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# Redesign and Operation of the National Home and Hospice Care Survey, 2007



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

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Program and Collection Procedures

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

Hyattsville, Maryland  
July 2010  
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**Objectives**

This methods report provides an overview of the redesigned National Home and Hospice Care Survey (NHHCS) conducted in 2007. NHHCS is a national probability sample survey that collects data on U.S. home health and hospice care agencies, their staffs and services, and the people they serve. The redesigned survey included computerized data collection, greater survey content, increased sample sizes for current home health care patients and hospice care discharges, and a first-ever supplemental survey called the National Home Health Aide Survey.

**Methods**

The 2007 NHHCS was conducted between August 2007 and February 2008. NHHCS used a two-stage probability sampling design in which agencies providing home health and/or hospice care were sampled. Then, up to 10 current patients were sampled from each home health care agency, up to 10 discharges from each hospice care agency, and a combination of up to 10 patients/discharges from each agency that provided both home health and hospice care services. In-person interviews were conducted with agency directors and their designated staff; no interviews were conducted directly with patients. The survey instrument contained agency- and person-level modules, sampling modules, and a self-administered staffing questionnaire.

**Results**

Data were collected on 1,036 agencies, 4,683 current home health care patients, and 4,733 hospice care discharges. The first-stage agency weighted response rate (for differential probabilities of selection) was 59%. The second-stage patient/discharge weighted response rate was 96%. Three public-use files were released: an agency-level file, a patient/discharge-level file, and a medication file. The files include sampling weights, which are necessary to generate national estimates, and design variables to enable users to calculate accurate standard errors.

**Keywords:** home health • hospice • long-term care • agencies

# Redesign and Operation of the National Home and Hospice Care Survey, 2007

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National Center for Health Statistics, Office of Research and  
Methodology

## Introduction

The National Home and Hospice Care Survey (NHHCS) is a periodic, nationally representative sample survey of home health and hospice care agencies in the United States. NHHCS was inaugurated in September 1992 (preceded by a feasibility test in 1990 and a pretest in 1991) by the National Center for Health Statistics (NCHS) as part of the long-term care component of the National Health Care Surveys (NHCS) (1). NCHS surveys are legislated under the National Health Survey Act (P.L. 84-652) of 1956. Section 306 (42 U.S.C. 242k) of the Public Health Service Act authorizes NCHS to collect statistics on health resources and the utilization of health care, which includes “home health agencies and other health institutions” (2).

Originally designed as an annual paper-and-pencil, interviewer-administered questionnaire that collected basic information on home health and hospice care agencies (1), NHHCS was first conducted in 1992 and repeated in 1993, 1994, 1996, 1998, and 2000. Data collected during these early years included agency certification status, patient health status and sources of payment for care, and characteristics of the staff employed by the agencies. After 2000, NHHCS was taken out of the field to be redesigned. When the survey was reintroduced into the field in 2007, it was administered by a private

contractor; in previous years, the survey had been administered by the U.S. Census Bureau. This report describes the redesign of NHHCS and the methods used to collect information on home health and hospice care agencies in the 21st century.

## Background

Several factors contributed to the NHHCS redesign. Increasingly, persons aged 65 and over—who are expected to account for nearly 20% of the U.S. population by the year 2030 (3)—are choosing to remain in their communities as they age (4). Many of these elderly persons live with complex medical needs and disability resulting from chronic illness (5) and can benefit from the assistance of home health care agencies. Postacute patients discharged from hospitals following surgery or other acute episodes receive care from home health care agencies as well. In 1999, the U.S. Supreme Court ruled in *Olmstead v. LC* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court also ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities. These decisions encouraged the provision of community-based care (when desired

and possible) for persons of all ages living with disabilities (6).

