____

_____

7. Does this agency maintain clinical records and/or progress notes of client visits or services provided?

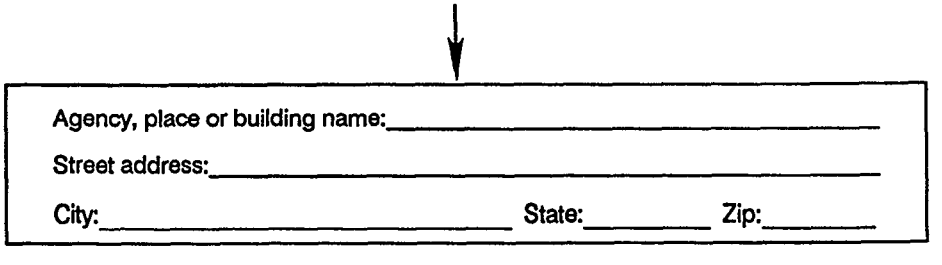
1 YES
2 NO [SKIP TO QUESTION 11 ON PAGE 5]

8. Where are clinical/progress records on <u>current/active</u> clients kept?

[CIRCLE ONE]

1 At this location.

2 At another location [PLEASE SPECIFY IN THE SPACE PROVIDED BELOW]

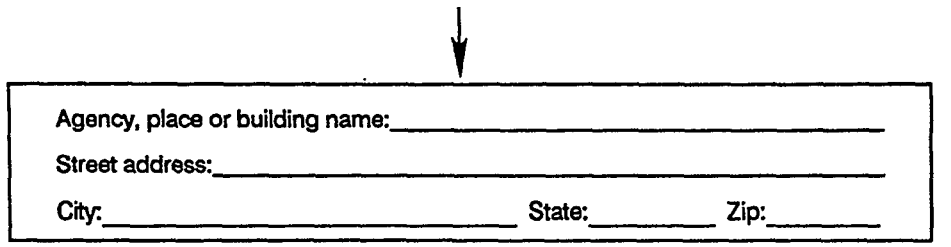


9. Where are clinical/progress records on discharged/inactive clients kept? [CIRCLE ONE CODE]

[CIRCLE ONE]

1 At this location.

2 At another location [PLEASE SPECIFY IN THE SPACE PROVIDED BELOW]



10. How long are the records on discharged/inactive clients kept?

Length of time kept: [Specify Number in one below]

|__|__| weeks

|__|__| months

|__|__| years

SECTION II: SERVICES PROVIDED

11. What is the primary service category of this agency. Is it primarily a home health agency, primarily a hospice, a "mixed" agency with equal emphasis on both home care and hospice, or an agency with a primary focus that is neither home care nor hospice? [CIRCLE ONLY ONE CODE]

[CIRCLE ONLY ONE]

1 Home care.

2 Hospice.

3 Both hospice and home care are equal.

4 Neither → PLEASE SPECIFY AGENCY'S PRIMARY FOCUS: _____

12. Does this agency provide hospice care to any of its clients?

1 YES
2 NO [SKIP TO QUESTION 14 ON PAGE 6]

13. What type of patient care is provided by this hospice?

[CIRCLE ALL THAT APPLY]

1 Hospice care for persons terminally ill with cancer

2 Hospice care for persons terminally ill with chronic obstructive pulmonary disease

3 Hospice care for persons terminally ill with neurologic diseases

4 Hospice care for persons terminally ill with AIDS

5 Hospice care for children who are terminally ill

6 Other [SPECIFY] _____

14. How many persons are serving your agency as volunteers (i.e., without remuneration)?

List number: _____

15. The table below lists categories of care providers who are often involved in home care and hospice care. In **Column A** of the table please indicate which types of providers are employed on the staff of this agency. In **Column B**, for each category of provider on staff, please indicate the number of full time equivalents (FTEs) currently employed by the agency. Finally, in **Column C** please indicate whether the agency contracts for services of providers, either as an alternative to employing them directly or in addition to employing them directly.

	A. Is/Are providers on staff?		B. List number of FTEs on agency staff?	C. Any part of services provided by contract?	
	YES	NO		YES	NO
a. Physicians	1	2		1	2
b. Registered nurses	1	2		1	2
c. LPNs or vocational nurses	1	2		1	2
d. Home health aides/personal care taker	1	2		1	2
e. Psychologists	1	2		1	2
f. Medical social workers	1	2		1	2
g. Health educators	1	2		1	2
h. Physical therapists	1	2		1	2
i. Nurse's aides, orderlies, student nurses and attendants	1	2		1	2
j. Other medical providers (e.g., dentists, podiatrists)	1	2		1	2
k. Other [SPECIFY] _____ _____ _____ _____ _____	1	2		1	2

16. The table below lists services that home health and hospice agencies may provide to clients. Please indicate whether or not each service listed below is provided by this agency.

	Is this service provided?	
	YES	NO
a. Dietary and nutritional services	1	2
b. Occupational therapy/vocational therapy	1	2
c. Speech therapy/audiology	1	2
d. Homemaker/companion services	1	2
e. Meals on wheels	1	2
f. Transportation	1	2
g. Enterostomal therapy	1	2
h. Bereavement care	1	2
i. Pastoral care	1	2
j. Counseling (client and family)	1	2
k. Medications	1	2
l. Respite care	1	2
m. High tech care (e.g., IV therapy)	1	2
n. Referral services	1	2
o. Other [SPECIFY] _____ _____ _____ _____	1	2

SECTION III: AGENCY SIZE AND CERTIFICATION

17. What is the number of active hospice and other home care clients currently on the agency rolls? If this is unavailable, give the "average daily census" for the last period tallied.

a. Enter number of active hospice clients: ..... _____

b. Enter number of other active home care clients: ..... _____

c. Enter total number of active clients: ..... _____

Check source: current ☐ average daily census ☐

18. During 1989 what was the number of hospice and other home care clients enrolled by the agency?

a. Enter number of hospice clients in 1989: ..... _____

b. Enter number of home care clients in 1989: ..... _____

c. Enter number of clients who were enrolled as **both** home care and hospice clients in 1989: [DO NOT INCLUDE THESE CLIENTS IN 18 "a" OR 18 "b" ABOVE] ..... _____

d. Enter total number of clients enrolled in 1989: ..... _____

19. What was the total number of hospice and/or home care **visits** provided by your agency in 1989? [INCLUDE VISITS PROVIDED BY AGENCY STAFF AND VISITS PROVIDED THROUGH CONTRACT SERVICES]

Enter total number of home visits in 1989: ..... _____

20. During 1989 what was the number of hospice and other home care clients who were discharged by the agency? [IF CLIENT WAS BOTH A HOSPICE CLIENT AND A "NONHOSPICE" HOME CARE CLIENT, PLACE THE CLIENT IN THE CATEGORY IN WHICH S/HE WAS ENROLLED AT DISCHARGE.]

a. Enter number of hospice clients discharged in 1989 ..... _____

b. Enter number of other home care clients discharged in 1989 ..... _____

c. Enter total number of discharged clients in 1989 ..... _____

21 Does this agency provide acute (inpatient) care to its hospice and/or home care clients?

1 YES
2 NO [SKIP TO QUESTION 24]

22. How many beds, including contract beds, does the agency have for acute care of hospice and home care clients?

Enter total number of beds: _____

23. How many of the agency's active hospice and home care clients are currently in acute (inpatient) care?

Enter total number of clients currently in acute (inpatient) care: _____

24. Is this agency certified by Medicare?

[CIRCLE ONE]
1 Certified

2 Certification pending

3 Not certified

25. Is this agency certified by Medicaid?

[CIRCLE ONE]
1 Certified

2 Certification pending

3 Not certified

26. Is this agency certified by Medicare to provide hospice care under the special hospice benefit provision?

[CIRCLE ONE]
1 Certified

2 Certification pending

3 Not certified

27. Enter date Agency Questionnaire was completed:

_____/_____/_____
month day year

28. Respondent's Name: _____

Respondent's Title: _____

Respondent's phone number: |__|__|__| |__|__|__| |__|__|__|__|

The National Center for Health Statistics along with Westat would like to thank you for your time and participation in this survey. We really appreciate your cooperation.

Interviewer Name: _____

Interviewer ID: _____

(Place label here)

Date completed: _____

OMB #: 0920-0236
Expires: 01/01/92

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control
National Center for Health Statistics

FEASIBILITY OF SURVEYING HOSPICES AND HOME HEALTH AGENCIES

ADMINISTRATOR'S QUESTIONNAIRE

Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

Conducted by:

WESTAT, INC.

SECTION I: AGENCY LOCATION AND OWNERSHIP

1. If your agency's name, mailing address or telephone number is not printed correctly on the label above, please make any necessary changes in the spaces provided below. If the label information is correct, skip this item and go on to Question 2.

Agency name:_____

Agency mailing address:_____

City:_____ State:_____ Zip:_____

Agency phone number: |__|__|__| |__|__|__| |__|__|__|__|

2. If your agency's location address is different than its mailing address, please write the location address in the spaces provided below. If the agency mailing address is the same as the location address, skip this item and go on to Question 3.

Agency location address:_____

_____

City:_____ State:_____ Zip:_____

Agency's phone number: |__|__|__| |__|__|__| |__|__|__|__|

3. What is the name, title and telephone number of the person who has day-to-day responsibility for administering or directing this agency?

Administrator's name: _____

Administrator's title: _____

Administrator's phone number: |__|__|__| |__|__|__| |__|__|__|__|

4. Is this agency . . . [CIRCLE ONE]

1 an independent organization? [SKIP TO QUESTION 6]

2 a branch of a parent agency or part of a chain?

3 owned or operated by a hospital?

4 owned or operated by a nursing home?

5 Owned or operated by a federal, state or local health department or agency?

6 Other [SPECIFY] _____

_____

5. In the space provided below, please enter the complete name and address of the agency or organization that owns, operates or is the "parent" or head office of this agency. [PLEASE DO NOT ABBREVIATE THE ORGANIZATION NAME]

Organization name:_____

Organization address:_____

City:_____ State:_____ Zip:_____

Organization phone number: |__|__|__| |__|__|__| |__|__|__|__|

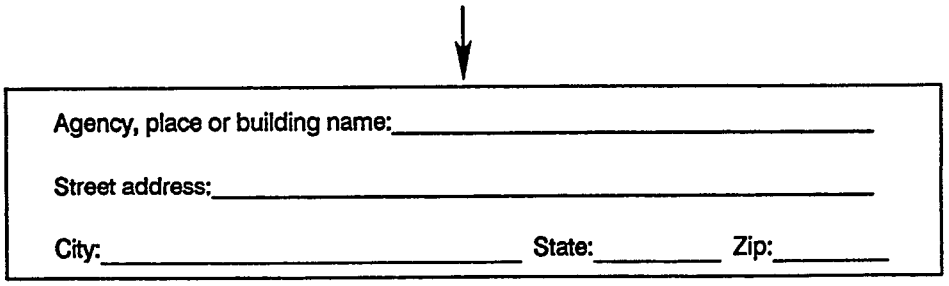
6. Does this agency maintain clinical records and/or progress notes of client visits or services provided?

1 YES
2 NO [SKIP TO QUESTION 9 ON PAGE 3]

7. Where are clinical/progress records on current/active clients kept? [CIRCLE ALL THAT APPLY]

1 At this location.

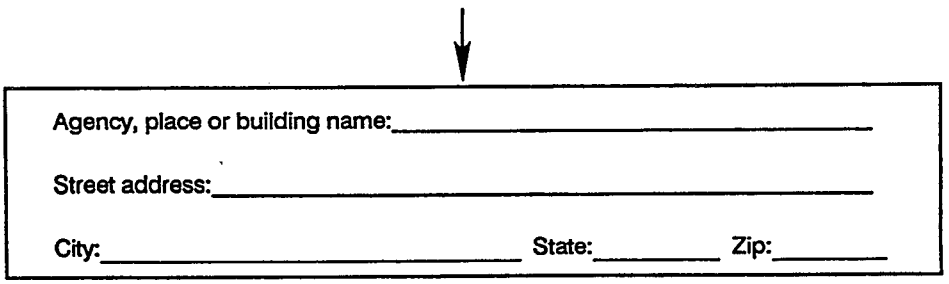
2 At another location [PLEASE SPECIFY IN THE SPACE PROVIDED BELOW]



8. Where are clinical/progress records on discharged/inactive clients kept? [CIRCLE ALL THAT APPLY]

1 At this location.

2 At another location [PLEASE SPECIFY IN THE SPACE PROVIDED BELOW]



9. Does this agency provide hospice care to any of its clients?

1 YES
2 NO

10. What is the primary service category of this agency? Is it primarily a home health agency, primarily a hospice, a "mixed" agency with equal emphasis on both home care and hospice, or an agency with a primary focus that is neither home care nor hospice? [CIRCLE ONLY ONE CODE]

1 Home care.

2 Hospice.

3 Both hospice and home care are equal.

4 Neither ——→

PLEASE SPECIFY AGENCY'S PRIMARY FOCUS: _____

_____

_____

11. During 1989 what was the number of hospice and other home care clients served by the agency?

a.	Enter number of hospice clients served in 1989:	_____
b.	Enter number of home care clients served in 1989:	_____
c.	Enter number of clients who were served as both home care and hospice clients in 1989: [DO NOT INCLUDE THOSE CLIENTS IN 11a OR 11b ABOVE]	_____
d.	Enter total number of clients served in 1989:	_____

12. During 1989 what was the number of hospice and other home care clients who were discharged, both alive and deceased, by the agency? [IF A CLIENT WAS BOTH A HOSPICE CLIENT AND A "NONHOSPICE" HOME CARE CLIENT, PLACE THE CLIENT IN THE CATEGORY IN WHICH S/HE WAS ENROLLED AT DISCHARGE.

a.	Enter number of hospice clients discharged in 1989:	_____
b.	Enter number of other home care clients discharged in 1989:	_____
c.	Enter total number of discharged clients in 1989:	_____

13. Is this agency certified by Medicare? [THIS CERTIFICATION STATUS REFERS TO THE PART OF THE AGENCY SAMPLED, I.E., HOSPICE OR HOME HEALTH CARE AGENCY REGARDLESS OF WHETHER THEY PROVIDE BOTH TYPES OF SERVICE. IF RESPONSE IS "NO," ASK IF CERTIFICATION IS PENDING CIRCLE ONE.]

1 Certified

2 Certification pending

3 Not certified

14. Is this agency certified by Medicaid? [THIS CERTIFICATION STATUS REFERS TO THE PART OF THE AGENCY SAMPLED, I.E., HOSPICE OR HOME HEALTH CARE AGENCY REGARDLESS OF WHETHER THEY PROVIDE BOTH TYPES OF SERVICE. IF RESPONSE IS "NO," ASK IF CERTIFICATION IS PENDING CIRCLE ONE.]

1 Certified

2 Certification pending

3 Not certified

On behalf of the National Center for Health Statistics and Westat, Inc., I would like to thank you for your time and participation in this survey. We really appreciate your cooperation.

(Place label here)

Interviewer Name: _____

Interviewer ID: _____

OMB #: 0920-0236
Expires: 01/01/92

Date:____/____/1990
Client #: _____
Listing Line: _____
CLIENT: CURRENT ☐
DISCHARGED ☐

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control
National Center for Health Statistics

FEASIBILITY OF SURVEYING HOSPICES AND HOME HEALTH AGENCIES

CLIENT QUESTIONNAIRE

Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

Conducted by:

WESTAT, INC.

SECTION I: CLIENT DESCRIPTION

1. What is/was this client's date of birth?

|__|__| |__|__| |__|__|__|__|
month day year

2. What is/was the sex of this client?

1 Male

2 Female

3. What is/was the racial background that best describes this client? [CIRCLE ONE CODE]

1 White

2 Black

3 Asian, Pacific Islander

4 American Indian, Eskimo, Aleut

5 Other [SPECIFY]_____

_____

4. Is/was this client of Hispanic origin? [CIRCLE ONE CODE]

1 Hispanic origin

2 Not Hispanic

5. What is/was this client's current marital status? [CIRCLE ONE CODE]

1 Married

2 Widowed

3 Divorced

4 Separated

5 Never married

As a part of this survey, we would like to have this client's Social Security Number. Provision of this number is voluntary and not providing the number will have no effect in any way on this client's benefits. This number will be useful in conducting future follow-up studies. It will be used to match against the vital statistics records maintained by the National Center for Health Statistics. This information is collected under the authority of Section 306 of the Public Health Service Act.

6. What is/was this client's Social Security Number?

Social Security Number:

|__|__|__| |__|__| |__|__|__|__|

X6. Where did you obtain the information used to answer items 1 through 6?

1 Primary client record
2 Supplementary record
3 Your personal knowledge
4 Consulted another person

---

7. What was the date of this client's most recent enrollment with your agency?

Date of enrollment:

|__|__| |__|__| |1|9|__|__|
month day year

8. Who referred this client to your agency? [CIRCLE ALL THAT APPLY]

1 Self/family referral

2 Nursing home

3 Hospital

4 Physician

5 Health department

6 Other [SPECIFY]_____

_____

9. Does/did this client have any living children?

1 Yes

2 No

10. Is/was the family of this client actively involved in providing care for the client?

1 Yes

2 No

11. Is/was there an identified individual (such as a family member, neighbor, or friend) not associated with your agency who is the client's primary caregiver?

1 Yes

2 No ——→ SKIP TO QUESTION 13

12. What is/was the relationship of the primary caregiver to this client? [CIRCLE ONE CODE]

1 Spouse
2 Parent
3 Child
4 Other relative
5 Neighbor
6 Friend
7 Volunteer group
8 Other [SPECIFY] _____

_____

_____

13. Does/Did the family of this client receive services (such as counseling) from your agency, as a part of the plan of care for this client?

1 Yes

2 No

14. Has this client been formally discharged?

1 Yes

2 No ——→ SKIP TO QUESTION 18 ON PAGE 4

15. On what date was this client discharged?

Date of discharge:

|__|__| |__|__| |1|9|__|__|
month day year

16. What is this client's discharge status?

1 Discharged alive

2 Discharged dead → SKIP TO QUESTION 21 ON PAGE 6

17. What was the primary reason for discharge from agency services?

_____

_____

_____

_____

18. Where is this client currently living? [CIRCLE ONE CODE]

1 Private residence (house or apartment)

2 Rented room, boarding house

3 Retirement home

4 A health facility (including mental health facility) → SKIP TO QUESTION 21 ON PAGE 6

5 Other [SPECIFY] _____

_____

_____

19. Is this client living with family members, nonfamily members, or alone? [CIRCLE ONE CODE]

1 With family members

2 With nonfamily members

3 With both family and nonfamily members

4 Alone

20. Has a safety assessment been done of this client's home environment? [CIRCLE ONE CODE]

1 Yes, assessment was done by this agency.

2 Yes, assessment was done by another agency.

3 No, assessment not done.

X20. Where did you obtain the information to answer questions 7 through 20?

1 Primary client record
2 Supplementary record
3 Your personal knowledge
4 Consulted another person

SECTION II: CLIENT FUNCTIONAL ABILITIES

The questions in this section of the questionnaire pertain to the client's functional capabilities at the time of the most recent assessment by agency staff. It is not intended or suggested that a new assessment be conducted for the purpose of answering these questions.

21. At the time of the most recent assessment, how well did this client see (with corrective lenses if the client usually wore them)? [CIRCLE ONE CODE]

1 **Normal vision.** (Sees adequately in most situations; can see newsprint, public notices, televisions, medications, etc.)

2 **Partially impaired.** (Cannot see newsprint or public notices or television or medications labels, but can see obstacles in path, and the surrounding layout; can count figures at arms length.)

