

DEVELOPMENT OF THE NATIONAL HOME AND HOSPICE CARE SURVEY

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The National Center for Health Statistics (NCHS) collects and disseminates data covering many aspects of the health field, including births, deaths, overall health status, and the use of health care providers.

Statistical information about health providers is collected and maintained by NCHS in the National Health Provider Inventory (NHPI). The NHPI contains information on inpatient facilities such as nursing and related-care homes and on hospices and home health agencies. In addition to data about health care providers, NCHS also collects information on client populations served by these providers.

The National Home and Hospice Care Survey (NHHCS) is one of the newest of these surveys. This survey will be implemented in September 1992 and will be conducted annually. Data from this survey will provide estimates on the use of home and hospice care services, the characteristics of the people using these services, the types of services provided, and the charges for these services.

FEASIBILITY STUDY

The first step in the development of the NHHCS was the Feasibility Study for Surveying Hospices and Home Health Agencies. This study was done in 1990; its purposes were 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 NHPI.

Sampling Frame and Sample Selection

There were two elements of interest in the Feasibility Study: the facility and the client served. The facility sampling frame was a list of hospices and home health agencies developed from lists of facilities 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. 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 facility.

The sample for the Feasibility Study was a multi-stage design. The first stage consisted of eight purposively selected Primary Sampling Units (PSU's) which were geographically dispersed throughout the contiguous United States and which included both urban and nonurban areas. Within each of the PSU's a systematic random sample of 192 facilities was selected -- ten hospices and fourteen home health agencies in each. Information was obtained about current and discharged patients from half of these facilities.

Data Collection Instruments

Three data collection instruments were used in the Feasibility Study: an Agency Questionnaire, an Administrator Questionnaire, and a Client Questionnaire.

The Agency Questionnaire included the types of facility data that were to be collected primarily through the NHPI such as identification information, operating status, type of ownership, Medicare and Medicaid certification, and information on the maintenance of clinical records by the facility. Also included were questions on the types of services provided by the facility, 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.

The Administrator Questionnaire was a shortened version of the Agency Questionnaire and included

facility data that were to be collected through the NHHCS. This included identification information, type of ownership of the facility, 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 was used to collect data on both current and discharged clients. Through this questionnaire information was obtained about clients' demographic characteristics including their home environment; services provided to the clients; health and functional status of the clients, including presenting diagnoses; charges and sources of payment for the services provided; sources of referral to the facility; date of enrollment and, for discharged clients, date, status, and reason for discharge. Sources of the information used to answer the items on this questionnaire were also 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.

Data Collection Methods

The Study itself was done in two phases. In Phase I (the NHPI part) the Agency Questionnaire was mailed to all of the 192 sample facilities. Facilities not responding to the first mailout received a second questionnaire. If no response was received to the second mailout, a telephone contact was made with the facility. An interview was then conducted by telephone in which the information on the Agency Questionnaire was obtained.

Half (96) of the facilities selected for Phase I were randomly selected to participate in Phase II (the NHHCS part). Five hospices and seven home health agencies were selected in each of the eight PSU's. These 96 facilities were then randomly

assigned to one of two groups. Interviewers contacted both groups by telephone to gain their participation and to set up an appointment with the facility administrator.

At the appointed time, the interviewer met with the facility administrator to conduct the interview using the Administrator Questionnaire. With the cooperation of the facility staff, the interviewer then constructed two client sampling lists: one of current clients and one of discharges. In facilities selected as home health agencies only home health clients were listed, and only hospice clients were listed in facilities 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 facilities 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 facility staff designated by the administrator. In the facilities 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. When the interviewer returned to these facilities to collect the completed questionnaires, the interviewer verified the information reported in half of them either by interviewing the staff member who completed the questionnaires or by abstracting the data from the patient's medical records.

Results of the Feasibility Study

The major finding of the Feasibility Study is that data about hospices, home health agencies, and the patients they serve are available and can be collected through a national survey.

Some procedural changes were made for the pretest. The pretest was an entirely interviewer-administered survey rather than partially self-

administered. 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%) than for the self-administrator group (91%). Moreover, the interviewers have to visit the facility anyway to construct the sampling lists and to draw the sample.

Other procedural changes made for the pretest include the use of a table, rather than a programmable calculator, to select the sample cases; the selection of five current patients and five discharges per facility rather than four each; and a change in the reference period for discharges. In the Feasibility Study, all discharges in the previous calendar year were used for the sampling frame; for the pretest, all discharges during the twelve month period as of midnight of the day before the day of the survey (the interviewer's visit date) were used.

Changes were also made to the questionnaires as a result of the Feasibility Study. One facility questionnaire and two patient questionnaires (one for current patients and one for discharges) were used for the pretest. Two separate patient questionnaires were used because results of the Feasibility Study indicated that using only one questionnaire for the two different types of patients was confusing. More detailed staffing information but less patient information was collected on the facility questionnaire. The numbers of hospice and of home health patients were obtained only for those facilities indicating that both hospice and home health care were their primary type of service. Facilities were considered to be out of scope for the survey if the administrator responded that neither hospice nor home health care was their primary service function.