More Americans are also becoming aware of and open to hospice care, leading more people to choose hospice care in the final stages of life. According to the Centers for Medicare & Medicaid Services (CMS), the number of Medicare hospice patients more than doubled between 1998 and 2008; the average length of stay for hospice patients increased by 48% during that time (7). As the number of patients served by home health and hospice care agencies increases, the long-term care industry is working to enhance its services and technologies—such as special end-of-life programs, pain management alternatives, and electronic information systems to track patient care—to provide high-quality care.

In previous years, NHHCS collected a limited amount of data on patients (e.g., demographics, medical conditions, and functional ability) and agency characteristics. In 2000, CMS required that Medicare-certified home health care agencies submit health data on their patients, thereby creating another public source of home health care data. Other data collection efforts such as the 1996 Medical Expenditure Panel Survey—Nursing Home Component, the National Long-term Care Survey (1982–2004), the ongoing Medicare Current Beneficiary Survey, and the annual National Hospice and Palliative Care Organization's National Data Set Survey obtain related information. NHHCS was redesigned to complement these data sources and to provide more data on patient services, treatments, and outcomes, as well as on agency characteristics, to allow the exploration of relationships between patient and provider characteristics and patient outcomes. The resulting 2007 NHHCS collected valuable data on changes and developments in this important sector of the nation's long-term care system.

## Redesign Process

NHHCS was redesigned in response to new developments in the home health

and hospice care sectors, including changes in reimbursement systems and performance monitoring. The survey was expanded to better meet the data needs of researchers and health care planners who are working to ensure that high-quality long-term care will be available for younger persons with disabilities and for the nation's growing senior population. The original survey items were developed in the early 1990s to address the growth in what was then a relatively new sector of the health care system: home health and hospice care. Between 1990 and 1996, Medicare had a more than fourfold increase in home health care expenditures, largely due to an increase in the number of visits per home health care patient; spending increased from \$4 billion to \$17 billion (8).

Following that period, the use of home health care declined dramatically through 2000, which resulted in many agencies closing. This occurred in part because of the Medicare interim payment system that, starting in October 1997, lowered the payment limits per home health care visit and imposed a per-beneficiary average cost limit on home health care agencies. Another reason for the dramatic decline was the Medicare prospective payment system, which went into effect in 1999 and further drove reductions in home health care utilization. The addition of quality indicators derived from the Outcome and Assessment Information Set (OASIS) and public reporting of quality measures by CMS, which aggregates home health care patient information and reports it at the agency level, also contributed to changes in the delivery of home health care.

Changes in payment for home health and hospice care services in the late 1990s, changes in the overall health care system, and the major redesign of the National Nursing Home Survey (NNHS) in 2004 led to the redesign of NHHCS. The survey was redesigned to collect the following information:

- National baseline data on the characteristics of home health and hospice care agencies, their services, and their patients, regardless of whether they were participating in

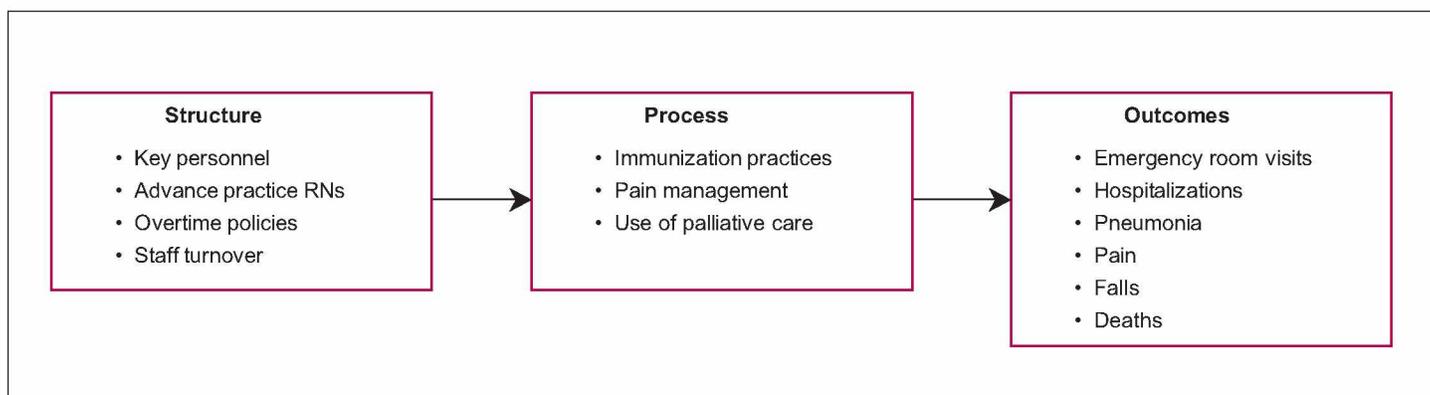
publicly administered systems of health insurance, such as Medicare and Medicaid.