3 **Severely impaired.** (Cannot find way around without feeling or using cane; cannot locate objects without hearing or touching them; can tell light from dark.)

4 **Blind, vision completely lost.** (No vision at all; cannot tell light from dark.)

22. At the time of the most recent assessment, how well did this client hear (with hearing aids if the client usually wore them)? [CIRCLE ONE CODE]

1 **Normal hearing.** (Hears adequately in most situations; can carry on an unrestricted conversation or otherwise responds appropriately without speaker raising voice or altering normal pace and style of diction, in groups as well as one-to-one.)

2 **Partially impaired.** (Hears adequately only in special situations, such as one-to-one conversations; with firm, clear diction; or with raised volume on radio, television, etc.)

3 **Severely impaired.** (Hears with difficulty even in special situations, such that conversation is restricted; there are many misunderstandings; or there is frequent failure to respond.)

4 **Deaf, hearing completely lost.** (No hearing at all that is useful for conversation.)

23. At the time of the most recent assessment, did this client require help or supervision in carrying out the daily activities liste in the table below? If this client does not do an activity because of a physical or mental health problem, circle code 4 for th item. [CIRCLE ONE CODE FOR EACH ACTIVITY]

At the time of the most recent assessment did the client require help or supervision:	Yes Help	Yes Supervision	No	Does not do
a. Bathing or showering	1	2	3	4
b. Dressing	1	2	3	4
c. Eating	1	2	3	4
d. Transferring in or out of beds or chairs	1	2	3	4
e. Walking	1	2	3	4
f. Using the toilet room	1	2	3	4

24. At the time of the most recent assessment, did this client have an ostomy? [CIRCLE ONE CODE]

1 Yes

2 No → SKIP TO QUESTION 26

25. Did the client require any assistance from another person in caring for this device?

1 Yes

2 No

26. What was the date of the assessment used to answer the questions on this client's functional capabilities?

Date of assessment:

|__|__| |__|__| |1|9|__|__|
month day year

27. At the time of the most recent assessment, did this client have any difficulty in controlling his/her bowels?

1 Yes

2 No

28. At the time of the most recent assessment, did this client have an indwelling catheter or similar device?

1 Yes

2 No → SKIP TO QUESTION 30

29. Did the client require any assistance from another person in caring for this device?

1 Yes

2 No → SKIP TO QUESTION 31

30. At the time of the most recent assessment, did this client have any difficulty in controlling his/her bladder?

1 Yes

2 No

31. At the time of the most recent assessment, did this client require help or supervision in carrying out the daily activities listed in the table below? If this client does not do an activity because of a physical or mental health problem, circle code 4 for that item. [CIRCLE ONE CODE FOR EACH ACTIVITY]

At the time of the most recent assessment did the client require help or supervision:	Yes Actual Help	Yes Supervision Only	No	Does not do
a. Doing light housework	1	2	3	4
b. Handling money	1	2	3	4
c. Shopping for groceries or clothes	1	2	3	4
d. Using the telephone (dialing or receiving calls)	1	2	3	4
e. Preparing meals	1	2	3	4
f. Taking medication	1	2	3	4

32. At the time of the most recent assessment, did the client display any of the following types of behavior problems: disrobing/ exposing oneself; screaming; being physically abusive to self or others; stealing; getting lost or wandering into unacceptable places; being unable to avoid simple dangers; or other behavioral problems? (Assess the client's behavior with medications if they are customarily taken.)

1 Yes

2 No

33. Is the client disoriented or memory impaired to such a degree that he/she was impaired nearly every day in performing the basic activities of daily living, mobility and adaptive tasks? For example, is he/she unable to remember dates or times; unable to identify familiar locations or people; unable to recall important aspects of recent events; unable to make straightforward judgments; or other cognitive problems?

1 Yes

2 No

34. At the time of the most recent assessment, did the client display any psychiatric symptoms to such a degree that he/she was distressed or restricted in functioning nearly every day? For example, did he/she have delusions (beliefs not keeping with reality); have hallucinations (seeing or hearing things that are not there); threaten or talk about suicide; act depressed, unresponsive, or withdrawn; have extreme anxiety; lack trust in other people; or have other psychiatric problems?

1 Yes

2 No

35. What were this client's primary presenting and other diagnoses at the time of enrollment with your agency? (If this client has been enrolled with this agency more than one time, please specify the diagnoses at the time of the most recent enrollment.)

	Office Use Only	
	ICD9	E/V code
Primary presenting diagnosis: a. _____		
Other diagnoses: b. _____		
c. _____		
d. _____		
e. _____		
f. _____		
g. _____		

X35. Where did you obtain the information used to answer questions 21 through 35?

1 Primary client record
2 Supplementary record
3 Your personal knowledge
4 Consulted another person

36. During the last billing month, which of the following services were provided to this client by your agency? [CIRCLE ONE CODE FOR EACH TYPE OF SERVICE]

Type of Service	Provided	Not provided
a. Personal care	1	2
b. Nursing services	1	2
c. Physician services	1	2
d. Other medical services	1	2
e. Mental health services	1	2
f. Social services	1	2
g. Physical therapy	1	2
h. Occupational therapy	1	2
i. Speech and hearing therapy	1	2
j. Vocational rehabilitation	1	2
k. Special education	1	2
l. Nutritionist services	1	2
m. Sheltered employment	1	2
n. Homemaker-household services	1	2
o. Transportation	1	2
p. Meals on wheels	1	2
q. Recreational services	1	2
r. Housing services	1	2
s. Protective oversight services	1	2
t. Medication	1	2
u. Other services [SPECIFY] _____ _____ _____	1	2

37. During the last billing month, how many visits did your agency make to this client? [INCLUDE BOTH VISITS MADE BY AGENCY STAFF AND VISITS PROVIDED THROUGH CONTRACT SERVICES.]

Number of Visits _____

38. In the table below, please indicate all sources who have paid or are expected to pay for this client's most recent month o care by your agency. Then enter the amount billed for that month of care by each of the payment sources.

Sources	Source of payment for this client? Yes	Source of payment for this client? No	Amount billed for most recent month of care
a. Private insurance	1	2	$_____
b. Own income, family support,retirement funds, Social Security, etc.	1	2	$_____
c. Medicare	1	2	$_____
d. Medicaid	1	2	$_____
e. Religious organizations, foundations or volunteer agencies	1	2	$_____
f. No charge made for care	1	2	$_____
g. Other	1	2	
SPECIFY: _____			$_____
_____			$_____
_____			$_____
_____			$_____
_____			$_____

39. Is this client's care paid by the Medicare special hospice benefit, or by a private insurance company's hospice benefit or neither? [CIRCLE ONE CODE]

1 Paid by Medicare special hospice benefit

2 Paid by private insurance hospice benefit

3 Not paid by Medicare special hospice benefit
or by private insurance hospice benefit

40. During this client's most recent enrollment with your agency, how many days of respite care did s/he receive in an inpatient unit of a hospice, nursing home, or hospital?

a. Number of respite days in hospice:_____

b. Number of respite days in nursing home:_____

c. Number of respite days in a hospital:_____

X40. Where did you obtain the information used to answer questions 36 through 40?
1 Primary client record
2 Supplementary record
3 Your personal knowledge
4 Consulted another person

---

41. Date Client Questionnaire completed:

_____/_____/19_____
month day year

42. Respondent's Name: _____

Respondent's Title: _____

Respondent's Phone Number: |__|__|__| |__|__|__| |__|__|__|__|

The National Center for Health Statistics along with Westat would like to
thank you for your time and participation in this survey.
We really appreciate your cooperation.

OMB#: 0920-0236
Expiration Date: nn/nn/nn

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control
National Center for Health Statistics

Date: |_|_| - |_|_| - |_|_|
Month Day Year

Start Time: _____ am/pm

End Time: _____ am/pm

FEASIBILITY OF SURVEYING HOSPICES AND HOME CARE AGENCIES

CURRENT CLIENT LISTING FORM

NOTICE Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated in this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

A. AGENCY MINI LABEL

B. INTERVIEWER NAME _____

C. Sheet 1 of ___ Sheets

1. LINE #	2. CLIENT IDENTIFIER	3. ENROLLMENT DATE (MM/DD/YY)

Sheet ____ of ____ Sheets

CURRENT CLIENT LISTING FORM - CONTINUED

1. LINE #	2. CLIENT IDENTIFIER	3. ENROLLMENT DATE (MM/DD/YY)

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control
National Center for Health Statistics

OMB#: 0920-0236
Expiration Date: 01/01/92

Date: |_|_| - |_|_| - |_|_|
Month Day Year

Start Time: _____ am/pm

End Time: _____ am/pm

FEASIBILITY OF SURVEYING HOSPICES AND HOME CARE AGENCIES

DISCHARGED CLIENT LISTING FORM

NOTICE Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated in this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

A. AGENCY MINI LABEL

B. INTERVIEWER NAME _____

C. Sheet 1 of ___ Sheets

1. LINE #	2. CLIENT IDENTIFIER	3. DISCHARGE DATE (MM/DD/YY)

Sheet ____ of ____ Sheets

DISCHARGED CLIENT LISTING FORM - CONTINUED

1. LINE #	2. CLIENT IDENTIFIER	3. DISCHARGE DATE (MM/DD/YY)

Appendix IV
Letters, data collection instruments, and sample selection tables for the Pretest for the National Home and Hospice Care Survey

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control

National Center for Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782

Dear Administrator:

The National Center for Health Statistics (NCHS), one of the Centers for Disease Control, collects and provides information on the health of the Nation and the utilization of its health resources. As part of this continuing program, the NCHS is conducting a pretest for the National Home and Hospice Care Survey. This survey is authorized under section 306 (42 USC 242K) of the Public Health Service Act.

The purpose of the pretest is to test a data collection plan and data collection instruments to be used in conducting a National Home and Hospice Care Survey. The ultimate goal of the larger survey is to provide a more complete information base on available long-term care services and utilization of those services.

The pretest includes a small sample of hospices and home health agencies. Information about your facility will be collected through a personal interview that should take no longer than 15 minutes of your time. In addition, time involving some of your staff will be required to complete interviews for a small sample of patients. No patients will be contacted at any time. Although your participation is voluntary and there are no penalties for refusing to answer any questions, it is essential that we obtain data from all sample facilities to evaluate the data collection procedures and questionnaires.

I want to emphasize that the information you and your staff supply will be used only by the National Center for Health Statistics. In accordance with Section 308(d) (42 USC 242m) of the Public Health Service Act, no information collected in this survey may be used for any purpose other than the purpose for which it was collected. Such information may not be published or released in any form if the individual or establishment is identifiable unless the individual or establishment has consented to its release.

Within the next few days, a field representative will contact you for an appointment. This person will be with the Bureau of the Census, the agency under contract to conduct this survey. I greatly appreciate your cooperation in this survey.

Sincerely yours,

MANNING FEINLEIB, M.D., Dr. P.H.
Director, National Center for Health Statistics

HHCS-10(L)X (3-1-91)

HOW WAS THIS FACILITY CHOSEN?

A sample of hospices and home health facilities was chosen from a list to represent similar facilities in the United States. Since each represents several others, it's full participation is very important to the outcome of this pretest.

WHAT ARE YOU GOING TO DO WITH THE RESULTS OF THE PRETEST?

Because this is a pretest, the data will be used to evaluate questionnaire content for the National survey that will include a much larger number of hospices and home health facilities. These data will not be used for publication.

Information on hospices and home health facility providers and the populations they serve is needed by policymakers for assessing the availability of and need for hospice and home health services. Data from the National survey could assist policymakers in determining where and by whom these types of care are needed as well as identifying who is already receiving hospice or home care. Eventually these data could be used to identify any increased demand for hospice and home care services which could tax the ability of social service facilities to meet the needs of the terminally and chronically ill.

WE'VE ALREADY PROVIDED SIMILAR INFORMATION.

The information we are collecting in this survey may be similar to what you have provided in other surveys, but it is not identical. For this pretest to be worthwhile, we have to collect the same information from all participating facilities in exactly the same way. So using information collected for other purposes would not meet our needs for comparability of method and completeness of data.

WE'RE TOO BUSY AND DON'T HAVE ENOUGH STAFF.

We can work around the schedule and availability of your staff. We know they are busy. We can interview any staff member who is knowledgeable about the patient records. Eventually your help will increase the visability of hospice and home health facilities and their essential contribution to the care and comfort of patients and their families.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control

National Center for Health Statistic
6525 Belcrest Road
Hyattsville, MD 20782

Thank you

I want to personally thank you for participating in the pretest for the National Home and Hospice Care Survey and for assisting the field representative from the Bureau of the Census, who conducted the pretest in your facility. It is only through the cooperation of administrators like yourself that we are able to conduct a survey such as this one. The experience we gain from this pretest will be invaluable in helping us to collect data to support effective treatment of long-term health problems.

Again, I appreciate the time and effort you have given in support of this survey.

Sincerely yours,

M Feinleib

MANNING FEINLEIB, M.D., Dr. P.H.
Director, National Center for Health Statistics

FORM **HHCS-1(X)**
(3-1-91)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

FACILITY QUESTIONNAIRE

NATIONAL HOME AND HOSPICE CARE SURVEY

PRETEST

NOTICE — Public reporting burden for this collection of information is estimated to average 15 minutes per response. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to PHS Reports Clearance Officer; ATTN: PRA; Hubert H. Humphrey Bldg., Rm 721-B; 200 Independence Ave., SW; Washington, DC 20201, and to the Office of Management and Budget; Paperwork Reduction Project (0920-0283); Washington, DC 20503. Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308d of the Public Health Service Act (42 USC 242m).

Section A — ARRANGING THE ADMINISTRATOR APPOINTMENT

1. Facility telephone number

2. Administrator name

3. Record of calls

Day (a)	Date (b)	Time (c)	Notes (d)
		a.m. p.m.	
		a.m. p.m.	
		a.m. p.m.	

4. INTRODUCTION

Good morning (afternoon). My name is . . . . I'm from the Bureau of the Census. We are currently conducting the National Home and Hospice Care Survey pretest for the National Center for Health Statistics of the Centers for Disease Control. We are studying home health agencies and hospices and their patients. You should have received a letter from Dr. Manning Feinleib, the Director of the National Center for Health Statistics, which describes this project. Have you received this letter?

☐ Yes — *SKIP to Item 6, NAME VERIFICATION.*

☐ No — *Continue with Item 5, SURVEY EXPLANATION.*

5. SURVEY EXPLANATION

If administrator wants a copy of the letter, explain that you will bring a copy when you visit the facility.

I'm sorry that you did not receive the letter. Let me briefly outline its contents.

The National Home and Hospice Care Survey is authorized under Section 306 of the Public Health Service Act to collect baseline information about home and hospice care facilities, their services, and patients. The statistics compiled from the data will be used to support research for effective treatment of long-term health problems and to study utilization of hospice and home care facilities and the efficient use of the Nation's health care resources.

The purpose of this pretest is to test the data collection plan and data collection instruments that will be used in conducting the National Home and Hospice Care Survey. All information which would permit identification of the individual patient or facility will be held in strict confidence, will be used ONLY by persons involved in the survey and only for the purposes of the survey, and will not be disclosed or released to others for any purpose.

The pretest includes a small sample of hospices and home health agencies. Although your participation is voluntary and there are no penalties for refusing to answer any questions, it is essential that we obtain data from all sample facilities to evaluate the data collection procedures and questionnaires.

Continue with Item 6, NAME VERIFICATION.

6. NAME VERIFICATION

I would like to verify some information from my records. Is *(Name of facility on label)* **the correct name of your facility?**

☐ Yes — *Go to Item 7, ADDRESS VERIFICATION.*

☐ No — *Enter correct facility name below.* →

7. ADDRESS VERIFICATION

Is *(Address of facility on label)* **the correct address?**

☐ Yes — *Go to Item 8 — SET APPOINTMENT.*

☐ No — *Enter correct facility address below.* →

Number	Street	P.O. Box, Route, etc.
City or town		County
State		ZIP Code

8. SET APPOINTMENT

I would like to arrange a morning appointment at your convenience to conduct the survey. What would be a convenient date and time to visit your facility?

Day	Date	Time	
			a.m. p.m.

9. FIELD REPRESENTATIVE CONTACT

I would like to give you my telephone number and that of my supervisor in the event that you need to contact me prior to my visit. If you can't reach me, you can leave a message with my supervisor. My name is *(name)***. My number is** *(Number)***. My supervisor's name is** *(name)***. My supervisor's number is** *(Number)***.**

Thank you very much for your time. I will see you at *(Time)* **on** *(Date)***. Good-bye.**

Section B — RECORD OF INTERVIEW

1. STATUS OF INTERVIEW — *Mark (X) appropriate box.*

01 ☐ Complete interview
02 ☐ Partial interview
03 ☐ Refusal
04 ☐ Not a Hospice/Home Health Agency
05 ☐ No longer operating
06 ☐ Temporarily closed
07 ☐ Not yet in operation
08 ☐ Unable to locate
09 ☐ Other noninterview — *Specify* _____

2. RO number

3. Field Representative
Name | Code

4. Date of interview
Month | Day | Year

NOTES

Section C — QUESTIONS ABOUT THE FACILITY

Before I begin the interview, I'd like to take a moment to explain the purpose of the survey. I believe you (received/did not receive) the letter from the National Center for Health Statistics.

If administrator did not receive the letter, hand him/her a copy. Allow him/her to read it through briefly.

As it says in the letter, the purpose of this survey is to test a data collection plan and data collection instruments to be used in conducting a National Home and Hospice Care Survey. The ultimate goal of the larger survey is to provide a more complete information base on available long-term care services and utilization of those services. The information you provide is confidential and will be used only by persons involved in the survey and only for the purposes of the survey.

1a. Is the PRIMARY service category of this facility a home health agency or a hospice?

Mark (X) only ONE box.

- 01 ☐ Home Health Agency — *SKIP to item 2*
- 02 ☐ Hospice — *SKIP to item 2*
- 03 ☐ Both Hospice and Home Health are equal — *SKIP to item 1b*
- 04 ☐ Neither — *Go to Check Item A*

CHECK ITEM A

THIS FACILITY IS OUT-OF-SCOPE FOR THE SURVEY

Probe as necessary to determine the facility's primary function, the service(s) they now provide (if any) and any other information describing the status of this facility. Explain in detail.

Thank the respondent and END THE INTERVIEW. Fill Section B on the front of the form.

1b. During the last 30 days, what was the number of hospice patients served by this facility?

_____ Number

00 ☐ None

c. During the last 30 days, what was the number of home health patients served by this facility?

_____ Number

00 ☐ None

2. What is the name, title, and telephone number of the person who has the day-to-day responsibility for administering or directing this facility?

Administrator name

Title

Area code Number

3a. *HAND FLASHCARD 1*

What is the type of ownership of this facility as shown on this card?

Mark (X) only ONE box.

- 01 ☐ FOR PROFIT — Includes individual or private, partnership, corporation.
- 02 ☐ NONPROFIT — Includes church-related, nonprofit corporation, other nonprofit ownership
- 03 ☐ STATE OR LOCAL GOVERNMENT — Includes State, county, city, city-county, hospital district or authority
- 04 ☐ FEDERAL GOVERNMENT — Includes USPHS, Armed Forces, Veterans Administration
- 05 ☐ Other — *Specify*

b. Is this facility operated by a hospital?

- 01 ☐ Yes
- 02 ☐ No

c. Is this facility operated by a nursing home?