Many of the items on the patient questionnaires were reworded to allow for the fact that

hospices and home health agencies serve a wider variety of patients than are usually served by more traditional long-term care facilities. Data items added included 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 are those who have 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 facility (for example, they may not have met the requirements of the facility for provision of services or they may have elected not to receive services from the facility).

PRETEST FOR THE NATIONAL HOME AND HOSPICE CARE SURVEY

The pretest, the "dress rehearsal" for the NHHCS, was conducted in 1991. The purpose of the pretest was to evaluate all aspects of the data collection plans that were to be used in conducting the final survey.

Sampling Frame and Sample Selection

The sampling frame for the pretest consisted of 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 facilities were selected for participation.

The ultimate sampling unit for the pretest was the patient served by each facility. The design used to select the patients was a multi-stage design. The first stage consisted of five purposively selected PSU's that were geographically dispersed throughout the contiguous United States and that included

facilities in both urban and nonurban locations. The second stage consisted of the selection of twenty facilities within each PSU.

The third stage of sample selection consisted of a systematic probability sample of five current patients and five discharges selected from lists that were prepared by the interviewer during the visit to the facility.

Data Collection Instruments

Three data collection instruments, all completed by personal interview, were used in the pretest: a Facility Questionnaire, a Current Patient Questionnaire, and a Discharged Patient Questionnaire.

Facility data was collected through the Facility Questionnaire and included identification information, type of ownership, and Medicare and Medicaid certification. The Facility Questionnaire also included questions on the types of personnel providing the services and a few questions on the types of services provided.

The Current and Discharged Patient Questionnaires were very similar. The information collected through these questionnaires included data on the patients' 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 facility; date of admission, and, for discharged patients, date and reason for discharge.

Data Collection Methods

The pretest began with the mailing of a letter to the administrators of the sampled facilities to inform them of the survey. An interviewer then contacted each facility by telephone to gain their participation and to set up an appointment with the facility

administrator.

At the appointed time, the interviewer met with the facility administrator to conduct the interview using the Facility Questionnaire. With the cooperation of facility staff designated by the administrator, the interviewer then constructed two lists: one of current patients and one of discharges. Using a sample selection table, the interviewer drew a systematic random sample of five current patients and five discharges. 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 facility staff. 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 facility.

Results of the Pretest

Very few changes were made as a result of the pretest. A sample of six current patients and six discharges will be selected for the National Survey (compared to five each for the pretest). The reference period for discharges will be the last twelve months as of the last day of the of the month prior to the interview rather than as of the day prior to the interview. If necessary, discharges for less than a 12 month period will be accepted as long as the available time period can be identified and it falls within the 12-month reference period of the NHHCS. The interviewers will also be instructed to make return visits to the facilities if necessary in order to obtain the information requested. In addition, the facilities will be able to mail in the staffing information collected on the Facility Questionnaire if additional time is required to respond to that item. Some re-wording and re-ordering of data items was done to the questionnaires as a result of the pretest. A few items were

deleted and some were added to the questionnaires.

The item in the Facility Questionnaire asking for the primary service category of the facility was deleted. Instead, the facility administrator will be asked a series of questions to determine if the facility currently provides home health or hospice care services, if the facility provided these types of services to patients during the past twelve months, and if the facility currently has any active home health or hospice care patients. If the answers to all three of these questions is "No", the facility will be considered out of scope for the survey.

An item was added to the patient questionnaires asking for the types(s) of care the patient received from the facility (hospice, home health, or other). The next of kin item was deleted from the patient questionnaires. The pretest results indicated that it is possible to obtain this type of information; however, it will not be collected by the NHHCS until follow-up studies will be done.

THE NATIONAL HOME AND HOSPICE CARE SURVEY

The National Home and Hospice Care Survey (NHHCS) will begin operation in September 1992 and will be conducted annually.

Sampling Frame and Sample Selection

The sampling frame for the 1992 NHHCS is the hospice and home health agency part of the 1991 NHPI. A representative sample of 1,500 facilities was selected.

The elementary sampling unit of the NHHCS is the patient served by the facility. The design used to select the patients is a three-stage design. The first stage consists of 112 PSU's that comprise a probability subsample of PSU's used in the 1985-94 NCHS National Health Interview Survey. Within each

PSU, a systematic sample of hospices and home health agencies was selected with probability proportional to the annual patient size.

In the third stage, a systematic probability sample of current patients and discharges will be done using a sample selection table. The sampling will be done from lists that the interviewers construct for each facility, as was done in the pretest.

Data Collection Instruments and Methods

As in the pretest, three data collection instruments will be used (a Facility Questionnaire, a Current Patient Questionnaire, and a Discharged Patient Questionnaire) and all of them will be completed by personal interview.

Facility data will be collected through the Facility Questionnaire. This includes identification information, type of ownership, and Medicare and Medicaid certification. This questionnaire also includes questions on the numbers and types of patients served, the types of personnel providing the services, and some questions on the types of services provided.

The Current and Discharged Patient Questionnaires are very similar both 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 provided to the patient (home health or hospice) was added.

Except for the changes mentioned earlier, the data collection procedures for the National Survey are the same as those used for the pretest. Perhaps next year we'll be able to report on some of the findings of the first year of operation of the NHHCS.