- Agency and patient data on utilization, services offered, charges for care, and quality of care, including specific information on end-of-life care.
- Information about priority populations and disparities in care.
- Information about agency staffing characteristics, such as staffing mix, educational preparation, and turnover rates.

In addition to changes in the content of NHHCS, other aspects of the survey (i.e., sampling design, the data collection instrument, and field procedures) were redesigned. The overall redesign of NHHCS was informed by the NNHS redesign, also conducted by NCHS. The conceptual model for the redesign process of both NHHCS and NNHS was Donabedian's model of structure-process-outcomes: structure influences process, which in turn produces outcomes (9). For example, structural elements of home health care, such as key personnel, advance practice registered nurses, overtime policies, and staff turnover, are thought to be factors associated with various processes, such as immunization practices and the use of palliative care. These processes in turn may be studied in relation to various outcomes among patients, such as emergency room visits and hospitalizations, pneumonia, falls, pain management, and death (see [Figure 1](#)).

## Content Redesign

A number of key groups participated in the content redesign activities: NCHS experts in content, statistical analysis, and survey methods; NCHS' Board of Scientific Counselors; collaborating federal agencies; academicians and long-term care researchers; and industry representatives. Two separate technical advisory groups were convened—one for home health care and the other for hospice care—thus allowing each group to examine the distinct attributes of the two similar, but different, long-term care



**Figure 1. Application of Donabedian's model of assessing quality of medical care to home health and hospice care**

settings and to shape the survey redesign appropriately.

The initial NHHCS redesign work began in February 2001, when the Hospice Care Survey Technical Advisory Group met to discuss possible modifications to NHHCS and to the methods for gathering useful data about hospice patients. The group was charged with reviewing research and policy data needs for information about hospice patients and providers and developing recommendations for potential data items, sampling frames, and survey design changes. The group identified a number of important issues that the redesigned survey should address (see [Appendix I](#)). The following recommendations were incorporated into NHHCS:

- Understand how people are cared for and supported at the end of life and how resources are being used.
- Obtain empirical data on the volume of hospice care provided in this country and the outcomes of that care.
- Examine unplanned transfers from hospice to nursing home care and hospital.
- Examine the quality of hospice care in nursing homes.
- Monitor changes in access to, and the quality and cost of, hospice care, with a focus on staffing.
- Gain a better understanding of the types of providers involved in hospice and end-of-life care.
- Estimate the number of patients and family members receiving hospice services.

- Elucidate the treatments provided, standards of practice and performance, medical management, role of medical directors, and needs of hospice providers.
- Determine how well hospices implement advance directives.

Some of the subsequent NHHCS redesign activities overlapped with the redesign of NNHS. In January 2002, as the content for the 2004 NNHS was being finalized, an expert meeting of select Department of Health and Human Services stakeholders (i.e., the Agency for Healthcare Research and Quality, the Assistant Secretary for Planning and Evaluation, CMS, and NCHS) was convened. One outcome of this meeting was a "wish list" for the NCHS surveys of long-term care providers. Some survey items that were included in the redesigned NNHS were also considered for inclusion in the redesigned NHHCS. This wish list is given in [Appendix II](#), where items or related items in the 2007 NHHCS are noted with an asterisk. Not all of the wish list items were incorporated into the survey because of the infeasibility, time constraints, or cost of collecting the recommended item.