- 01 ☐ Yes
- 02 ☐ No

CHECK ITEM B *Refer to item 3a.*

- 01 ☐ If one of boxes 01, 02, or 05 is marked — *Go to item 3d*
- 02 ☐ If none of boxes 01, 02, or 05 are marked — *SKIP to item 4*

3d. Is *(Name of facility)* **a member of a group of facilities operating under one general authority or general ownership?**

- 01 ☐ Yes — *Continue with item 3e*
- 02 ☐ No — *SKIP to item 4*

e. What is the name of the parent organization?

Parent organization

4. Is this facility certified under Medicare?

- 01 ☐ Yes
- 02 ☐ No
- 03 ☐ Certification pending

5. Is this facility certified under Medicaid?

- 01 ☐ Yes
- 02 ☐ No
- 03 ☐ Certification pending

6a. Does this facility provide bereavement care to the families of the patients you serve?

- 01 ☐ Yes
- 02 ☐ No

b. Does this facility provide pastoral care?

- 01 ☐ Yes
- 02 ☐ No

7. How many persons served your facility as volunteers during the last 7 days?	_____ Number 00 ☐ None
CHECK ITEM C *Refer to item 2, on page 2.*	01 ☐ Respondent is the person listed — *SKIP to item 9a* 02 ☐ Respondent is NOT the person listed — *Go to item 8*
8. What is your name, title, and telephone number?	Respondent name Title Area code Number
9a. I need to list all current patients from which I will draw a sample of no more than 5 persons. From whom shall I obtain the list of current patients?	Name Title
I will need these patients' medical records and the cooperation of a staff member best acquainted with these patients in order to obtain the information on this questionnaire. *Hand the administrator a copy of the current patient questionnaire. Allow him/her to examine it briefly. Retrieve the questionnaire and continue reading.* **I will not be contacting or interviewing the patients in any way. I will depend on your staff to consult the medical records.** **b. Would** *(person named in item 9a)* **know which staff member I should interview for those patients selected for the sample?**	01 ☐ Yes — *Go to item 10a* 02 ☐ No — *Determine which staff member would have this knowledge and enter the name and title below.* Name Title
10a. I also need to list all patients discharged alive or deceased during the last year. From the list I will sample no more than 5 discharges. From whom should I obtain the list of discharges?	Name Title
I will need the help of a staff person familiar with the discharge records to aid me in completing the information requested in this questionnaire. *Hand the administrator a copy of the discharged patient questionnaire. Allow him/her to examine if briefly. Retrieve the questionnaire and continue reading.* **b. Would** *(person listed in item 10a)* **know which staff member I should interview for those discharges that fall into the sample?**	01 ☐ Yes — *Go to item 11 below* 02 ☐ No — *Determine which staff member would have this knowledge and enter the name and title below.* Name Title
HAND FORM 1A(X) **11a. I also need this information about your staff. From whom shall I obtain this information?**	Name Title
b. At this time, could you introduce me to (this/those) person(s)?	

NOTES

12. *HAND FORM HHCS-1A(X).* *Please provide the information requested about the number of employees and services provided for each type of employee listed, even if the answer is zero.*	Number of full-time staff (35 + hours per week) on your payroll (a)	Number of full-time budgeted positions that are vacant (b)	Number of part-time staff (less than 35 hours per week) on your payroll (c)	Number of part-time budgeted positions that are vacant (d)	Total hours worked by all full-time and part-time staff on your payroll in the last 7 days (e)	Total hours of service provided by staff not on your payroll in the last 7 days. For example, temporary employment services, visiting nurses services, or any other service contracts (f)	Total number of visits in the last 7 days by payroll and nonpayroll staff (g)
Physicians							
Registered nurses							
Licensed practical or vocational nurses							
Nursing aides and attendants							
Home health aides							
Homemakers/personal caretakers							
Dieticians/nutritionists							
Occupational therapists							
Speech pathologists and audiologists							
Physical therapists							
Social workers							
Health educators							
Other health care providers — *Specify*							

FORM HHCS-1(X) (3-1-91)

OMB No. 0920-0283: Approval Expires 03/31/92

FORM **HHCS-1A(X)** (5-29-91) U.S. DEPARTMENT OF COMMERCE BUREAU OF THE CENSUS

FACILITY STAFF WORKSHEET
NATIONAL HOME AND HOSPICE CARE SURVEY
PRETEST

1. Facility name

2. Control number

For each category listed below, enter the information requested about the staff of this facility. Enter zero if appropriate.

	Number of full-time staff (35+ hours per week) on your payroll (a)	Number of full-time budgeted positions that are vacant (b)	Number of part-time staff (less than 35 hours per week) on your payroll (c)	Number of part-time budgeted positions that are vacant (d)	Total hours worked by all full-time and part-time staff on your payroll in the last 7 days (e)	Total hours of service provided by staff not on your payroll in the last 7 days. For example, temporary employment services, visiting nurses services, or any other service contracts (f)	Total number of visits in the last 7 days by payroll and nonpayroll staff (g)
Physicians							
Registered nurses							
Licensed practical or vocational nurses							
Nursing aides and attendants							
Home health aides							
Homemakers/personal caretakers							
Dieticians/nutritionists							
Occupational therapists							
Speech pathologists and audiologists							
Physical therapists							
Social workers							
Health educators							
Other health care providers — *Specify* 7							

OMB No. 0920-0283: Approval Expires 03/31/92

FORM **HHCS-2(X)**
(3-1-91)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

CURRENT PATIENT SAMPLING LIST

NATIONAL HOME AND HOSPICE CARE SURVEY

PRETEST

1.RO number	2.Field representative name	Code	3.Date of listing

4.Respondent name	5.Respondent title

READ INTRODUCTION —

In order to obtain national data about the patients of hospices and home health agencies such as this one, we are collecting information about a sample of current patients. This information and the list of names you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey. Please give me the names of all current patients; that is all patients on the rolls of this facility as of midnight last night, so that I may select the sample.

FOLLOW THE STEPS BELOW TO LIST CURRENT PATIENTS —

STEP 1. Start listing the patients on line number 1 on page 3 of this form. List the patients consecutively in the order in which they are given to you. Be sure to complete the "Page of Page" item. If patient names are not used, explain the type of identifier used. . . . . Type of identifier used

NOTE — If the facility supplies an appropriate list that you can use, do not transcribe the information onto the sampling list(s). If you can keep this list, attach it to this form; write the control number and facility name on each page of the list. In either case, number the patients on the provided list; and go to step 2.

STEP 2. Review the list. Verify that all eligible patients have been listed. Delete any duplicate entries and any patients that do not meet the definition of a current patient. Renumber the lines if you delete any names.

STEP 3. Enter the total number of patients listed. . . . . Number

STEP 4. Look at Form HHCS-30(X), Sample Selection Tables. Find the number in the column labeled "Total number listed" that matches the total number of patients listed.

STEP 5. Circle the line numbers on the listing sheets that correspond to those in the columns labeled "Sample line numbers."

STEP 6. Enter the amount of circled line numbers on the listing sheets. . . . . Number

STEP 7. The current patients to be sampled are those listed on lines with a circled line number. Enter the name or other identifier and line number of each sampled patient in section B of a Form HHCS-3(X), Current Patient Questionnaire.

STEP 8. Make sure you complete all information on the front of this form. Use the notes section on page 2 to describe the types of files you used and any problems you encountered in using these files to prepare the list. This information will help us properly train FRs for the survey.

GO TO FORM HHCS-3(X)

CURRENT PATIENT SAMPLING LIST

Line number (a)	Patient name (or other identifier) (b)
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	
11	
12	
13	
14	
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OMB No. 0920-0283: Approval Expires 03/31/92

FORM **HHCS-4(X)**
(3-1-91)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

DISCHARGED PATIENT SAMPLING LIST

NATIONAL HOME AND HOSPICE CARE SURVEY

PRETEST

1.RO number	2.Field representative name	Code	3.Date of listing

4.Respondent name	5.Respondent title

READ INTRODUCTION —

In order to obtain national data about discharged patients of hospices and home health agencies such as this one, we are collecting information about a sample of discharges. This information and the list of names you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey. Please give me the names of all patients discharged alive or deceased between *(See page 2 for reference period).* **If any patient was discharged more than once during the reference period, give me their name and the discharge date for EACH time they were discharged. Be sure to include the name and discharge date for patients currently being served by your facility who were also discharged between** *(First and last day of reference period),* **so that I may select the sample.**

FOLLOW THE STEPS BELOW TO LIST DISCHARGED PATIENTS —

STEP 1. Start listing the patients on line number 1 on page 3 of this form. List the patients consecutively in the order in which they are given to you. Be sure to complete the "Page of Page" item. If patient names are not used, explain the type of identifier used. . . . . Type of identifier used

NOTE — If the facility supplies an appropriate list that you can use, do not transcribe the information onto the sampling list(s). If you can keep this list, attach it to this form; write the control number and facility name on each page of the list. In either case, number the discharges on the provided list; and go to step 2.

STEP 2. Review the list. Verify that all eligible discharges have been listed. Delete any duplicate discharges and any discharge that does not fall into the reference period. If both the patient name and date of discharge are the same, probe to determine if it is a duplicate entry. Renumber the lines if you delete any names.

STEP 3. Enter the total number of discharges listed. . . . . Number

STEP 4. Look at Form HHCS-30(X), Sample Selection Tables. Find the number in the column labeled "Total number listed" that matches the total number of discharges listed.

STEP 5. Circle the line numbers on the listing sheets that correspond to those in the columns labeled "Sample line numbers."

STEP 6. Enter the amount of circled line numbers on the listing sheets. . . . . Number

STEP 7. The discharged patients to be sampled are those listed on lines with a circled line number. Enter the name or other identifier, line number, and discharge date of each sampled patient in section B of a form HHCS-5(X), Discharged Patient Questionnaire.

STEP 8. Make sure you complete all information on the front of this form. Use the notes section on page 2 to describe the types of files you used and any problems you encountered in using these files to prepare the list. This information will help us properly train FRs for the survey.

GO TO FORM HHCS-5(X)

LIST OF REFERENCE PERIODS FOR DISCHARGED PATIENTS

Date of interview	Discharged	
August 26	from August 26, 1990	through midnight August 25, 1991
August 27	from August 27, 1990	through midnight August 26, 1991
August 28	from August 28, 1990	through midnight August 27, 1991
August 29	from August 29, 1990	through midnight August 28, 1991
August 30	from August 30, 1990	through midnight August 29, 1991
August 31	from August 31, 1990	through midnight August 30, 1991
September 1	from September 1, 1990	through midnight August 31, 1991
September 2	from September 2, 1990	through midnight September 1, 1991
September 3	from September 3, 1990	through midnight September 2, 1991
September 4	from September 4, 1990	through midnight September 3, 1991
September 5	from September 5, 1990	through midnight September 4, 1991
September 6	from September 6, 1990	through midnight September 5, 1991
September 7	from September 7, 1990	through midnight September 6, 1991
September 8	from September 8, 1990	through midnight September 7, 1991
September 9	from September 9, 1990	through midnight September 8, 1991
September 10	from September 10, 1990	through midnight September 9, 1991
September 11	from September 11, 1990	through midnight September 10, 1991
September 12	from September 12, 1990	through midnight September 11, 1991
September 13	from September 13, 1990	through midnight September 12, 1991
September 14	from September 14, 1990	through midnight September 13, 1991
September 15	from September 15, 1990	through midnight September 14, 1991
September 16	from September 16, 1990	through midnight September 15, 1991
September 17	from September 17, 1990	through midnight September 16, 1991
September 18	from September 18, 1990	through midnight September 17, 1991
September 19	from September 19, 1990	through midnight September 18, 1991
September 20	from September 20, 1990	through midnight September 19, 1991

NOTES

DISCHARGED PATIENT SAMPLING LIST

Line number (a)	Patient name (or other identifier) (b)	Discharge date *(Month/Day/Year)* (c)
01		
02		
03		
04		
05		
06		
07		
08		
09		
10		
11		
12		
13		
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FORM HHCS-6(X) (3-1-91) U.S. DEPARTMENT OF COMMERCE BUREAU OF THE CENSUS

SAMPLING LIST (Continued)

PRETEST

A. Control number

B. Facility name

C. Sampling list type *Mark (X) one*

☐ Current patient *(Do not complete column (c)*

☐ Discharged patient

IMPORTANT — Add appropriate first digit to preprinted line numbers.

Line number (a)	Patient name (or other identifier) (b)	Discharge date *(Month/Day/Year)* (c)
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FORM **HHCS-3(X)**
(3-1-91)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

CURRENT PATIENT QUESTIONNAIRE

NATIONAL HOME AND HOSPICE CARE SURVEY

PRETEST

Section A — ADMINISTRATIVE INFORMATION

1. RO	2. Field representative name	3. FR code

Section B — PATIENT INFORMATION

1. Facility name	2. Control number	3. Patient line number

4. Patient name First	M.I.	Last	5. Date of interview Month/Day/Year
			/ /

Section C — RESPONDENT INFORMATION

1a. Respondent name

b. Title

c. Provided answers for items ☐ to ☐

2a. Respondent name

b. Title

c. Provided answers for items ☐ to ☐

Section D — STATUS OF INTERVIEW

01 ☐ Complete
02 ☐ Partial
03 ☐ Refused
04 ☐ Unable to locate record
05 ☐ Assessment only/Not admitted
06 ☐ Other noninterview — *Specify* _____

NOTES

Read to each new respondent.

In order to obtain national level data about the patients of hospices and home health agencies such as this one, we are collecting information about a sample of current patients. I will be asking questions about the background, health status, treatment, social contacts, and billing information for each sampled patient.

The information you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey.

In answering these questions, it is especially important to locate the information in the patient's medical record. Do you have the medical file(s) and record(s) for *(Read name(s) of selected current patient(s))*?

If not, ask the respondent to get it/them prior to beginning the interview. Fill sections A and B on the front of the five current patient forms while the respondent gets the records. If no record is available for a patient, try to obtain as much information as possible from whatever administrative records are available and/or from the respondent's memory.

1. What is . . .'s sex?

01 ☐ Male
02 ☐ Female

2. What is . . .'s date of birth?

Month ☐☐ Day ☐☐ Year ☐☐☐☐ OR Age (at admission) ☐☐☐

Hand Flashcard 3.

3a. Which of these best describes . . .'s race?

Mark (X) only one box.

01 ☐ White
02 ☐ Black
03 ☐ American Indian, Eskimo, Aleut
04 ☐ Asian, Pacific Islander
05 ☐ Other — *Specify* _____
99 ☐ Don't know

b. Is . . . of Hispanic origin?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

4. What is . . .'s current marital status?

Mark (X) only one box.

01 ☐ Married
02 ☐ Widowed
03 ☐ Divorced
04 ☐ Separated
05 ☐ Never married
99 ☐ Don't know

Read the introductory paragraph for the Social Security Number only once for each respondent.

As part of this survey, we would like to have . . .'s Social Security Number. Provision of this number is voluntary and not providing the number will have no effect in any way on . . .'s benefits. This number will be useful in conducting future followup studies. It will be used to match against the vital statistics records maintained by the National Center for Health Statistics. This information is collected under the authority of Section 306 of the Public Health Service Act.

5. What is . . .'s Social Security Number?

If the patient does not have a Social Security Number, obtain whatever Social Security Number is in the record. Mark the box that best describes the Social Security Number entered.

Social Security Number ☐☐☐ – ☐☐ – ☐☐☐☐

01 ☐ Patient's number
02 ☐ Spouse's number
03 ☐ Parent's number
04 ☐ No Social Security Number available
97 ☐ Refused
99 ☐ Don't know

Hand Flashcard 4.

6. Who referred . . . to this facility?

Mark (X) all that apply.

01 ☐ Self/Family
02 ☐ Nursing home
03 ☐ Hospital
04 ☐ Physician
05 ☐ Health department
06 ☐ Social service agency
07 ☐ Other — *Specify* _____
99 ☐ Don't know

7. What was the date of . . .'s most recent admission to this facility, that is, the date on which . . . was admitted for the current episode of care?

Month ☐☐ Day ☐☐ Year ☐☐

00 ☐ Only an assessment was done for this patient (patient was not provided services by this facility)

8a. According to . . .'s medical record, what were the primary and other diagnoses at the time of that (admission/assessment)? Please provide the ICD-9-CM code if one is available.

Probe:
Any other conditions?

	Written form	ICD-9-CM codes if available
Primary: 1	_____	____.__
Others: 2	_____	____.__
3	_____	____.__
4	_____	____.__
5	_____	____.__
6	_____	____.__

CHECK ITEM A — *Refer to item 7.*

01 ☐ Box 00 is NOT marked — *Go to item 8b*
02 ☐ Box 00 is marked — *END THE INTERVIEW. Complete sections C and D on the cover.*

8b. According to . . .'s medical records, what are . . .'s CURRENT primary and other diagnoses? Please provide the ICD-9-CM code if one is available.

Probe:
Any other conditions?

	Written form	ICD-9-CM codes if available
Primary: 1	_____	____.__
Others: 2	_____	____.__
3	_____	____.__
4	_____	____.__
5	_____	____.__
6	_____	____.__

9. Does . . . have any living children?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

10a. Does . . . have a primary caregiver?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 11a*
99 ☐ Don't know }

Hand flashcard 5.

b. What is the relationship of the primary caregiver to . . .?

Mark (X) only one box.

01 ☐ Spouse
02 ☐ Parent
03 ☐ Child
04 ☐ Daughter/son-in-law
05 ☐ Other relative — *Specify* ↴

_____

06 ☐ Neighbor
07 ☐ Friend
08 ☐ Volunteer group
09 ☐ Other — *Specify* ↴

_____

99 ☐ Don't know

Hand flashcard 6.

11a. Where is . . . currently living?

Mark (X) only one box.

01 ☐ Private residence
02 ☐ Rented room, boarding house
03 ☐ Retirement home
04 ☐ Board and care or residential care facility
05 ☐ Hospice inpatient
06 ☐ Other type health facility (including mental health facility) — *SKIP to item 12*
07 ☐ Other — *Specify* ⇒ _____

b. Is . . . living with family members, nonfamily members, both family and nonfamily members, or alone?

01 ☐ With family members
02 ☐ With nonfamily members
03 ☐ With both family members and nonfamily members
04 ☐ Alone — *SKIP to item 12*

CHECK ITEM B *Refer to item 10a*

01 ☐ Either box 02 or 99 is marked — *SKIP to item 12*
02 ☐ Box 01 is marked — *Go to item 11c*

c. Does . . . usually live with (his/her) primary caregiver?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

Read the question below and fill in as many names and addresses as available. Ask the respondent to indicate which contact is the "Best contact" and Mark (X) the box above that name.

12. In order to followup on . . .'s complete history of health care utilization, we would like any information you have that will allow us to locate . . .'s next of kin. Please give me the names, addresses, and telephone numbers of . . .'s next of kin, as well as any other relatives, friends, or anyone else who might know about . . ..

(The sponsor may contact these people in the future to obtain additional information about . . .'s complete history of heath care. No information provided by you will be verified with relatives or friends.)

If more than 3 names and addresses are provided; mark (X) this box ⟶ ☐

Use form HHCS-7(X) to list additional names, addresses, and telephone numbers.

Kin/friend/other

☐ Best contact
First name | Middle initial | Last name
Number | Street name | P.O. box, RR No., etc.
City | State | ZIP Code
Area Code | Telephone number
Relationship to patient

Kin/friend/other

☐ Best contact
First name | Middle initial | Last name
Number | Street name | P.O. box, RR No., etc.
City | State | ZIP Code
Area Code | Telephone number
Relationship to patient

Kin/friend/other

☐ Best contact
First name | Middle initial | Last name
Number | Street name | P.O. box, RR No., etc.
City | State | ZIP Code
Area Code | Telephone number
Relationship to patient

Hand flashcard 7.

13. Which of these aids does . . . currently use?

Mark (X) all that apply.

- 01 ☐ Eye glasses (including contact lenses)
- 02 ☐ Dentures (full or partial)
- 03 ☐ Hearing aid
- 04 ☐ Wheelchair
- 05 ☐ Cane
- 06 ☐ Walker
- 07 ☐ Crutches
- 08 ☐ Brace (any type)
- 09 ☐ Other aids or devices — *Specify* _____
- 10 ☐ No aids used
- 99 ☐ Don't know

14a. Does . . . have any difficulty in seeing (when wearing glasses)?

- 01 ☐ Yes
- 02 ☐ No . . . . . } *SKIP to item 15a*
- 03 ☐ Not applicable (e.g., comatose) } *SKIP to item 15a*
- 99 ☐ Don't know . . . . . } *SKIP to item 15a*

Hand flashcard 8.

b. Is . . .'s sight (when wearing glasses) partially, severely, or completely impaired as defined on this card?

- 01 ☐ Partially impaired
- 02 ☐ Severely impaired
- 03 ☐ Completely lost, blind
- 99 ☐ Don't know

15a. Does . . . have any difficulty in hearing (when wearing a hearing aid)?

- 01 ☐ Yes
- 02 ☐ No . . . . . } *SKIP to item 16*
- 03 ☐ Not applicable (e.g., comatose) } *SKIP to item 16*
- 99 ☐ Don't know . . . . . } *SKIP to item 16*

Hand flashcard 9.

b. Is . . .'s hearing (when wearing a hearing aid) partially, severely, or completely impaired, as defined on this card?

- 01 ☐ Partially impaired
- 02 ☐ Severely impaired
- 03 ☐ Completely lost, deaf
- 99 ☐ Don't know

Hand flashcard 10.

16. Does . . . currently need ANY assistance in any of the following activities as defined on this card — —

Mark (X) one box for each activity.

	Yes needs assistance	No does not need assistance	Unable to do	Doesn't do	Don't know
a. Bathing or showering?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
b. Dressing?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
c. Eating?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
d. Transferring in or out of beds or chairs?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
e. Walking?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
f. Using the toilet room?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐

17a. Does . . . have an ostomy, an indwelling catheter or similar device?

- 01 ☐ Yes
- 02 ☐ No . . . . . } *SKIP to item 18, page 6*
- 99 ☐ Don't know } *SKIP to item 18, page 6*

17b. Does . . . require ANY assistance from another person in caring for this device?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

18. Does . . . currently have any difficulty in controlling (his/her) bowels?

01 ☐ Yes
02 ☐ No
03 ☐ Not applicable (e.g., infant, has an ostomy)
99 ☐ Don't know

If patient has an indwelling catheter or an ostomy, mark box 03 without asking.

19. Does . . . currently have any difficulty in controlling (his/her) bladder?

01 ☐ Yes
02 ☐ No
03 ☐ Not applicable (e.g., infant, has an indwelling catheter or ostomy)
99 ☐ Don't know

Hand flashcard 11.

20. Does . . . receive personal help or supervision in any of the following activities — —

Mark (X) one box for each activity.

	Yes receives help	No does not receive help	Unable to do	Doesn't do	Don't know
a. Doing light housework?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
b. Managing money?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
c. Shopping for groceries or clothes?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
d. Using the telephone (dialing or receiving calls)?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
e. Preparing meals?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
f. Taking medications?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐

Hand flashcard 12.

21a. During the last 30 days, which of these services were provided to . . . by your facility?

Mark (X) all that apply.

01 ☐ Dietary and nutritional services
02 ☐ Occupational therapy/vocational therapy
03 ☐ Speech therapy/audiology
04 ☐ Homemaker/companion services
05 ☐ Meals on wheels
06 ☐ Transportation
07 ☐ Enterostomal therapy
08 ☐ Counseling
09 ☐ Medications
10 ☐ Respite care
11 ☐ High tech care (e.g., IV therapy)
12 ☐ Referral services
13 ☐ Personal care
14 ☐ Skilled nursing services
15 ☐ Physician services
16 ☐ Social services
17 ☐ Physical therapy
18 ☐ Other services — *Specify* _____

Hand flashcard 13.

b. Which of these service providers visited . . . during the last 30 days?

Mark (X) all that apply.

01 ☐ Physicians
02 ☐ Registered nurses
03 ☐ Liscensed practical or vocational nurses
04 ☐ Nursing aides and attendants
05 ☐ Home health aides
06 ☐ Home makers/personal caretakers
07 ☐ Dieticians/nutritionists
08 ☐ Occupational therapists
09 ☐ Speech pathologists and audiologists
10 ☐ Physical therapists
11 ☐ Social workers
12 ☐ Health educators
13 ☐ Other providers — *Specify* _____

22. How many visits were made to . . . during the last 30 days?

_____ Number of visits

00 ☐ None
99 ☐ Don't know

23a. For your most recent billing period, what was the total charge billed for . . .'s care, including all charges for services, drugs and special medical supplies?

$ _____ .00

96 ☐ Was not a patient during most recent billing period — *SKIP to item 24*
00 ☐ No charge was made for care — *END INTERVIEW. Complete sections C and D on the front of this form.*
99 ☐ Don't know — *SKIP to item 24*

b. What time period does this cost refer to?

01 ☐ 1 Day
02 ☐ 1 Week
03 ☐ 1 Month
04 ☐ Other period — *Specify* →

_____

99 ☐ Don't know (not billed yet, etc.)

Hand flashcard 14.

24. What are ALL the (expected) sources of payment (for this bill/when billed)?

Mark (X) all that apply.

01 ☐ Private insurance
02 ☐ Own income, family support, Social Security benefits, retirement funds
03 ☐ Supplemental Security Income (SSI)
04 ☐ Medicare
05 ☐ Medicaid
06 ☐ Other government assistance or welfare
07 ☐ Religious organizations, foundations, agencies
08 ☐ VA contract, pensions, or other VA compensation
09 ☐ Payment source not yet determined
10 ☐ Other — *Specify* →

_____

99 ☐ Don't know

Hand flashcard 14.

25. What was the PRIMARY (expected) source of payment (for this bill/when billed)?

Mark (X) only one box.

01 ☐ Private insurance
02 ☐ Own income, family support, Social Security benefits, retirement funds
03 ☐ Supplemental Security Income (SSI)
04 ☐ Medicare
05 ☐ Medicaid
06 ☐ Other government assistance or welfare
07 ☐ Religious organizations, foundations, agencies
08 ☐ VA contract, pensions, or other VA compensation
09 ☐ Payment source not yet determined
10 ☐ Other — *Specify* →

_____

99 ☐ Don't know

FILL SECTIONS C AND D ON THE COVER OF THIS FORM.

NOTES

OMB No. 0920-0283: Approval Expires 03/31/92

FORM **HHCS-5(X)**
(3-1-91)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

DISCHARGED PATIENT QUESTIONNAIRE

NATIONAL HOME AND HOSPICE CARE SURVEY

PRETEST

Section A — ADMINISTRATIVE INFORMATION

1. RO	2. Field representative name	3. FR code

Section B — PATIENT INFORMATION

1. Facility name	2. Control number	3. Patient line number

4. Patient name First	M.I.	Last	5. Date of interview Month/Day/Year	6. Date of discharge Month/Day/Year
			/ /	/ /

Section C — RESPONDENT INFORMATION

1a. Respondent name

b. Title

c. Provided answers for items ☐ to ☐

2a. Respondent name

b. Title

c. Provided answers for items ☐ to ☐

Section D — STATUS OF INTERVIEW

01 ☐ Complete
02 ☐ Partial
03 ☐ Refused
04 ☐ Unable to locate record
05 ☐ Assessment only/Not admitted
06 ☐ Other noninterview — *Specify* _____

NOTES

Read to each new respondent.

In order to obtain national level data about patients who are discharged from hospices and home health agencies such as this one, we are collecting information about a sample of discharges. I will be asking questions about the background, health status, treatment, social contacts and billing information for each sampled discharge.

The information you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey.

In answering these questions, it is especially important to locate the information in the patient's medical record. Do you have the medical file(s) and record(s) with the details for *(Read name(s) of selected discharged patients)*?

If not, ask the respondent to get it/them prior to beginning the interview. Fill sections A and B on the front of the five discharged patient forms while the respondent gets the records. If no record is available for a patient, try to obtain as much information as possible from whatever administrative records are available and/or from the respondent's memory.

1. What was . . .'s sex?

01 ☐ Male
02 ☐ Female

2. What was . . .'s date of birth?

Month ☐☐ Day ☐☐ Year ☐☐☐☐ OR Age (at admission) ☐☐☐

Hand Flashcard 3.

3a. Which of these best described . . .'s race?

Mark (X) only one box.

01 ☐ White
02 ☐ Black
03 ☐ American Indian, Eskimo, Aleut
04 ☐ Asian, Pacific Islander
05 ☐ Other — *Specify* _____
99 ☐ Don't know

b. Was . . . of Hispanic origin?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

4. What was . . .'s marital status at the time of discharge?

Mark (X) only one box.

01 ☐ Married
02 ☐ Widowed
03 ☐ Divorced
04 ☐ Separated
05 ☐ Never married
99 ☐ Don't know

Read the introductory paragraph for the Social Security Number only once for each respondent.

As part of this survey, we would like to have . . .'s Social Security Number. Provision of this number is voluntary and not providing the number will have no effect in any way on . . .'s benefits. This number will be useful in conducting future followup studies. It will be used to match against the vital statistics records maintained by the National Center for Health Statistics. This information is collected under the authority of Section 306 of the Public Health Service Act.

5. What was . . .'s Social Security Number?

If the patient did not have a Social Security Number, obtain whatever Social Security Number is in the record. Mark the box that best describes the Social Security Number entered.

Social Security Number ☐☐☐ – ☐☐ – ☐☐☐☐

01 ☐ Patient's number
02 ☐ Spouse's number
03 ☐ Parent's number
04 ☐ No Social Security Number available
97 ☐ Refused
99 ☐ Don't know

Hand Flashcard 4.

6. Who referred . . . to this facility?

Mark (X) all that apply.

01 ☐ Self/Family
02 ☐ Nursing home
03 ☐ Hospital
04 ☐ Physician
05 ☐ Health department
06 ☐ Social service agency
07 ☐ Other — *Specify* _____
99 ☐ Don't know

7. What was the date of . . .'s admission for the period of care which ended on *(Date of discharge)*?

Month ☐☐ Day ☐☐ Year ☐☐

00 ☐ Only an assessment was done for this patient (patient was not provided services by this facility)

8a. According to . . .'s medical record, what were the primary and other diagnoses at the time of . . .'s admission that ended with this (discharge/assessment)? Please provide the ICD-9-CM code if one is available.

Probe:
Any other conditions?

	Written form	ICD-9-CM codes if available
Primary: 1	_____	____.__
Others: 2	_____	____.__
3	_____	____.__
4	_____	____.__
5	_____	____.__
6	_____	____.__

CHECK ITEM A *Refer to item 7.*

01 ☐ Box 00 is NOT marked — *Go to item 8b*
02 ☐ Box 00 is marked — *END THE INTERVIEW. Complete sections C and D on the cover.*

8b. According to . . .'s medical records, what were . . .'s primary and other diagnoses at the time of discharge — that is, on *(Date of discharge)*? **Please provide the ICD-9-CM code if one is available.**

Probe:
Any other conditions?

	Written form	ICD-9-CM codes if available
Primary: 1	_____	____.__
Others: 2	_____	____.__
3	_____	____.__
4	_____	____.__
5	_____	____.__
6	_____	____.__

c. Why was . . . discharged?

01 ☐ Recovered
02 ☐ Stabilized
03 ☐ Moved out of district
04 ☐ Deceased
05 ☐ Admitted to hospital inpatient service
06 ☐ Admitted to nursing home
07 ☐ Other — *Specify* _____
99 ☐ Don't know

9. Did . . . have any living children?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

10a. Did . . . have a primary caregiver?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 11a*
99 ☐ Don't know }

Hand flashcard 5.

b. What was the relationship of the primary caregiver to . . .?

Mark (X) only one box.

01 ☐ Spouse
02 ☐ Parent
03 ☐ Child
04 ☐ Daughter/son-in-law
05 ☐ Other relative — *Specify* _____
06 ☐ Neighbor
07 ☐ Friend
08 ☐ Volunteer group
09 ☐ Other — *Specify* _____
99 ☐ Don't know

Hand flashcard 6.

11a. During the episode of care that ended on *(Date of discharge)*, where was . . . living?

Mark (X) only one box.

01 ☐ Private residence
02 ☐ Rented room, boarding house
03 ☐ Retirement home
04 ☐ Board and care or residential care facility
05 ☐ Hospice inpatient
06 ☐ Other type health facility (including mental health facility) — *SKIP to item 12*
07 ☐ Other — *Specify*

_____

b. Was . . . living with family members, nonfamily members, both family and nonfamily members, or alone?

01 ☐ With family members
02 ☐ With nonfamily members
03 ☐ With both family members and nonfamily members
04 ☐ Alone — *SKIP to item 12*

CHECK ITEM B *Refer to item 10a*

01 ☐ Either box 02 or 99 is marked — *SKIP to item 12*
02 ☐ Box 01 is marked — *Go to item 11c*

c. Did . . . usually live with (his/her) primary caregiver?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

Read the question below and fill in as many names and addresses as available. Ask the respondent to indicate which contact is the "Best contact" and Mark (X) the box above that name.

12. In order to followup on . . .'s complete history of health care utilization, we would like any information you have that will allow us to locate . . .'s next of kin. Please give me the names, addresses, and telephone numbers of . . .'s next of kin, as well as any other relatives, friends, or anyone else who might know about . . ..

(The sponsor may contact these people in the future to obtain additional information about . . .'s complete history of heath care. No information provided by you will be verified with relatives or friends.)

If more than 3 names and addresses are provided; mark (X) this box ☐

Use form HHCS-7(X) to list additional names, addresses, and telephone numbers.

Kin/ friend/ other

☐ Best contact
First name | Middle initial | Last name
Number | Street name | P.O. box, RR No., etc.
City | State | ZIP Code
Area Code | Telephone number
Relationship to patient

Kin/ friend/ other

☐ Best contact
First name | Middle initial | Last name
Number | Street name | P.O. box, RR No., etc.
City | State | ZIP Code
Area Code | Telephone number
Relationship to patient

Kin/ friend/ other

☐ Best contact
First name | Middle initial | Last name
Number | Street name | P.O. box, RR No., etc.
City | State | ZIP Code
Area Code | Telephone number
Relationship to patient

For items 13 through 20, use the phrase "AT THE TIME OF DISCHARGE" if the patient was discharged alive. Use the phrase "IMMEDIATELY PRIOR TO DISCHARGE" if the patient was discharged dead.

Hand flashcard 7

13. The following questions refer to the patient's status (at the time of discharge/immediately prior to discharge) on *(Date of discharge).*

(At the time of discharge/immediately prior to discharge), which of these aids did . . . regularly use?

Mark (X) all that apply.

- 01 ☐ Eye glasses (including contact lenses)
- 02 ☐ Dentures (full or partial)
- 03 ☐ Hearing aid
- 04 ☐ Wheelchair
- 05 ☐ Cane
- 06 ☐ Walker
- 07 ☐ Crutches
- 08 ☐ Brace (any type)
- 09 ☐ Other aids or devices — *Specify* _____
- 10 ☐ No aids used
- 99 ☐ Don't know

14a. (At the time of discharge/immediately prior to discharge), did . . . have any difficulty in seeing (when wearing glasses)?

- 01 ☐ Yes
- 02 ☐ No . . . . . } *SKIP to item 15a*
- 03 ☐ Not applicable (e.g., comatose) } *SKIP to item 15a*
- 99 ☐ Don't know . . . . . } *SKIP to item 15a*

Hand flashcard 8.

b. Was . . .'s sight (when wearing glasses) partially, severely, or completely impaired as defined on this card?

- 01 ☐ Partially impaired
- 02 ☐ Severely impaired
- 03 ☐ Completely lost, blind
- 99 ☐ Don't know

15a. (At the time of discharge/immediately prior to discharge), did . . . have any difficulty in hearing (when wearing a hearing aid)?

- 01 ☐ Yes
- 02 ☐ No . . . . . } *SKIP to item 16*
- 03 ☐ Not applicable (e.g., comatose) } *SKIP to item 16*
- 99 ☐ Don't know . . . . . } *SKIP to item 16*

Hand flashcard 9.

b. Was . . .'s hearing (when wearing a hearing aid) partially, severely, or completely impaired, as defined on this card?

- 01 ☐ Partially impaired
- 02 ☐ Severely impaired
- 03 ☐ Completely lost, deaf
- 99 ☐ Don't know

Hand flashcard 10.

16. (At the time of discharge/immediately prior to discharge), did . . . need ANY assistance in any of the following activities as defined on this card — —

Mark (X) one box for each activity.

	Yes needed asssistance	No did not need assistance	Unable to do	Didn't do	Don't know
a. Bathing or showering?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
b. Dressing?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
c. Eating?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
d. Transferring in or out of beds or chairs?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
e. Walking?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
f. Using the toilet room?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐

17a. (At the time of discharge/immediately prior to discharge), did . . . have an ostomy, an indwelling catheter or similar device?

- 01 ☐ Yes
- 02 ☐ No . . . . . } *SKIP to item 18, page 6*
- 03 ☐ Don't know } *SKIP to item 18, page 6*

17b. Did . . . require ANY assistance from another person in caring for this device?	01 ☐ Yes 02 ☐ No 99 ☐ Don't know
18. (At the time of discharge/immediately prior to discharge), did . . . have any difficulty in controlling (his/her) bowels?	01 ☐ Yes 02 ☐ No 03 ☐ Not applicable (e.g., infant, had an ostomy) 99 ☐ Don't know
If patient had an indwelling catheter or an ostomy mark box 03 without asking. **19. (At the time of discharge/immediately prior to discharge), did . . . have any difficulty controlling (his/her) bladder?**	01 ☐ Yes 02 ☐ No 03 ☐ Not applicable (e.g., infant, had an indwelling catheter or ostomy) 99 ☐ Don't know

Hand flashcard 11.

20. (At the time of discharge/immediately prior to discharge), did . . . receive personal help or supervision in any of the following activities — —

Mark (X) one box for each activity.

	Yes received help	No did not receive help	Unable to do	Didn't do	Don't know
a. Doing light housework?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
b. Managing money?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
c. Shopping for groceries or clothes?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
d. Using the telephone (dialing or receiving calls)?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
e. Preparing meals?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐
f. Taking medications?	01 ☐	02 ☐	03 ☐	04 ☐	99 ☐

Hand flashcard 12.

21a. During the 30 days prior to discharge, which of these services were provided to . . . by your facility?

Mark (X) all that apply.

01 ☐ Dietary and nutritional services
02 ☐ Occupational therapy/vocational therapy
03 ☐ Speech therapy/audiology
04 ☐ Homemaker/companion services
05 ☐ Meals on wheels
06 ☐ Transportation
07 ☐ Enterostomal therapy
08 ☐ Counseling
09 ☐ Medications
10 ☐ Respite care
11 ☐ High tech care (e.g., IV therapy)
12 ☐ Referral services
13 ☐ Personal care
14 ☐ Skilled nursing services
15 ☐ Physician services
16 ☐ Social services
17 ☐ Physical therapy
18 ☐ Other services — *Specify* _____

Hand flashcard 13.

b. Which of these service providers visited . . . during the 30 days prior to discharge?