The Home Health Care Survey Technical Advisory Group met in January 2002. This meeting followed a format similar to the Hospice Care Survey Technical Advisory Group working meeting, in which previous versions of NHHCS were reviewed and research and policy questions for the redesigned survey were suggested and discussed. Suggested topics included the following:

- Limitations in access to care as measured by waiting lists for admission to programs or programs not accepting new admissions.
- Involvement of informal caregivers while patients receive home health care services.
- Impact of all reimbursement sources on types of care received.
- Home health care staffing information, such as number of employees, temporary employees and contract staff, hours worked, wages, availability of fringe benefits, recruitment, and retention measures.
- Variation in staffing practices and impact on patients.
- Factors correlated with rehospitalization.
- Level of computerized records in the industry: Are medical records computerized? Are management data computerized? Do agencies have any data from customer satisfaction surveys they conducted?
- Trends in special needs of nonelderly home health care patients, such as use of special equipment and devices and home modification.

The Home Health Care Survey Technical Advisory Group also prioritized home health care data items for the 2007 survey; these items are listed in [Appendix III](#).

In addition to expert opinion provided by the technical advisory groups, NCHS conducted an environmental scan of other relevant data collection efforts, both within the

federal system and through profit and not-for-profit agencies within the long-term care industry. This was done to determine what data gaps existed and the ways that NHHCS could provide data to fill these gaps. To the extent possible, items were used from existing survey instruments, including those that were not necessarily created for a nationally representative sample. The findings from the technical advisory groups and the environmental scan culminated in a new questionnaire that attempted to address the key recommendations of the various stakeholders. Although the technical advisory groups felt strongly that each component of NHHCS—home health care and hospice care—merited separate surveys, a combined survey was maintained and fielded for the following reasons: (a) a significant overlap in information relevant to both agency types and their patients; (b) the large number of agencies that provided both home health and hospice care services, which would have experienced an additional burden if asked to participate in two separate surveys; and (c) the substantial cost and personnel necessary to conduct separate surveys.

In April 2005, the draft questionnaire containing the proposed list of agency- and patient-level items was distributed to major stakeholders who participated in the technical advisory groups and other working groups, as well as to the members of the NCHS Long-term Care Listserv community, many of whom had used NHHCS data in the past. These individuals were asked to evaluate and rate each survey item based on its importance (i.e., extremely important, moderately important, or unimportant) and to provide NCHS with comments on the wording of the items. All of the comments were compiled, summarized, and reviewed by NCHS staff, who weighed the importance of the content and the participants' comments versus the feasibility of collecting the data. Some items were eventually eliminated from the survey based on experience gained in the redesigned NNHS. For example, some survey items (e.g., the reason that medication was prescribed and the adverse events experienced by

the patient) underperformed in the field and in the pilot test and pretest of the redesigned NHHCS, preventing NCHS from collecting the intended information. Although these items were highly relevant and important, obtaining valid and reliable responses for these items was found not to be feasible when they were piloted and pretested, hence these items were eliminated from the national survey. Four examples of such items are listed here:

- Number of full- and part-time clinical nurse specialists and nurse practitioners working in the agency. For the national survey, the item was changed to a “yes” or “no” response to indicate the presence or absence of these nursing staff.
- Whether the patient’s primary caregiver outside of the agency was paid for providing care to the patient.
- Independent activities of daily living.
- Frequency of the patient experiencing pain.

Finalizing the content redesign of NHHCS required many iterations and consultation with industry experts. The outcome of this effort led to the development of the survey content that was used in the pilot test, the pretest, and eventually in the national survey. Additional details on the pilot test and pretest are discussed later in this report.