Mark (X) all that apply.

01 ☐ Physicians
02 ☐ Registered nurses
03 ☐ Liscensed practical or vocational nurses
04 ☐ Nursing aides and attendants
05 ☐ Home health aides
06 ☐ Home makers/personal caretakers
07 ☐ Dieticians/nutritionists
08 ☐ Occupational therapists
09 ☐ Speech pathologists and audiologists
10 ☐ Physical therapists
11 ☐ Social workers
12 ☐ Health educators
13 ☐ Other providers — *Specify* _____

22. How many visits were made to . . . during this time — that is, during the 30 days prior to discharge?

_____ Number of visits

00☐ None
99☐ Don't know

23a. For the billing period that included *(Date of discharge)* what was the total charge billed for . . .'s care including all charges made for drugs, services, and special medical supplies?

$ _____ .00

00☐ No charge was made for care — *END INTERVIEW. Complete sections C and D on the front of this form.*
99☐ Don't know — *SKIP to item 24*

b. What time period does this cost refer to?

01☐ 1 Day
02☐ 1 Week
03☐ 1 Month
04☐ Other period — *Specify* →

_____

99☐ Don't know (not billed yet, etc.)

Hand flashcard 14.

24. What were ALL the (expected) sources of payment for the amount billed?

Mark (X) all that apply.

01☐ Private insurance
02☐ Own income, family support, Social Security benefits, retirement funds
03☐ Supplemental Security Income (SSI)
04☐ Medicare
05☐ Medicaid
06☐ Other government assistance or welfare
07☐ Religious organizations, foundations, agencies
08☐ VA contract, pensions, or other VA compensation
09☐ Payment source not yet determined
10☐ Other — *Specify* →

_____

99☐ Don't know

Hand flashcard 14.

25. What was the PRIMARY (expected) source of payment for . . .'s entire episode of care?

Mark (X) only one box.

01☐ Private insurance
02☐ Own income, family support, Social Security benefits, retirement funds
03☐ Supplemental Security Income (SSI)
04☐ Medicare
05☐ Medicaid
06☐ Other government assistance or welfare
07☐ Religious organizations, foundations, agencies
08☐ VA contract, pensions, or other VA compensation
09☐ Payment source not yet determined
10☐ Other — *Specify* →

_____

99☐ Don't know

FILL SECTIONS C AND D ON THE COVER OF THIS FORM.

NOTES

OMB No. 0920-0283: Approval Expires 03/31/92

FORM HHCS-7(X)
(3-1-91)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

CONTINUATION SHEET

For Question 12

NATIONAL HOME AND HOSPICE CARE SURVEY PRETEST

1. SHEET _____ OF _____ SHEETS

2. Type of patient — *Mark (X) one*
   - ☐ Current patient
   - ☐ Discharged patient

3. Facility name

4. Control number

5. Patient name

6. Patient line number

Kin/ friend/ other	☐ Best contact		Kin/ friend/ other	☐ Best contact	
First name	Middle initial	Last name	First name	Middle initial	Last name
Number	Street name	P.O. box, RR No., etc.	Number	Street name	P.O. box, RR No., etc.
City	State	ZIP Code	City	State	ZIP Code
Area Code	Telephone number		Area Code	Telephone number	
Relationship to patient			Relationship to patient		
Kin/ friend/ other	☐ Best contact		Kin/ friend/ other	☐ Best contact	
First name	Middle initial	Last name	First name	Middle initial	Last name
Number	Street name	P.O. box, RR No., etc.	Number	Street name	P.O. box, RR No., etc.
City	State	ZIP Code	City	State	ZIP Code
Area Code	Telephone number		Area Code	Telephone number	
Relationship to patient			Relationship to patient		
Kin/ friend/ other	☐ Best contact		Kin/ friend/ other	☐ Best contact	
First name	Middle initial	Last name	First name	Middle initial	Last name
Number	Street name	P.O. box, RR No., etc.	Number	Street name	P.O. box, RR No., etc.
City	State	ZIP Code	City	State	ZIP Code
Area Code	Telephone number		Area Code	Telephone number	
Relationship to patient			Relationship to patient		

If additional sheets are used, mark (x) this box. → ☐

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

FLASHCARD BOOKLET

NATIONAL HOME AND HOSPICE CARE SURVEY

PRETEST

CARD 1

1. **FOR PROFIT** — includes individual or private, partnership, corporation

2. **NONPROFIT** — includes church-related, nonprofit corporation, other nonprofit ownership

3. **STATE OR LOCAL GOVERNMENT** — includes State, county, city, city-county, hospital district or authority

4. **FEDERAL GOVERNMENT** — includes USPHS, Armed Forces, Veterans Administration

5. **OTHER**

CARD 2

EMPLOYEES ON PAYROLL

Full-time (35 or more hours per week)

Employed
Budgeted vacant positions

Part-time (less than 35 hours per week)

Employed
Budgeted vacant positions

SERVICES PROVIDED DURING THE LAST 7 DAYS

Total hours worked by full-time and part-time staff

Total hours of service provided by those not on your payroll

Total visits made

TYPE OF EMPLOYEE

Physicians

Registered nurses

Licensed practical or vocational nurses

Nursing aides and attendants

Home health aides

Homemakers/personal caretakers

Dieticians/nutritionists

Occupational therapists

Speech pathologists and audiologists

Physical therapists

Social workers

Health educators

Other providers

CARD 3

1. White
2. Black
3. American Indian, Eskimo, Aleut
4. Asian, Pacific Islander

CARD 4

1. Self/Family
2. Nursing home
3. Hospital
4. Physician
5. Health department
6. Social service agency
7. Other

CARD 5

1. Spouse
2. Parent
3. Child
4. Daughter- or son-in-law
5. Other relative
6. Neighbor
7. Friend
8. Volunteer group
9. Other

CARD 6

1. **PRIVATE RESIDENCE** — rented or owned

2. **RENTED ROOM, BOARDING HOUSE** — room or boarding house open to anyone as defined by the landlord for rental payment

3. **RETIREMENT HOME** — a retirement facility that provides room and board to elderly or impaired persons; often includes a separate hospice wing or unit that provides nursing, medical, personal care, etc., to those needing it

4. **BOARD AND CARE OR RESIDENTIAL CARE FACILITY** — a facility having three beds or more and that provides personal care or supervision to its residents, not just room and board (for example, help with bathing, dressing, eating, walking, shopping, or corresponding)

5. **HOSPICE INPATIENT**

6. **OTHER TYPE OF HEALTH FACILITY (including mental health facility)** — other facility or institution that provides lodging, board, and social and physical care including the recording of health information, dietary supervision and supervised hygienic services for three or more patients not related to the operator

7. **Other**

CARD 7

1. Eye glasses (including contact lenses)
2. Dentures (full or partial)
3. Hearing aid
4. Wheelchair
5. Cane
6. Walker
7. Crutches
8. Brace (any type)
9. Other aids or devices

CARD 8

1. **PARTIALLY IMPAIRED** — cannot read newspaper print but can watch television 8 to 12 feet away

2. **SEVERELY IMPAIRED** — cannot watch TV 8 to 12 feet away, but can recognize the features of familiar persons if they are within 2 to 3 feet

3. **COMPLETELY LOST, BLIND**

CARD 9

1. **PARTIALLY IMPAIRED** — can hear MOST of the things a person says
2. **SEVERELY IMPAIRED** — can hear only a few words a person says or loud noises
3. **COMPLETELY LOST, DEAF**

CARD 10

a. **BATHING or SHOWERING** — washing the whole body; includes the process of getting in or out of tub/shower

b. **DRESSING** — getting clothes from closets/drawers and putting them on. Includes managing buttons, zippers, and other fasteners; excludes tying shoes

c. **EATING** — getting food from plate to mouth; excludes assistance with cutting meat or buttering bread

d. **TRANSFERRING IN OR OUT OF BEDS OR CHAIRS** — getting into and out of bed or getting into and out of a chair/wheelchair

e. **WALKING** — moving from one place to another by advancing the feet and legs in turn at a moderate pace

f. **USING THE TOILET ROOM** — going to the toilet, transferring on and off the toilet, cleaning self after elimination and arranging clothes; excludes bowel and bladder functioning

CARD 11

a. Doing light housework

b. Managing money

c. Shopping for groceries or clothes

d. Using the telephone (dialing or receiving calls)

e. Preparing meals

f. Taking medication

CARD 12

1. **DIETARY AND NUTRITIONAL SERVICES** — direct counseling by a trained nutritionist; does NOT include supervision of special diets

2. **OCCUPATIONAL THERAPY/VOCATIONAL THERAPY** — from a registered or licensed occupational therapist; special restorative treatment

3. **SPEECH THERAPY/AUDIOLOGY** — evaluation, treatment, and monitoring of specific communication disorder(s)

4. **HOMEMAKER/COMPANION SERVICES** — services that are necessary for maintaining a safe and healthy home environment for the patient (e.g., cleaning the patient's kitchen, doing personal laundry, preparing meals) and other services to enable the patient to remain at home

5. **MEALS ON WHEELS** — program that provides regular delivery of food to elderly and handicapped persons with limited mobility. Often provided through a volunteer network

6. **TRANSPORTATION** — provision of transportation

7. **ENTEROSTOMAL THERAPY** — therapy designed to teach the proper method of caring for an ostomy site

8. **COUNSELING** — counseling and/or therapy that assists the patient in minimizing stresses and problems that arise from social, economical, or psychological situations and that assists the patient in maximizing positive aspects and opportunities for growth

9. **MEDICATIONS** — providing prescription medication

10. **RESPITE CARE** — care provided to the patient in the home or inpatient setting to relieve the family or primary caregiver, due to family psychological problems, caregiver fatigue, or required short-term absence of the caregiver

11. **HIGH TECH CARE** — specialized care, especially the setup of IV's in the home

12. **REFERRAL SERVICES** — referral to other sources for services that are not provided by the facility

13. **PERSONAL CARE** — aid in bathing, dressing, using the toilet, getting in and out of bed, eating, or walking

14. **SKILLED NURSING SERVICES** — coordination by an R.N. or an L.P.N. of a care plan; e.g., catheterization, injection

15. **PHYSICIAN SERVICES** — evaluation and/or treatment from a licensed M.D. (not including psychiatrist), D.O., or physician associate

16. **SOCIAL SERVICES** — counseling, advocacy coordination, information, referrals; e.g., legal aid, job, housing assistance

17. **PHYSICAL THERAPY** — from a certified or licensed physical therapist; treatment to restore function, relieve pain

18. **OTHER SERVICES**

CARD 13

1. Physicians
2. Registered nurses
3. Licensed practical or vocational nurses
4. Nursing aides and attendants
5. Home health aides
6. Homemakers/personal caretakers
7. Dieticians/nutritionists
8. Occupational therapists
9. Speech pathologists and audiologists
10. Physical therapists
11. Social workers
12. Health educators
13. Other providers

CARD 14

1. Private insurance
2. Own income, family support, Social Security benefits, retirement funds
3. Supplemental Security Income (SSI)
4. Medicare
5. Medicaid
6. Other government assistance or welfare
7. Religious organizations, foundations, agencies
8. VA contract, pension, or other VA compensation
9. Payment source not yet determined
10. Other

Total # Listed	Sample Line Numbers					Total # Listed	Sample Line Numbers				
1	1					31	3	9	15	21	28
2	1	2				32	2	9	15	22	28
3	1	2	3			33	4	11	17	24	31
4	1	2	3	4		34	1	8	15	21	28
5	1	2	3	4	5	35	6	13	20	27	43
6	1	2	3	5	6	36	1	8	16	23	30
7	2	3	4	6	7	37	6	14	21	28	36
8	2	4	5	7	8	38	5	12	20	28	35
9	2	4	5	7	9	39	2	10	18	25	33
10	1	3	5	7	9	40	7	15	23	31	39
11	2	4	6	8	10	41	4	12	21	29	37
12	2	5	7	10	12	42	3	12	20	28	37
13	3	5	8	11	13	43	1	10	18	27	35
14	3	6	8	11	14	44	5	14	22	31	40
15	2	5	8	11	14	45	4	13	22	31	40
16	2	5	8	11	14	46	7	16	26	35	44
17	3	6	9	13	16	47	3	13	22	31	41
18	4	8	11	15	18	48	5	15	25	34	44
19	1	5	8	12	16	49	10	20	30	40	49
20	1	5	9	13	17	50	4	14	24	34	44
21	4	8	13	17	21	51	7	18	20	38	48
22	2	7	11	16	20	52	1	11	21	32	42
23	5	9	14	18	23	53	11	21	32	43	53
24	3	8	13	18	22	54	3	14	25	36	47
25	2	7	12	17	22	55	5	16	27	38	49
26	3	8	13	18	24	56	9	20	31	42	54
27	3	9	14	20	25	57	11	23	34	46	57
28	2	7	13	18	24	58	1	13	24	36	48
29	2	8	13	19	25	59	7	19	31	43	54
30	1	7	13	19	25	60	5	17	29	41	53

NOTE: This is the first page of form HHCS-30(X)–Sample Selection Tables.

Appendix V
Letters, data collection instruments, and sample selection table for the National Home and Hospice Care Survey

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control

National Center for Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782

Dear Administrator:

The National Center for Health Statistics (NCHS), of the Centers for Disease Control, collects and provides information on the health of the Nation and the utilization of its health resources. As part of this continuing program, the NCHS is conducting the National Home and Hospice Care Survey. This survey is authorized under section 306 (42 USC 242k) of the Public Health Service Act. In addition, the survey is endorsed by the National Association for Home Care.

The purpose of the survey is to provide a more complete information base on available long-term care services and utilization of those services. The survey includes a small, randomly selected, nationwide sample of hospices and home health agencies, each of which represents a number of similar facilities. Information about your facility will be collected through a personal interview which will require about 20 minutes of your time. In addition, time involving some of your staff will be required to complete interviews for a small sample of patients. No patients will be contacted at any time. Your participation is voluntary and there are no penalties for refusing to participate or refusing to answer any question. We may need to contact you in about a year to update the information you provide during this survey.

I want to emphasize that the information you and your staff supply will be used only for statistical research and reporting purposes. In accordance with Section 308(d) (42 USC 242m) of the Public Health Service Act, no information collected in this survey may be used for any purpose other than the purpose for which it was collected. Such information may not be published or released in any form if the individual or establishment is identifiable unless the individual or establishment has consented to its release.

Within the next few weeks, a Census Bureau field representative will contact you for an appointment. The Census Bureau is under contract to conduct this survey. I greatly appreciate your cooperation in this survey.

Sincerely yours,

M Feinleib

MANNING FEINLEIB, M.D., Dr. P.H.
Director, National Center for Health Statistics

HHCS-10(L) (5-22-92)

SOME FREQUENTLY ASKED QUESTIONS/STATEMENTS

HOW WAS THIS FACILITY CHOSEN?

A sample of hospices and home health facilities was chosen from a National list to represent similar facilities in the United States. Since each represents several others, your full participation is very important to the outcome of this survey.

WHAT ARE YOU GOING TO DO WITH THE RESULTS OF THE SURVEY?

Information on hospices and home health facility providers and the populations they serve is needed by policymakers for assessing the availability of and need for hospice and home health services. Data from this National survey will assist policymakers in determining where and by whom these types of care are needed as well as identifying who is already receiving hospice or home care. Eventually these data could be used to identify any increased demand for hospice and home care services which could tax the ability of social service facilities to meet the needs of the terminally and chronically ill.

WE'VE ALREADY PROVIDED THIS INFORMATION.

The information we are collecting in this National survey may be similar to what you have provided in other surveys, but it is not the same. The laws governing confidentialit prohibit our obtaining similar information from other sources. In addition, for estimates from this survey to be accurate, we need to collect the same information from all participating facilities in exactly the same way.

WE'RE TOO BUSY AND DON'T HAVE ENOUGH STAFF.

We can work around the schedule and availability of your staff. We know they are busy. We can interview any staff member who is knowledgeable about the patient records. Eventually your help will increase the visibility of hospice and home health facilities anc their essential contribution to the care and comfort of patients and their families.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control

National Center for Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782

Thank You

I want to personally thank you for participating in the National Home and Hospice Care Survey and for assisting the field representative from the Bureau of the Census, who conducted the survey in your facility. It is only through the cooperation of administrators like yourself that we are able to conduct a survey such as this one. The information we collect from this survey will be invaluable in helping us to support effective treatment of long-term health problems.

Again, I appreciate the time and effort you have given in support of this survey.

Sincerely yours,

M Feinleib

MANNING FEINLEIB, M.D., Dr. P.H.
Director, National Center for Health Statistics

HHCS-11(L) (5-22-92)

HOMECARE™

NATIONAL ASSOCIATION FOR HOME CARE
519 C STREET, N.E., STANTON PARK
WASHINGTON, D.C. 20002-5809
Telephone: (202) 547-7424, FAX: (202) 547-3540

September 1992

Dear Administrator:

I am writing to encourage your participation in the 1992 National Home and Hospice Care Survey (NHHCS) to be conducted this month by the National Center for Health Statistics. This survey is the first in what will become an annual survey by NCHS to collect baseline and trend information about home health agencies and hospices in relationship to the patients they serve and the type of staff they employ.

Your support as a home care or hospice administrator is critical to the successful development of invaluable data for planning and organizing home care and hospice services, drafting health legislation and setting national policies and priorities to obtain high quality care for all home care and hospice recipients.

A minimal amount of your time and staff time will be involved and strict confidentiality will be maintained. Only summary data will be published and made available to health planners, researchers, health professionals and the public.

I am confident that the information derived from this survey will be worth the investment of your time and effort. Your participation assures that the development of information to be used in shaping public policy for home care and hospice will be based on the input of industry professionals. I urge your coorperation in this effort.

Sincerely,

Val J. Halamandaris
President

FORM **HHCS-1**
(5-27-92)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

FACILITY QUESTIONNAIRE

NATIONAL HOME AND HOSPICE CARE SURVEY

Section A – ARRANGING THE ADMINISTRATOR APPOINTMENT

1a. Facility telephone number

b. Alternate telephone number

c. Alternate telephone number

2. Administrator name

3. Record of calls

Day (a)	Date (b)	Time (c)	Notes (d)
		a.m. p.m.	
		a.m. p.m.	
		a.m. p.m.	
		a.m. p.m.	
		a.m. p.m.	

4. INTRODUCTION

Good morning (afternoon). My name is . . .. I'm from the Bureau of the Census. We are currently conducting the National Home and Hospice Care Survey for the National Center for Health Statistics which is part of the Centers for Disease Control. We are studying home health agencies, hospices and their patients. You should have received a letter from Dr. Manning Feinleib, the Director of the National Center for Health Statistics, which describes this project. Have you received this letter?

☐ Yes – *Skip to Item 6, NAME VERIFICATION.*
☐ No – *Continue with Item 5, SURVEY EXPLANATION.*

5. SURVEY EXPLANATION

If administrator wants a copy of the letter, explain that you will bring a copy when you visit the facility.

I'm sorry that you did not receive the letter. Let me briefly outline its contents.

The National Home and Hospice Care Survey is authorized under Section 306 of the Public Health Service Act to collect baseline information about home and hospice care facilities, their services, and patients. The statistics compiled from the data are used to support research for effective treatment of long-term health problems and to study utilization of hospice and home care facilities and the efficient use of the Nation's health care resources.

All information which would permit identification of the individual patient or facility will be held in strict confidence, will be used ONLY by persons involved in the survey and only for the purposes of the survey, and will not be disclosed or released to others for any purpose.

The survey includes a small sample of hospices and home health agencies. Although your participation is voluntary and there are no penalties for refusing to answer any questions, it is essential that we obtain data from all sample facilities.

Continue with Item 6, NAME VERIFICATION.

6. NAME VERIFICATION

I would like to verify some information from my records. Is *(Name of facility on label)* **the correct name of your facility?**

☐ Yes – *Go to Item 7, ADDRESS VERIFICATION.*
☐ No – *Enter correct facility name below.* ↙

7. ADDRESS VERIFICATION

Is *(Address of facility on label)* **the correct address?**

☐ Yes – *Go to Item 8 – SET APPOINTMENT*
☐ No – *Enter correct facility address below.* ↙

Number Street	P.O. Box, Route, etc.
City or town	
State	ZIP code

8. SET APPOINTMENT

I would like to arrange a morning appointment at your convenience to conduct the survey. What would be a convenient date and time to visit your facility?

Day	Date	Time	a.m. p.m.

9. **Could you give me directions to your facility from some easy to identify starting point?** *(Record directions in number 10 below.)*

Thank you very much for your time. I will see you at *(Time)* **on** *(Date)*. **Good-bye.**

10. DIRECTIONS TO FACILITY

Section B – RECORD OF INTERVIEW

1. STATUS OF INTERVIEW – *Mark (X) appropriate box.*

01 ☐ Complete interview
02 ☐ Partial interview
03 ☐ Refusal
04 ☐ Not a Hospice/Home Health Agency
05 ☐ No longer operating
06 ☐ Temporarily closed
07 ☐ Not yet in operation
08 ☐ Duplicate (Control No. of duplicate) _____
09 ☐ Unable to locate
10 ☐ Other noninterview – *Specify* _____

2. Date of interview
Month | Day | Year

3. Field Representative | Code

Section C – QUESTIONS ABOUT THE FACILITY

Before I begin the interview, I'd like to take a moment to explain the purpose of the survey. I believe you (received/did not receive) the letter from the National Center for Health Statistics.

If administrator did not receive the letter, hand him/her a copy. Allow him/her to read it through briefly.

As it says in the letter, the purpose of this survey is to collect baseline information about hospices and home health agencies such as yours. The information you provide is strictly confidential and will be used only by persons involved in the survey and only for the purposes of the survey.

1a. Does this facility currently provide home health or hospice care services?

01 ☐ Yes
02 ☐ No

b. Did this facility provide home health or hospice care services to patients during the last 12 months?

01 ☐ Yes – *GO to item 1c*
02 ☐ No – *SKIP to item 1d*

c. During the past 12 months, what was the number of home health and the number of hospice care patients served by this facility?

Use the combined category if the respondent cannot provide separate numbers for home health and hospice patients OR if the facility had patients who received both home health and hospice care.

_____ Number of home health patients
0000 ☐ None
9999 ☐ Don't know

_____ Number of hospice patients
0000 ☐ None
9999 ☐ Don't know

_____ Number of patients who were served as BOTH hospice and home health patients *(DO NOT INCLUDE IN NUMBERS ABOVE)*
0000 ☐ None
9999 ☐ Don't know

d. Does this facility currently have any active home health or hospice care patients?

01 ☐ Yes – *GO to item 1e*
02 ☐ No – *SKIP to CHECK ITEM A*

e. What is the number of home health and the number of hospice care patients currently being served by this facility?

Use the combined category if the respondent cannot provide separate numbers for home health and hospice patients OR if the facility has patients who receive both home health and hospice care.

_____ Number of home health patients
0000 ☐ None
9999 ☐ Don't know

_____ Number of hospice patients
0000 ☐ None
9999 ☐ Don't know

_____ Number of patients currently served as BOTH hospice and home health patients *(DO NOT INCLUDE IN NUMBERS ABOVE)*
0000 ☐ None
9999 ☐ Don't know

CHECK ITEM A

Refer to items 1a, 1b, and 1d.

01 ☐ *If 1a, 1b, and 1d are all marked "No," THIS FACILITY IS OUT OF SCOPE FOR THE SURVEY. THANK THE RESPONDENT AND END THE INTERVIEW*
02 ☐ Other – *GO to item 2a*

HAND FLASHCARD 1

2a. What is the type of ownership of this facility as shown on this card?

Mark (X) only ONE box.

01 ☐ FOR PROFIT – Includes individual or private, partnership, corporation
02 ☐ NONPROFIT – Includes church-related, nonprofit corporation, other nonprofit ownership
03 ☐ STATE OR LOCAL GOVERNMENT – Includes State, county, city, city-county, hospital district or authority
04 ☐ FEDERAL GOVERNMENT – Includes USPHS, Armed Forces, Veterans Administration
05 ☐ Other – *Specify*

_____
_____

b. Is this facility operated by a hospital?

01 ☐ Yes
02 ☐ No

c. Is this facility operated by a nursing home?

01 ☐ Yes
02 ☐ No

d. Is *(Name of facility)* a member of a group of facilities operating under one general authority or general ownership?

01 ☐ Yes – *Continue with item 2e*
02 ☐ No – *SKIP to item 3*

e. What is the name of the parent organization?

Parent organization

Section C – QUESTIONS ABOUT THE FACILITY – Continued

3a. Is this facility certified under Medicare as a Home Health Agency?

01 ☐ Yes
02 ☐ No
03 ☐ Certification pending

b. Is this facility certified under Medicare as a Hospice?

01 ☐ Yes
02 ☐ No
03 ☐ Certification pending

4a. Is this facility certified under Medicaid as a Home Health Agency?

01 ☐ Yes
02 ☐ No
03 ☐ Certification pending

b. Is this facility certified under Medicaid as a Hospice?

01 ☐ Yes
02 ☐ No
03 ☐ Certification pending

5a. Does this facility provide bereavement care to the families of the patients you serve?

01 ☐ Yes
02 ☐ No

b. Does this facility provide pastoral care?

01 ☐ Yes
02 ☐ No

6. How many persons served your facility as volunteers during the last 7 days?

_____ Number

00 ☐ None

7. What is your name, title, and telephone number?

Respondent name

Title

Area code Number

READ **To complete this survey, I will need a list of all current home health and hospice patients, and a list of all home health and hospice discharges within the past year. From these lists, I will draw a sample of 6 current patients and 6 discharged patients.**

8a. From whom shall I obtain the list of current patients?

Name

Title

I will need these patients' medical records and the cooperation of a staff member best acquainted with these patients in order to obtain the information on this questionnaire.

Hand the administrator a copy of the current patient questionnaire. Allow him/her to examine it briefly. Retrieve the questionnaire and continue reading.

I will not be contacting or interviewing the patients in any way. I will depend on your staff to consult the medical records.

01 ☐ Yes – *GO to item 9a*
02 ☐ No – *Determine which staff member would have this knowledge and enter the name and title below.* ↙

b. Would *(person named in item 8a)* **know which staff member I should interview for those patients selected for the sample?**

Name

Title

9a. From whom shall I obtain the list of discharges?

☐ Same as 8a

Name

Title

I will need the help of a staff person familiar with the discharge records to aid me in completing the information requested in this questionnaire.

Hand the administrator a copy of the discharged patient questionnaire. Allow him/her to examine it briefly. Retrieve the questionnaire and continue reading.

01 ☐ Yes – *GO to item 10 below*
02 ☐ No – *Determine which staff member would have this knowledge and enter the name and title below.* ↙

b. Would *(person named in item 9a)* **know which staff member I should interview for those discharges that fall into the sample?**

Name

Title

HAND FLASHCARD 2

10. I also need this information about your staff. From whom shall I obtain this information?

Name

Title

CHECK ITEM B

Refer to item 10.

01 ☐ Respondent will provide information – *GO to item 11*
02 ☐ Other – *Leave a copy of Form HHCS-1A, Facility Staff Worksheet (and self-addressed, stamped envelope) with respondent. SKIP to item 12*

11. *HAND FLASHCARD 2*

Please provide the information requested about the number of employees of this facility, the hours worked, and the number of visits made during your last pay period for each type of employee listed, even if the number is zero. Do not include volunteers in these numbers.

What are the dates of your last pay period? → Month | Day | Year – Month | Day | Year

	Number of full-time staff (35+ hours per week) on your payroll (a)	Number of full-time budgeted positions that are vacant (b)	Number of part-time staff (less than 35 hours per week) on your payroll (c)	Number of part-time budgeted positions that are vacant (d)	Total hours worked by all full-time and part-time staff on your payroll during your last pay period (e)	Total hours of service provided by staff not on your payroll during your last pay period. (For example, temporary employment services, visiting nurse services, and other contract services) (f)	Total number of visits made during your last pay period by both payroll and nonpayroll staff (g)
Physicians							
Registered nurses							
Licensed practical or vocational nurses							
Nursing aides and attendants							
Home health aides							
Homemakers/Personal caretakers							
Dieticians/Nutritionists							
Occupational therapists							
Speech pathologists and audiologists							
Physical therapists							
Social workers							
Health educators							
Pastoral/Bereavement staff							
Administrator/Director							
Case manager/Case coordinator (Not RNs or Social Workers)							
Secretarial/Clerical							
Other health personnel – *Specify*							
Other personnel – *Specify*							

12. Thank you for your time. I will be checking with you before I leave to say good-bye.

At this time, could you introduce me to *(Names of person(s) listed in items 8a, 8b, 9a and 9b).*

NOTES

FORM HHCS-1 (5-27-92)

*U.S. GOVERNMENT PRINTING OFFICE:1992-648-072/60114

OMB No. 0920-0298: Approval Expires 06/30/95

FORM **HHCS-1A** (5-27-92) U.S. DEPARTMENT OF COMMERCE BUREAU OF THE CENSUS

FACILITY STAFF WORKSHEET

NATIONAL HOME AND HOSPICE CARE SURVEY

1. Facility name

2. Control number

3. Dates of your last pay period — Month / Day / Year – Month / Day / Year

INSTRUCTIONS

(1) *Enter the dates of your last pay period in item 3.*

(2) *For each category listed below, enter the information requested about the staff of this facility. Enter zero if appropriate. Please fill all of columns a through g for all categories.*

(3) *Do not include volunteers in these numbers.*

(4) *Return the form in the attached postage paid envelope. It would be helpful if you could complete and return the form within the next TWO DAYS.*

	Number of full-time staff (35+ hours per week) on your payroll (a)	Number of full-time budgeted positions that are vacant (b)	Number of part-time staff (less than 35 hours per week) on your payroll (c)	Number of part-time budgeted positions that are vacant (d)	Total hours worked by all full-time and part-time staff on your payroll during your last pay period (e)	Total hours of service provided by staff not on your payroll during your last pay period. (Examples: temporary employment services, visiting nurse services, and other contract services) (f)	Total number of visits made during your last pay period by both payroll and nonpayroll staff (g)
Physicians							
Registered nurses							
Licensed practical or vocational nurses							
Nursing aides and attendants							
Home health aides							
Homemakers/Personal caretakers							
Dieticians/Nutritionists							
Occupational therapists							
Speech pathologists and audiologists							
Physical therapists							
Social workers							
Health educators							
Pastoral/Bereavement staff							
Administrator/Director							
Case manager/Case coordinator (Not RNs or Social Workers)							
Secretarial/Clerical							
Other health personnel – *Specify*							
Other personnel – *Specify*							

*U.S. GOVERNMENT PRINTING OFFICE:1992-648-072/60111

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FORM **HHCS-2**
(5-27-92)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

CURRENT PATIENT SAMPLING LIST

NATIONAL HOME AND HOSPICE CARE SURVEY

1. Field representative name	Code	2. Date of listing

3. Respondent name	4. Respondent title

READ INTRODUCTION –

In order to obtain national level data about the patients of hospices and home health agencies such as this one, we are collecting information about a sample of current patients. This information and the list of names you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey. Please give me the names of all current patients; that is, all patients on the rolls of this facility as of midnight last night, so that I may select the sample.

FOLLOW THE STEPS BELOW TO LIST CURRENT PATIENTS –

STEP 1. Start listing the patients on line number 1 on page 3 of this form. List the patients consecutively in the order in which they are given to you. Be sure to complete the "Page of Page" item.

NOTE – If the facility supplies an appropriate list that you can use, do not transcribe the information onto the sampling list(s). If you can keep this list, attach it to this form; write the control number and facility name on each page of the list. In either case, number the patients on the provided list; and go to step 2.

STEP 2. Review the list. Verify that all eligible patients have been listed. Delete any duplicate entries and any patients that do not meet the definition of a current patient. Renumber the lines if you add or delete any names.

STEP 3. Enter the total number of patients listed. . . . . _____
IMPORTANT – This number is vital for estimation purposes. Number

STEP 4. Look at the Sample Selection Table. Find the number in the column labeled "Total # listed" that matches the total number of patients listed.

STEP 5. Circle the line numbers on the listing sheets that correspond to those in the columns labeled "Sample line numbers."

STEP 6. Enter the amount of circled line numbers on the listing sheets. . . . . _____
Number

STEP 7. The current patients to be sampled are those listed on lines with a circled line number. Enter the line number and the name or other identifier of each sampled patient below. Use this information to complete Section B of a Form HHCS-3, Current Patient Questionnaire, for each sampled patient.

Line number	Current patient identifier
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

SAMPLING LIST FINAL STATUS

01 ☐ Complete listing
02 ☐ Partial listing as of ___ / ___ / ___
03 ☐ Refused listing information
04 ☐ Listing records not available
05 ☐ No current patients
06 ☐ Other – *Specify* _____

CURRENT PATIENT SAMPLING LIST

Line number (a)	Patient name (or other identifier) (b)
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	
11	
12	
13	
14	
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*U.S. GOVERNMENT PRINTING OFFICE:1992-648-072/60112

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FORM **HHCS-4**
(5-21-92)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

DISCHARGED PATIENT SAMPLING LIST

NATIONAL HOME AND HOSPICE CARE SURVEY

1. Field representative name | Code | **2.** Date of listing

3. Respondent name | **4.** Respondent title

5. Reference period for discharged sample
Month / Day / Year to Month / Day / Year

READ INTRODUCTION –

In order to obtain national level data about discharged patients of hospices and home health agencies such as this one, we are collecting information about a sample of discharges. This information and the list of names you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey. Please give me the names of all patients discharged alive or deceased from *(See item 5 for reference period)* **and their specific dates of discharge. If any patient was discharged more than once during the reference period, give me their name and the discharge date for EACH time they were discharged. Be sure to include the name and discharge date for patients currently being served by your facility who were also discharged from** *(First and last day of reference period)*, **so that I may select the sample.**

FOLLOW THE STEPS BELOW TO LIST DISCHARGED PATIENTS –

STEP 1. Start listing the patients on line number 1 on page 3 of this form. List the patients consecutively in the order in which they are given to you. Be sure to complete the "Page of Page" item.

NOTE – If the facility supplies an appropriate list that you can use, do not transcribe the information onto the sampling list(s). If you can keep this list, attach it to this form; write the control number and facility name on each page of the list. In either case, number the discharges on the provided list; and go to step 2.

STEP 2. Review the list. Verify that all eligible discharges have been listed. Delete any duplicate discharges and any discharge that does not fall into the reference period. If both the patient name and date of discharge are the same, probe to determine if it is a duplicate entry. Renumber the lines if you add or delete any names.

STEP 3. Enter the total number of discharges listed. . . . . _____ Number
IMPORTANT – This number is vital for estimation purposes.

STEP 4. Look at the Sample Selection Table. Find the number in the column labeled "Total # listed" that matches the total number of discharges listed.

STEP 5. Circle the line numbers on the listing sheets that correspond to those in the columns labeled "Sample line numbers."

STEP 6. Enter the amount of circled line numbers on the listing sheets. . . . . _____ Number

STEP 7. The discharged patients to be sampled are those listed on lines with a circled line number. Enter the line number, name or other identifier, and discharge date of each sampled patient below. Use this information to complete Section B of a Form HHCS-5, Discharged Patient Questionnaire, for each sampled patient.

Line number	Discharged patient identifier	Discharge date *(Month/Day/Year)*

SAMPLING LIST FINAL STATUS

01 ☐ Complete listing
02 ☐ Partial listing ___/___/___ to ___/___/___
03 ☐ Refused listing information
04 ☐ Listing records not available
05 ☐ No discharges
06 ☐ Other – *Specify* _____

DISCHARGED PATIENT SAMPLING LIST

Line number (a)	Patient name (or other identifier) (b)	Discharge date *(Month/Day/Year)* (c)
01		
02		
03		
04		
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PAGE ___ OF ___ PAGES

FORM **HHCS-6** (5-26-92)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS

SAMPLING LIST CONTINUATION SHEET

A. Control number

B. Facility name

C. Sampling list type
Mark (X) one

☐ Current patient
(Do not complete column (c))

☐ Discharged patient

IMPORTANT – Add appropriate first digit to preprinted line numbers.

Line number (a)	Patient name (or other identifier) (b)	Discharge date *(Month/Day/Year)* (c)
01		
02		
03		
04		
05		
06		
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FORM **HHCS-3**
(5-5-92)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

CURRENT PATIENT QUESTIONNAIRE

NATIONAL HOME AND HOSPICE CARE SURVEY

Section A – ADMINISTRATIVE INFORMATION

1. Field representative name	2. FR code	3. Date of interview Month/Day/Year
		/ /

Section B – PATIENT INFORMATION

1. Patient name or other identifier First	M.I.	Last	2. Patient line number

Section C – RESPONDENT INFORMATION

1a. Respondent name

b. Title

c. Provided answers for items ☐ to ☐ ☐ Provided answers for all items

2a. Respondent name

b. Title

c. Provided answers for items ☐ to ☐

Section D – STATUS OF INTERVIEW

01 ☐ Complete
02 ☐ Partial
03 ☐ Selected in error
04 ☐ Refused
05 ☐ Unable to locate record
06 ☐ Assessment only
07 ☐ Other noninterview – *Specify* _____

NOTES

Read to each new respondent.

In order to obtain national level data about the patients of hospices and home health agencies such as this one, we are collecting information about a sample of current patients. I will be asking questions about the background, health status, treatment, social contacts, and billing information for each sampled patient.

The information you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey.

In answering these questions, it is especially important to locate the information in the patient's medical record. Do you have the medical file(s) and record(s) for *(Read name(s) of selected current patient(s))*?

If not, ask the respondent to get it/them prior to beginning the interview. Fill sections A and B on the front of all the current patient forms while the respondent gets the records. If no record is available for a patient, try to obtain as much information as possible from whatever administrative records are available and/or from the respondent's memory.

1. What is . . .'s sex?

01 ☐ Male
02 ☐ Female

2. What is . . .'s date of birth?

Month	Day	Year

OR Age (at admission) _____ Years _____ Months

HAND FLASHCARD 1.

3a. Which of these best describes . . .'s race?

Mark (X) only one box.

01 ☐ White
02 ☐ Black
03 ☐ American Indian, Eskimo, Aleut
04 ☐ Asian, Pacific Islander
05 ☐ Other – *Specify* _____
99 ☐ Don't know

b. Is . . . of Hispanic origin?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

4. What is . . .'s current marital status?

Mark (X) only one box.

01 ☐ Married
02 ☐ Widowed
03 ☐ Divorced
04 ☐ Separated
05 ☐ Never Married
99 ☐ Don't know

HAND FLASHCARD 2.

5a. Where is . . . currently living?

Mark (X) only one box.