## Sampling Redesign

The sampling redesign was another critical element of the overall NHHCS redesign and included consultation with NCHS’ Office of Research and Methodology. This section provides the context for the sampling design used in the 2007 NHHCS, which was different from the 2000 NHHCS sampling design. The 2000 NHHCS sampled six current patients and six discharges from three types of agencies (home health care only, hospice care only, and mixed); no attempt was made to distinguish patient type (i.e., home health versus hospice care and patients versus discharges) in mixed agencies. For the 2000 NHHCS, current patients were defined as those patients who were on the rolls of the

home health or hospice care agency as of midnight on the day immediately before the date of the agency interview. Also for the 2000 NHHCS, discharges were defined as those patients who were discharged from care by the home health or hospice care agency during a designated month within the 12-month period from October 1, 1999, through September 30, 2000; included were discharges that occurred because of the death of the patient.

In contrast to the sampling design for the 2000 NHHCS, the 2007 NHHCS sampled only current home health care patients and only hospice care discharges. The 2007 NHHCS sampling design was developed, after much deliberation, to address three key sampling-related challenges and to do so within available resources:

1. If discharges were to be sampled in the 2007 NHHCS, NCHS needed to create a closer link between agency characteristics and practices at the time of interview and experiences and outcomes of patients who had been discharged than occurred in the 2000 NHHCS. In the 2000 NHHCS, each agency was randomly assigned one month of the year from which to sample all patients discharged from that agency. For example, an interview with a home health agency in September 2000 collected information about that agency’s characteristics on the day of the interview in that month. That agency could have been randomly assigned to collect information on home health care patients discharged in October 1999. As a result, the agency data collected at the time of interview (in the example, September 2000) were not always relevant to the experience of the discharges (in the example, October 1999) who may have received care as far back as 6–12 months prior to the day of agency interview. This time gap made it difficult to establish the relationship between agency characteristics and patient experiences and outcomes. This was a particular concern because levels of administrative and nursing staffs in these agencies can fluctuate

dramatically over the course of 6–12 months.

2. The survey needed greater numbers of cases to generate reliable estimates for subgroup comparisons of persons receiving home health or hospice care. This challenge applied to both current and discharged patients. Several options were explored to achieve this primary goal of obtaining better estimates of subgroups that were underrepresented in previous NHHCS years. Examples of desired subgroup analyses include comparing cancer and cardiovascular disease rates between black persons and white persons and comparing rates of cancer and diabetes between younger and older patients.
3. Because an increasing number of agencies provide both home health care and hospice care, it was important to clearly identify patient type (home health or hospice) in these mixed agencies.

The first challenge (relevant only for discharges) was to strengthen the ability to link agency characteristics and practices at the time of interview closer in time to the experiences and outcomes of patients who had been discharged. This had to be done in a way that enabled NHHCS to continue to provide unbiased national estimates of the annual number of discharges. To address this challenge, we used the 2000 NHHCS data to explore the level of monthly variation and seasonality in admission diagnoses, as well as the number of discharges among home health care discharges and among hospice care discharges. Because diagnoses for home health care discharges were found to vary across months, obtaining a sample of these discharges for the 3 months around the time of the survey would produce a biased annual estimate. These findings influenced our decision not to sample home health care discharges in the 2007 NHHCS.

In contrast to home health care discharges, diagnoses for hospice care discharges did not vary much across months according to the 2000 NHHCS data; hence, an unbiased annual national

estimate of the number of hospice care discharges could still be made if the survey sampled hospice care discharges from agencies over only the 3-month period before the agency interview. Also, this approach made it possible to explore relationships between outcomes of hospice care discharges closer to the time of the agency interview (compared with the 2000 NHHCS) and agency characteristics and practices at the time of agency interview. Further, hospice patients have a relatively short stay—an average length of service of 47 days and a median length of service of 16 days for hospice care discharges in 2000 (10)—compared with home health care patients and nursing home residents. Hence, the 3-month sampling window would enable information to be collected on the entire episode of hospice care for many of the hospice care discharges. Another consideration in deciding whether to sample discharges or current patients among agencies providing hospice services was the fact that there are no national data on hospice care patients comparable to Medicare's OASIS data on home health care patients.