01 ☐ Private residence
02 ☐ Rented room, boarding house
03 ☐ Retirement home
04 ☐ Board and care or residential care facility
05 ☐ Health facility (including mental health facility) – *SKIP to item 6 Introduction*
06 ☐ Other – *Specify* _____

b. Is . . . living with family members, nonfamily members, both family and nonfamily members, or alone?

01 ☐ With family members
02 ☐ With nonfamily members
03 ☐ With both family members and nonfamily members
04 ☐ Alone

Read the introductory paragraph for the Social Security Number only once for each respondent.

As part of this survey, we would like to have . . .'s Social Security Number. Provision of this number is voluntary and providing or not providing the number will have no effect in any way on . . .'s benefits. This number will be useful in conducting future followup studies. It will be used to match against the vital statistics records maintained by the National Center for Health Statistics. This information is collected under the authority of Section 306 of the Public Health Service Act.

6. What is . . .'s Social Security Number?

Social Security Number ☐☐☐ – ☐☐ – ☐☐☐☐

97 ☐ Refused
99 ☐ Don't know

HAND FLASHCARD 3.

7. Who referred . . . to this facility?

Mark (X) all that apply.

PROBE: **Any other sources?**

01 ☐ Self/Family
02 ☐ Nursing home
03 ☐ Hospital
04 ☐ Physician
05 ☐ Health department
06 ☐ Social service agency
07 ☐ Other – *Specify* _____
99 ☐ Don't know

8. What was the date of . . .'s most recent admission with your facility, that is, the date on which . . . was admitted for the current episode of care?

Month	Day	Year

00 ☐ Only an assessment was done for this patient (patient was not provided services by this facility)

9a. According to . . .'s medical record, what were the primary and other diagnoses at the time of that (admission/assessment)? Please provide the ICD-9-CM code if one is available.

PROBE: **Any other diagnoses?**

00 ☐ No diagnosis

		Written form	ICD-9-CM codes if available
Primary:	1	_____	____.__
Others:	2	_____	____.__
	3	_____	____.__
	4	_____	____.__
	5	_____	____.__
	6	_____	____.__

CHECK ITEM A *Refer to item 8.*

01 ☐ Box 00 is NOT marked – *Go to item 9b*
02 ☐ Box 00 is marked – *END THE INTERVIEW. Complete sections C and D on the cover.*

b. According to . . .'s medical records, what are . . .'s CURRENT primary and other diagnoses? Please provide the ICD-9-CM code if one is available.

PROBE: **Any other diagnoses?**

00 ☐ No diagnosis

		Written form	ICD-9-CM codes if available
Primary:	1	_____	____.__
Others:	2	_____	____.__
	3	_____	____.__
	4	_____	____.__
	5	_____	____.__
	6	_____	____.__

10. What type of care is . . . currently receiving from your facility? Is it home health care, hospice care or other care?

Mark (X) all that apply.

01 ☐ Home health care
02 ☐ Hospice care
03 ☐ Other – *Specify* _____

11a. Does . . . have a primary caregiver?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 12*
99 ☐ Don't know

b. Does . . . usually live with (his/her) primary caregiver?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

HAND FLASHCARD 4.

11c. What is the relationship of the primary caregiver to . . .?

Mark (X) only one box.

01 ☐ Spouse
02 ☐ Parent
03 ☐ Child
04 ☐ Daughter/Son-in-law
05 ☐ Other relative – *Specify* ➶

_____

06 ☐ Neighbor
07 ☐ Friend
08 ☐ Volunteer group
09 ☐ Other – *Specify* ➶

_____

99 ☐ Don't know

HAND FLASHCARD 5.

12. Which of these aids does . . . currently use?

Mark (X) all that apply.

PROBE: **Any other aids?**

01 ☐ Eye glasses (including contact lenses)
02 ☐ Dentures (full or partial)
03 ☐ Hearing aid
04 ☐ Wheelchair
05 ☐ Cane
06 ☐ Walker
07 ☐ Crutches
08 ☐ Brace (any type)
09 ☐ Oxygen
10 ☐ Hospital bed
11 ☐ Commode
12 ☐ Other aids or devices – *Specify* ➶

_____

00 ☐ No aids used
99 ☐ Don't know

For items 13a–14b, refer to item 12.

13a. Does . . . have any difficulty in seeing (when wearing glasses)?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 14a*
03 ☐ Not applicable (e.g., comatose)
99 ☐ Don't know . . . . . }

HAND FLASHCARD 6.

b. Is . . .'s sight (when wearing glasses) partially, severely, or completely impaired as defined on this card?

01 ☐ Partially impaired
02 ☐ Severely impaired
03 ☐ Completely lost, blind
99 ☐ Don't know

14a. Does . . . have any difficulty in hearing (when wearing a hearing aid)?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 15*
03 ☐ Not applicable (e.g., comatose)
99 ☐ Don't know . . . . . }

HAND FLASHCARD 7.

b. Is . . .'s hearing (when wearing a hearing aid) partially, severely, or completely impaired, as defined on this card?

01 ☐ Partially impaired
02 ☐ Severely impaired
03 ☐ Completely lost, deaf
99 ☐ Don't know

HAND FLASHCARD 8.

15. Does . . . currently receive personal help FROM YOUR FACILITY in any of the following activities as defined on this card - - *Mark (X) one box for each activity.*	Yes receives help	No does not receive help	Unable to do/Doesn't do	Don't know
a. Bathing or showering?	01 ☐	02 ☐	03 ☐	99 ☐
b. Dressing?	01 ☐	02 ☐	03 ☐	99 ☐
c. Eating?	01 ☐	02 ☐	03 ☐	99 ☐
d. Transferring in or out of beds or chairs?	01 ☐	02 ☐	03 ☐	99 ☐
e. Walking?	01 ☐	02 ☐	03 ☐	99 ☐
f. Using the toilet room?	01 ☐	02 ☐	03 ☐	99 ☐

16a. Does . . . have an ostomy, an indwelling catheter or similar device?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 17*
99 ☐ Don't know

b. Does . . . receive personal help FROM YOUR FACILITY in caring for this device?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

17. Does . . . currently have any difficulty in controlling (his/her) bowels?

01 ☐ Yes
02 ☐ No
03 ☐ Not applicable (e.g., infant, has a colostomy)
99 ☐ Don't know

18. Does . . . currently have any difficulty in controlling (his/her) bladder?

01 ☐ Yes
02 ☐ No
03 ☐ Not applicable (e.g., infant, has an indwelling catheter)
99 ☐ Don't know

HAND FLASHCARD 9.

19. Does . . . receive personal help FROM YOUR FACILITY in any of the following activities - - *Mark (X) one box for each activity.*	Yes receives help	No does not receive help	Unable to do/Doesn't do	Don't know
a. Doing light housework?	01 ☐	02 ☐	03 ☐	99 ☐
b. Managing money?	01 ☐	02 ☐	03 ☐	99 ☐
c. Shopping for groceries or clothes?	01 ☐	02 ☐	03 ☐	99 ☐
d. Using the telephone (dialing or receiving calls)?	01 ☐	02 ☐	03 ☐	99 ☐
e. Preparing meals?	01 ☐	02 ☐	03 ☐	99 ☐
f. Taking medications?	01 ☐	02 ☐	03 ☐	99 ☐

NOTES

HAND FLASHCARD 10.

20a. During your last billing period, which of these services were provided to . . . BY YOUR FACILITY?

Mark (X) all that apply.

PROBE: **Any other services?**

01 ☐ Skilled nursing services
02 ☐ Personal care
03 ☐ Social Services
04 ☐ Counseling
05 ☐ Medications
06 ☐ Physical therapy
07 ☐ Homemaker/Companion services
08 ☐ Respite care
09 ☐ Referral services
10 ☐ Dietary and nutritional services
11 ☐ Physician services
12 ☐ High tech care (e.g., IV therapy)
13 ☐ Occupational therapy/Vocational therapy
14 ☐ Speech therapy/Audiology
15 ☐ Transportation
16 ☐ Enterostomal therapy
17 ☐ Meals on wheels
18 ☐ Other services – *Specify*

_____

00 ☐ None

HAND FLASHCARD 11.

b. Which of these service providers FROM YOUR FACILITY visited . . . during your last billing period?

Mark (X) all that apply.

PROBE: **Any other providers?**

01 ☐ Registered nurses
02 ☐ Licensed practical or vocational nurses
03 ☐ Nursing aides and attendants
04 ☐ Home health aides
05 ☐ Homemakers/Personal caretakers
06 ☐ Social workers
07 ☐ Physical therapists
08 ☐ Physicians
09 ☐ Occupational therapists
10 ☐ Speech pathologists and audiologists
11 ☐ Dieticians/Nutritionists
12 ☐ Health educators
13 ☐ Volunteers
14 ☐ Other providers – *Specify*

_____

00 ☐ None

21. How many visits were made to . . . during your last billing period?

_____ Number of visits

00 ☐ None
96 ☐ 24 hour care
99 ☐ Don't know

22a. For your last billing period, what was the total charge billed for . . .'s care, including all charges for services, drugs and special medical supplies?

$ _____ .00

96 ☐ Was not a patient during last billing period – *SKIP to item 23*

00 ☐ No charge was made for care – *END INTERVIEW. Complete sections C and D on the front of this form.*

99 ☐ Don't know – *Skip to item 23*

b. What time period does this charge cover?

Month	Day		TO	Month	Day

99 ☐ Don't know (not billed yet, etc.)

FORM HHCS-3 (5-5-92)

HAND FLASHCARD 12.

23. What are ALL the (expected) sources of payment for the amount billed?

Mark (X) all that apply.

PROBE: **Any other sources of payment?**

- 01 ☐ Private insurance
- 02 ☐ Own income, family support, Social Security benefits, retirement funds
- 03 ☐ Supplemental Security Income (SSI)
- 04 ☐ Medicare
- 05 ☐ Medicaid
- 06 ☐ Other government assistance or welfare
- 07 ☐ Religious organizations, foundations, agencies
- 08 ☐ VA contract, pensions, or other VA compensation
- 09 ☐ Payment source not yet determined
- 10 ☐ Other – *Specify* _____

- 99 ☐ Don't know

HAND FLASHCARD 12.

24. What was the PRIMARY (expected) source of payment (for this bill/when billed)?

Mark (X) only one box.

- 01 ☐ Private insurance
- 02 ☐ Own income, family support, Social Security benefits, retirement funds
- 03 ☐ Supplemental Security Income (SSI)
- 04 ☐ Medicare
- 05 ☐ Medicaid
- 06 ☐ Other government assistance or welfare
- 07 ☐ Religious organizations, foundations, agencies
- 08 ☐ VA contract, pensions, or other VA compensation
- 09 ☐ Payment source not yet determined
- 10 ☐ Other – *Specify* _____

- 99 ☐ Don't know

FILL SECTIONS C AND D ON THE COVER OF THIS FORM.

NOTES

OMB No. 0920-0298: Approval Expires 06/30/95

FORM **HHCS-5**
(5-5-92)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

DISCHARGED PATIENT QUESTIONNAIRE

NATIONAL HOME AND HOSPICE CARE SURVEY

Section A – ADMINISTRATIVE INFORMATION

1. Field representative name	2. FR code	3. Date of interview Month/Day/Year
		/ /

Section B – PATIENT INFORMATION

1. Patient name or other identifier First / M.I. / Last	2. Patient line number	3. Date of Discharge Month/Day/Year
		/ /

Section C – RESPONDENT INFORMATION

1a. Respondent name

b. Title

c. Provided answers for items ____ to ____ ☐ Provided answers for all items

2a. Respondent name

b. Title

c. Provided answers for items ____ to ____

Section D – STATUS OF INTERVIEW

01 ☐ Complete
02 ☐ Partial
03 ☐ Selected in error
04 ☐ Refused
05 ☐ Unable to locate record
06 ☐ Assessment only
07 ☐ Other noninterview – *Specify*

NOTES

Read to each new respondent.

In order to obtain national level data about patients who are discharged from hospices and home health agencies such as this one, we are collecting information about a sample of discharges. I will be asking questions about the background, health status, treatment, social contacts, and billing information for each sampled discharge.

The information you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey.

In answering these questions, it is especially important to locate the information in the patient's medical record. Do you have the medical file(s) and record(s) for *(Read name(s) of selected discharged patient(s))***?**

If not, ask the respondent to get it/them prior to beginning the interview. Fill sections A and B on the front of all the discharged patient forms while the respondent gets the records. If no record is available for a patient, try to obtain as much information as possible from whatever administrative records are available and/or from the respondent's memory.

1. What was . . .'s sex?

01 ☐ Male
02 ☐ Female

2. What was . . .'s date of birth?

Month	Day	Year

OR Age (at admission) _____ Years _____ Months

HAND FLASHCARD 1.

3a. Which of these best described . . .'s race?

Mark (X) only one box.

01 ☐ White
02 ☐ Black
03 ☐ American Indian, Eskimo, Aleut
04 ☐ Asian, Pacific Islander
05 ☐ Other – *Specify* _____
99 ☐ Don't know

b. Was . . . of Hispanic origin?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

4. What was . . .'s marital status at the time of discharge?

Mark (X) only one box.

01 ☐ Married
02 ☐ Widowed
03 ☐ Divorced
04 ☐ Separated
05 ☐ Never Married
99 ☐ Don't know

HAND FLASHCARD 2.

5a. During the episode of care that ended on *(date of discharge)***, where was . . . living?**

Mark (X) only one box.

01 ☐ Private residence
02 ☐ Rented room, boarding house
03 ☐ Retirement home
04 ☐ Board and care or residential care facility
05 ☐ Health facility (including mental health facility) – *SKIP to item 6 Introduction*
06 ☐ Other – *Specify* _____

b. Was . . . living with family members, nonfamily members, both family and nonfamily members, or alone?

01 ☐ With family members
02 ☐ With nonfamily members
03 ☐ With both family members and nonfamily members
04 ☐ Alone

Read the introductory paragraph for the Social Security Number only once for each respondent.

As part of this survey, we would like to have . . .'s Social Security Number. Provision of this number is voluntary and providing or not providing the number will have no effect in any way on . . .'s benefits. This number will be useful in conducting future followup studies. It will be used to match against the vital statistics records maintained by the National Center for Health Statistics. This information is collected under the authority of Section 306 of the Public Health Service Act.

6. What was . . .'s Social Security Number?

Social Security Number ☐☐☐ – ☐☐ – ☐☐☐☐

97 ☐ Refused
99 ☐ Don't know

HAND FLASHCARD 3.

7. Who referred . . . to this facility?

Mark (X) all that apply.

PROBE: **Any other sources?**

01 ☐ Self/Family
02 ☐ Nursing home
03 ☐ Hospital
04 ☐ Physician
05 ☐ Health department
06 ☐ Social service agency
07 ☐ Other – *Specify* _____
99 ☐ Don't know

8. What was the date of . . .'s admission for the period of care which ended on *(Date of discharge)*?

Month	Day	Year

00 ☐ Only an assessment was done for this patient (patient was not provided services by this facility)

9a. According to . . .'s medical record, what were the primary and other diagnoses at the time of . . .'s admission that ended with this (discharge/assessment)? Please provide the ICD-9-CM code if one is available.

PROBE: **Any other diagnoses?**

00 ☐ No diagnosis

		Written form	ICD-9-CM codes if available
Primary:	1	_____	____.__
Others:	2	_____	____.__
	3	_____	____.__
	4	_____	____.__
	5	_____	____.__
	6	_____	____.__

CHECK ITEM A *Refer to item 8.*

01 ☐ Box 00 is NOT marked – *Go to item 9b*
02 ☐ Box 00 is marked – *END THE INTERVIEW. Complete sections C and D on the cover.*

b. According to . . .'s medical records, what were . . .'s primary and other diagnoses at the time of discharge – that is, on *(Date of discharge)*? **Please provide the ICD-9-CM code if one is available.**

PROBE: **Any other diagnoses?**

00 ☐ No diagnosis

		Written form	ICD-9-CM codes if available
Primary:	1	_____	____.__
Others:	2	_____	____.__
	3	_____	____.__
	4	_____	____.__
	5	_____	____.__
	6	_____	____.__

c. Why was . . . discharged?

01 ☐ Recovered
02 ☐ Stabilized
03 ☐ Moved out of district
04 ☐ Deceased
05 ☐ Admitted to hospital inpatient service
06 ☐ Admitted to nursing home
07 ☐ Other – *Specify* _____
99 ☐ Don't know

10. What type of care was . . . receiving at the time of discharge? Was it home health care, hospice care or other care?

Mark (X) all that apply.

01 ☐ Home health care
02 ☐ Hospice care
03 ☐ Other – *Specify* _____

11a. Did . . . have a primary caregiver?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to INSTRUCTION BOX above item 12*
99 ☐ Don't know

b. Did . . . usually live with (his/her) primary caregiver?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

HAND FLASHCARD 4.

c. What was the relationship of the primary caregiver to . . .?

Mark (X) only one box.

01 ☐ Spouse
02 ☐ Parent
03 ☐ Child
04 ☐ Daughter/Son-in-law
05 ☐ Other relative – *Specify* _____
06 ☐ Neighbor
07 ☐ Friend
08 ☐ Volunteer group
09 ☐ Other – *Specify* _____
99 ☐ Don't know

INSTRUCTION BOX

For items 12 through 19, use the phrase "AT THE TIME OF DISCHARGE" if the patient was discharged alive. Use the phrase "IMMEDIATELY PRIOR TO DISCHARGE" if the patient was discharged dead.

HAND FLASHCARD 5.

12. The following questions refer to the patient's status (at the time of discharge/immediately prior to discharge) on *(Date of discharge).*

(At the time of discharge/immediately prior to discharge), which of these aids did . . . regularly use?

Mark (X) all that apply.

PROBE: **Any other aids?**

01 ☐ Eye glasses (including contact lenses)
02 ☐ Dentures (full or partial)
03 ☐ Hearing aid
04 ☐ Wheelchair
05 ☐ Cane
06 ☐ Walker
07 ☐ Crutches
08 ☐ Brace (any type)
09 ☐ Oxygen
10 ☐ Hospital bed
11 ☐ Commode
12 ☐ Other aids or devices – *Specify*

_____

00 ☐ No aids used
99 ☐ Don't know

For items 13a–14b, refer to item 12.

13a. (At the time of discharge/immediately prior to discharge), did . . . have any difficulty in seeing (when wearing glasses)?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 14a*
03 ☐ Not applicable (e.g., comatose)
99 ☐ Don't know . . . . . }

HAND FLASHCARD 6.

b. Was . . .'s sight (when wearing glasses) partially, severely, or completely impaired as defined on this card?

01 ☐ Partially impaired
02 ☐ Severely impaired
03 ☐ Completely lost, blind
99 ☐ Don't know

14a. (At the time of discharge/immediately prior to discharge), did . . . have any difficulty in hearing (when wearing a hearing aid)?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 15*
03 ☐ Not applicable (e.g., comatose)
99 ☐ Don't know . . . . . }

HAND FLASHCARD 7.

b. Was . . .'s hearing (when wearing a hearing aid) partially, severely, or completely impaired, as defined on this card?

01 ☐ Partially impaired
02 ☐ Severely impaired
03 ☐ Completely lost, deaf
99 ☐ Don't know

HAND FLASHCARD 8.

15. (At the time of discharge/immediately prior to discharge), did . . . receive personal help FROM YOUR FACILITY in any of the following activities as defined on this card - - *Mark (X) one box for each activity.*	Yes received help	No did not receive help	Unable to do/Didn't do	Don't know
a. Bathing or showering?	01 ☐	02 ☐	03 ☐	99 ☐
b. Dressing?	01 ☐	02 ☐	03 ☐	99 ☐
c. Eating?	01 ☐	02 ☐	03 ☐	99 ☐
d. Transferring in or out of beds or chairs?	01 ☐	02 ☐	03 ☐	99 ☐
e. Walking?	01 ☐	02 ☐	03 ☐	99 ☐
f. Using the toilet room?	01 ☐	02 ☐	03 ☐	99 ☐

16a. (At the time of discharge/immediately prior to discharge), did . . . have an ostomy, an indwelling catheter or similar device?

01 ☐ Yes
02 ☐ No . . . . . } *SKIP to item 17*
99 ☐ Don't know

b. Did . . . receive personal help FROM YOUR FACILITY in caring for this device?

01 ☐ Yes
02 ☐ No
99 ☐ Don't know

17. (At the time of discharge/immediately prior to discharge), did . . . have any difficulty in controlling (his/her) bowels?

01 ☐ Yes
02 ☐ No
03 ☐ Not applicable (e.g., infant, had a colostomy)
99 ☐ Don't know

18. (At the time of discharge/immediately prior to discharge), did . . . have any difficulty controlling (his/her) bladder?

01 ☐ Yes
02 ☐ No
03 ☐ Not applicable (e.g., infant, had an indwelling catheter)
99 ☐ Don't know

HAND FLASHCARD 9.

19. (At the time of discharge/immediately prior to discharge), did . . . receive personal help FROM YOUR FACILITY in any of the following activities – *Mark (X) one box for each activity.*	Yes received help	No did not receive help	Unable to do/Didn't do	Don't know
a. Doing light housework?	01 ☐	02 ☐	03 ☐	99 ☐
b. Managing money?	01 ☐	02 ☐	03 ☐	99 ☐
c. Shopping for groceries or clothes?	01 ☐	02 ☐	03 ☐	99 ☐
d. Using the telephone (dialing or receiving calls)?	01 ☐	02 ☐	03 ☐	99 ☐
e. Preparing meals?	01 ☐	02 ☐	03 ☐	99 ☐
f. Taking medications?	01 ☐	02 ☐	03 ☐	99 ☐

NOTES

HAND FLASHCARD 10.

20a. During the billing period that included *(Date of discharge)*, **which of these services were provided to . . . BY YOUR FACILITY?**

Mark (X) all that apply.

PROBE: **Any other services?**

01 ☐ Skilled nursing services
02 ☐ Personal care
03 ☐ Social services
04 ☐ Counseling
05 ☐ Medications
06 ☐ Physical therapy
07 ☐ Homemaker/Companion services
08 ☐ Respite care
09 ☐ Referral services
10 ☐ Dietary and nutritional services
11 ☐ Physician services
12 ☐ High tech care (e.g., IV therapy)
13 ☐ Occupational therapy/Vocational therapy
14 ☐ Speech therapy/Audiology
15 ☐ Transportation
16 ☐ Enterostomal therapy
17 ☐ Meals on wheels
18 ☐ Other services – *Specify* ➶

_____

00 ☐ None

HAND FLASHCARD 11.

b. During the billing period that included *(Date of discharge)*, **which of these service providers FROM YOUR FACILITY visited . . .?**

Mark (X) all that apply.

PROBE: **Any other providers?**

01 ☐ Registered nurses
02 ☐ Licensed practical or vocational nurses
03 ☐ Nursing aides and attendants
04 ☐ Home health aides
05 ☐ Homemakers/Personal caretakers
06 ☐ Social workers
07 ☐ Physical therapists
08 ☐ Physicians
09 ☐ Occupational therapists
10 ☐ Speech pathologists and audiologists
11 ☐ Dieticians/Nutritionists
12 ☐ Health educators
13 ☐ Volunteers
14 ☐ Other providers – *Specify* ➶

_____

00 ☐ None

21. How many visits were made to . . . during the billing period that included *(Date of discharge)*?

_____ Number of visits

00 ☐ None
96 ☐ 24 hour care
99 ☐ Don't know

22a. For the billing period that included *(Date of discharge)*, **what was the total charge billed for . . .'s care including all charges made for drugs, services and special medical supplies?**

$ _____ .00

00 ☐ No charge was made for care – *END INTERVIEW. Complete sections C and D on the front of this form.*

99 ☐ Don't know – *Skip to item 23*

b. What time period does this charge cover?

Month	Day		Month	Day
		TO		

99 ☐ Don't know (not billed yet, etc.)

HAND FLASHCARD 12.

23. What were ALL the (expected) sources of payment for the amount billed?

Mark (X) all that apply.

PROBE: **Any other sources of payment?**

01 ☐ Private insurance
02 ☐ Own income, family support, Social Security benefits, retirement funds
03 ☐ Supplemental Security Income (SSI)
04 ☐ Medicare
05 ☐ Medicaid
06 ☐ Other government assistance or welfare
07 ☐ Religious organizations, foundations, agencies
08 ☐ VA contract, pensions, or other VA compensation
09 ☐ Payment source not yet determined
10 ☐ Other – *Specify* ↙

_____

99 ☐ Don't know

HAND FLASHCARD 12.

24. What was the PRIMARY (expected) source of payment (for this bill/when billed)?

Mark (X) only one box.

01 ☐ Private insurance
02 ☐ Own income, family support, Social Security benefits, retirement funds
03 ☐ Supplemental Security Income (SSI)
04 ☐ Medicare
05 ☐ Medicaid
06 ☐ Other government assistance or welfare
07 ☐ Religious organizations, foundations, agencies
08 ☐ VA contract, pensions, or other VA compensation
09 ☐ Payment source not yet determined
10 ☐ Other – *Specify* ↙

_____

99 ☐ Don't know

FILL SECTIONS C AND D ON THE COVER OF THIS FORM.

NOTES

FORM **HHCS-20**
(5-22-92)

U.S. DEPARTMENT OF COMMERCE
BUREAU OF THE CENSUS
ACTING AS COLLECTING AGENT FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. PUBLIC HEALTH SERVICE
CENTERS FOR DISEASE CONTROL
NATIONAL CENTER FOR HEALTH STATISTICS

FLASHCARD BOOKLET

NATIONAL HOME AND HOSPICE CARE SURVEY

(Cut along broken lines)

FACILITY CARD 1

1. **FOR PROFIT** – includes individual or private, partnership, corporation

2. **NONPROFIT** – includes church-related, nonprofit corporation, other nonprofit ownership

3. **STATE OR LOCAL GOVERNMENT** – includes State, county, city, city-county, hospital district or authority

4. **FEDERAL GOVERNMENT** – includes USPHS, Armed Forces, Veterans Administration

5. **OTHER**

FACILITY CARD 2

FACILITY CARD 1 (Left)

FACILITY CARD 2 (Right)

EMPLOYEES ON PAYROLL (as of last pay period)

Full-time (35 or more hours per week)

Employed
Budgeted vacant positions

Part-time (less than 35 hours per week)

Employed
Budgeted vacant positions

SERVICES PROVIDED DURING THE LAST PAY PERIOD

Total hours worked by full-time and part-time staff
Total hours of service provided by those not on your payroll
Total visits made

TYPE OF EMPLOYEE

Physicians
Registered nurses
Licensed practical or vocational nurses
Nursing aides and attendants
Home health aides
Homemakers/Personal caretakers
Dieticians/Nutritionists
Occupational therapists
Speech pathologists and audiologists
Physical therapists
Social workers
Health educators
Pastoral/Bereavement staff
Administrator/Director
Case manager/Case coordinator
Secretarial/Clerical
Other health personnel
Other personnel

(Cut along broken lines)

PATIENT CARD 1

1. White
2. Black
3. American Indian, Eskimo, Aleut
4. Asian, Pacific Islander

PATIENT CARD 2

1. **PRIVATE RESIDENCE** – house or apartment, rented or owned

2. **RENTED ROOM, BOARDING HOUSE** – room or boarding house open to anyone as defined by the landlord for rental payment

3. **RETIREMENT HOME** – a retirement facility that provides room and board to elderly or impaired persons; often includes a separate hospice wing or unit that provides nursing, medical, personal care, etc., to those needing it

4. **BOARD AND CARE OR RESIDENTIAL CARE FACILITY** – a facility having three beds or more and that provides personal care or supervision to its residents, not just room and board (for example, help with bathing, dressing, eating, walking, shopping, or corresponding)

5. **OTHER TYPE OF HEALTH FACILITY (including mental health facility)** – other facility or institution that provides lodging, board, and social and physical care including the recording of health information, dietary supervision and supervised hygienic services for three or more patients not related to the operator

6. **OTHER**

PATIENT CARD 1 (Left)

PATIENT CARD 2 (Right)

(Cut along broken lines)

PATIENT CARD 3

1. Self/Family
2. Nursing home
3. Hospital
4. Physician
5. Health department
6. Social service agency
7. Other

PATIENT CARD 4

1. Spouse
2. Parent
3. Child
4. Daughter- or son-in-law
5. Other relative
6. Neighbor
7. Friend
8. Volunteer group
9. Other

PATIENT CARD 3 (Left)

PATIENT CARD 4 (Right)

(Cut along broken lines)

PATIENT CARD 5

1. Eye glasses (including contact lenses)
2. Dentures (full or partial)
3. Hearing aid
4. Wheelchair
5. Cane
6. Walker
7. Crutches
8. Brace (any type)
9. Oxygen
10. Hospital bed
11. Commode
12. Other aids or devices

PATIENT CARD 6

1. **PARTIALLY IMPAIRED** – cannot read newspaper print but can watch television 8 to 12 feet away

2. **SEVERELY IMPAIRED** – cannot watch TV 8 to 12 feet away, but can recognize the features of familiar persons if they are within 2 to 3 feet

3. **COMPLETELY LOST, BLIND**

PATIENT CARD 5 (Left)

PATIENT CARD 6 (Right)

(Cut along broken lines)

PATIENT CARD 7

1. **PARTIALLY IMPAIRED** – can hear MOST of the things a person says

2. **SEVERELY IMPAIRED** – can hear only a few words a person says or loud noises

3. **COMPLETELY LOST, DEAF**

PATIENT CARD 8

a. **BATHING or SHOWERING** – washing the whole body; includes the process of getting in or out of tub/shower

b. **DRESSING** – getting clothes from closets/drawers and putting them on. Includes managing buttons, zippers, and other fasteners; excludes tying shoes

c. **EATING** – getting food from plate to mouth; excludes assistance with cutting meat or buttering bread

d. **TRANSFERRING IN OR OUT OF BEDS OR CHAIRS** – getting into and out of bed or getting into and out of a chair/wheelchair

e. **WALKING** – moving from one place to another by advancing the feet and legs in turn at a moderate pace

f. **USING THE TOILET ROOM** – going to the toilet, transferring on and off the toilet, cleaning self after elimination and arranging clothes; excludes bowel and bladder functioning

PATIENT CARD 7 (Left)

PATIENT CARD 8 (Right)

(Cut along broken lines)

PATIENT CARD 9

a. Doing light housework

b. Managing money

c. Shopping for groceries or clothes

d. Using the telephone (dialing or receiving calls)

e. Preparing meals

f. Taking medication

PATIENT CARD 10

1. **SKILLED NURSING SERVICES** – coordination by an R.N. or an L.P.N. of a care plan; e.g., catheterization, injection
2. **PERSONAL CARE** – aid in bathing, dressing, using the toilet, getting in and out of bed, eating, or walking
3. **SOCIAL SERVICES** – counseling, advocacy coordination, information, referrals; e.g., legal aid, job, housing assistance
4. **COUNSELING** – counseling and/or therapy that assists the patient in minimizing stresses and problems that arise from social, economical, or psychological situations and that assists the patient in maximizing positive aspects and opportunities for growth
5. **MEDICATIONS** – providing prescription medication
6. **PHYSICAL THERAPY** – from a certified or licensed physical therapist; treatment to restore function, relieve pain
7. **HOMEMAKER/COMPANION SERVICES** – services that are necessary for maintaining a safe and healthy home environment for the patient (e.g., cleaning the patient's kitchen, doing personal laundry, preparing meals) and other services to enable the patient to remain at home
8. **RESPITE CARE** – care provided to the patient in the home or inpatient setting to relieve the family or primary caregiver, due to family psychological problems, caregiver fatigue, or required short-term absence of the caregiver
9. **REFERRAL SERVICES** – referral to other sources for services that are not provided by the facility
10. **DIETARY AND NUTRITIONAL SERVICES** – direct counseling by a trained nutritionist; does NOT include supervision of special diets
11. **PHYSICIAN SERVICES** – evaluation and/or treatment from a licensed M.D. (not including psychiatrist), D.O., or physician associate
12. **HIGH TECH CARE** – specialized care, in the home: examples include; respirator/ventilation therapy, IV therapy, chemotherapy, renal dialysis, etc.
13. **OCCUPATIONAL THERAPY/VOCATIONAL THERAPY** – from a registered or licensed occupational therapist; special restorative treatment
14. **SPEECH THERAPY/AUDIOLOGY** – evaluation, treatment, and monitoring of specific communication disorder(s)
15. **TRANSPORTATION** – provision of transportation
16. **ENTEROSTOMAL THERAPY** – therapy designed to teach the proper method of caring for an ostomy site or caring for an ostomy site
17. **MEALS ON WHEELS** – program that provides regular delivery of food to elderly and handicapped persons with limited mobility. Often provided through a volunteer network
18. **OTHER SERVICES**

PATIENT CARD 9 (Left)

PATIENT CARD 10 (Right)

(Cut along broken lines)

PATIENT CARD 11

1. Registered nurses
2. Licensed practical or vocational nurses
3. Nursing aides and attendants
4. Home health aides
5. Homemakers/Personal caretakers
6. Social workers
7. Physical therapists
8. Physicians
9. Occupational therapists
10. Speech pathologists and audiologists
11. Dieticians/Nutritionists
12. Health educators
13. Volunteers
14. Other providers

PATIENT CARD 12

1. Private insurance
2. Own income, family support, Social Security benefits, retirement funds
3. Supplemental Security Income (SSI)
4. Medicare
5. Medicaid
6. Other government assistance or welfare
7. Religious organizations, foundations, agencies
8. VA contract, pension, or other VA compensation
9. Payment source not yet determined
10. Other

PATIENT CARD 11 (Left)

PATIENT CARD 12 (Right)

(Cut along broken lines)

1991

JANUARY

S	M	T	W	T	F	S
		(1)	2	3	4	5
6	7	8	9	10	11	12
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20	(21)	22	23	24	25	26
27	28	29	30	31		

FEBRUARY

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24	25	26	27	28		

MARCH

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31						

APRIL

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MAY

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JUNE

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30						

◯ Holiday

JULY

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AUGUST

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25	26	27	28	29	30	31

SEPTEMBER

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8	9	10	11	12	13	14
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OCTOBER

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6	7	8	9	10	11	12
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27	28	29	30	31		

NOVEMBER

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3	4	5	6	7	8	9
10	(11)	12	13	14	15	16
17	18	19	20	21	22	23
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DECEMBER

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22	23	24	(25)	26	27	28
29	30	31				

1992

JANUARY

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			(1)	2	3	4
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19	(20)	21	22	23	24	25
26	27	28	29	30	31	

FEBRUARY

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16	(17)	18	19	20	21	22
23	24	25	26	27	28	29

MARCH

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22	23	24	25	26	27	28
29	30	31				

APRIL

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MAY

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17	18	19	20	21	22	23
24	(25)	26	27	28	29	30
31						

JUNE

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7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

JULY

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19	20	21	22	23	24	25
26	27	28	29	30	31	

AUGUST

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23	24	25	26	27	28	29
30	31					

SEPTEMBER

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6	(7)	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

OCTOBER

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				1	2	3
4	5	6	7	8	9	10
11	(12)	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

NOVEMBER

S	M	T	W	T	F	S
1	2	3	4	5	6	7
8	9	10	(11)	12	13	14
15	16	17	18	19	20	21
22	23	24	25	(26)	27	28
29	30					

DECEMBER

S	M	T	W	T	F	S
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	(25)	26
27	28	29	30	31		

◯ Holiday

SAMPLE SELECTION TABLE [1 - 3,000]

Total # Listed	Sample Line Numbers					
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2	1	2				
3	1	2	3			
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7	1	2	3	4	5	6
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31	5	10	15	20	25	30
32	2	7	12	17	22	27
33	6	11	16	21	26	31
34	4	9	14	19	24	29
35	4	9	14	19	24	29
36	6	12	18	24	30	36
37	6	12	18	24	30	36
38	4	10	16	22	28	34
39	2	8	14	20	26	32
40	4	10	16	22	28	34
41	1	7	13	19	25	31
42	2	9	16	23	30	37
43	3	10	17	24	31	38
44	4	11	18	25	32	39
45	2	9	16	23	30	37
46	1	8	15	22	29	36
47	5	12	19	26	33	40
48	7	15	23	31	39	47
49	4	12	20	28	36	44
50	6	14	22	30	38	46

NOTE: This is the first page of sample selection table [1–3,000]

*U.S. Government Printing Office: 1994 — 301-019/00010

Reviews of New Reports

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

National Hospital Discharge Survey: Annual Summary, 1991

Series 13–114
(PHS) 93–1775

Authors: Graves, E.J. and Kozak, L.J.

For information contact:

Kathy Brannan
Scientific and Technical Information Branch
6525 Belcrest Road, Rm. 1064
Hyattsville, MD 20782

Tel: (301) 436-8500

An estimated 31.1 million patients, excluding newborn infants, were discharged from short-stay non-Federal hospitals in the United States in 1991. This and other inpatient data are presented in a new report from the National Center for Health Statistics (NCHS).

Inpatients in 1991 used 199.1 million days of hospital care. The average length of stay was 6.4 days and the discharge rate was 124.1 discharges per 1,000 civilian population. These statistics, along with other inpatient data by diagnosis, procedures, sex, age, and geographic region, are presented in the NCHS report, *National Hospital Discharge Survey: Annual Summary, 1991.*

Of the 31.1 million patients discharged, 68 percent underwent one or more surgical, diagnostic, or therapeutic procedures. Approximately 14 percent of all surgical procedures and 20 percent of all nonsurgical procedures were performed on patients 75 years of age and over.

According to the report, 165,000 patients with a diagnosis of human immunodeficiency virus (HIV) infection were discharged from short-stay hospitals in 1991. This figure contrasts sharply with the 10,000 HIV patients discharged in 1984, the first year that HIV discharge statistics were collected for this study.

Data on hospital discharges are collected through NCHS' annual National Hospital Discharge Survey. Information is obtained from a national sample of the hospital records of discharged inpatients.

Copies of this report can be obtained from the U.S. Government Printing Office by using the order form on the back of this release.

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

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SERIES 22. **Data From the National Mortality and Natality Surveys**—Discontinued in 1975. Reports from these sample surveys, based on vital records, are now published in Series 20 or 21.

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SERIES 24. **Compilations of Data on Natality, Mortality, Marriage, Divorce, and Induced Terminations of Pregnancy**—These include advance reports of births, deaths, marriages, and divorces based on final data from the National Vital Statistics System that were published as supplements to the *Monthly Vital Statistics Report* (MVSR). These reports provide highlights and summaries of detailed data subsequently published in *Vital Statistics of the United States*. Other supplements to the MVSR published here provide selected findings based on final data from the National Vital Statistics System and may be followed by detailed reports in Series 20 or 21.

For answers to questions about this report or for a list of reports published in these series, contact:

Data Dissemination Branch
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Centers for Disease Control and Prevention
Public Health Service
6525 Belcrest Road, Room 1064
Hyattsville, MD 20782

(301) 436–8500

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