OASIS is a standardized assessment instrument used as part of a comprehensive assessment of all patients receiving skilled care that is reimbursable by Medicare or Medicaid. OASIS data, which include demographic, clinical, and functional information, are used to monitor the quality of patient care and to adjust reimbursement for patient case mix. Home health care agencies must submit these data to the states, which then transmit the data to CMS. Unlike with current home health care patients, agencies that provide hospice care services are not required to complete OASIS on hospice care patients; thus there are no comprehensive assessment data to link with current hospice care patients to create an entire episode of care. These factors influenced the decision to sample hospice care discharges only and not current hospice care patients in the 2007 NHHCS.

The third challenge in the sampling redesign involved distinguishing patient type in mixed agencies, which had been problematic in previous NHHCS

surveys. However, during the redesign process and the pilot test of the computer-assisted personal interviewing (CAPI) instrument for the 2007 survey, agencies were, in fact, able to distinguish patient type and could provide separate lists of home health care patients and hospice care patients. This enabled the number of each patient type sampled to be monitored and controlled and enabled the sampling of equal numbers of home health care patients and hospice care discharges. If a mixed agency did not have sufficient numbers of one patient/discharge type, a larger sample of the other patient/discharge type could be selected to reach the per-agency target. This helped NCHS to obtain the projected sample sizes of current home health care patients and hospice care discharges necessary for subgroup comparisons.

Distinguishing patient type in mixed agencies was also important in deciding how many home health care patients and hospice care discharges to sample in mixed agencies. This decision needed to be based on which was more important: making patient-level estimates by agency type (i.e., home health care only, hospice care only, and mixed) or making agency-level estimates by agency type. The 2000 NHHCS data showed that the sample of current home health care patients and hospice care discharges was not sufficient to make comparisons among agency types. Moreover, trend data from previous survey years indicated that the distribution of agency types had changed over time, with the percentage of mixed agencies increasing. Although it was initially believed that making comparisons by agency type was a reasonable objective, preliminary estimates indicated that the sample size of mixed-typed agencies would need to be doubled, which would make the cost of the survey prohibitive. This would also reduce the number of single-type agencies sampled, even though more patients actually receive care from such agencies, and would compromise our ability to make estimates of patient/discharge subgroups within single-type agencies. NCHS consulted with major trade associations (the National Association for Home Care and Hospice, the National Hospice and

Palliative Care Organization, and the American Board of Palliative and Hospice Medicine) and with the NCHS Board of Scientific Counselors. The consensus among these groups was that making comparisons by agency type was interesting but not a high priority for the industry; therefore, NCHS made this a secondary goal for the redesigned survey.

## Data Collection Instrument Redesign

A key enhancement to the 2007 NHHCS was the CAPI system—a departure from the paper-and-pencil mode used in previous surveys. The only part of the redesigned NHHCS that used paper and pencil was the self-administered staffing questionnaire (SAQ) that was mailed to agency directors in their confirmation packages. This strategy was also used for the 2004 NNHS. Because information on many of the staffing items needed to be retrieved from several different sources, the SAQ enabled administrators to gather this information prior to the survey interview, saving valuable administrative time during the onsite interview.

CAPI provided many benefits over the data collection approach used in previous years. First, the survey content could be expanded significantly, something that would have been burdensome to both the interviewer and respondent if the survey were administered by paper and pencil. Second, CAPI made it easier to collect data by patient type (e.g., questions on end-of-life care for hospice care discharges and use of assistive devices for home health care patients) because of the programmed skip patterns. Third, sampling algorithms programmed into CAPI made the sampling of patients and home health aides much easier than if it was conducted by hand. Fourth, CAPI had the potential to enhance data quality. The system included automatic data checks when responses were entered that were outside of predetermined ranges (i.e., “soft edits,” which issue a warning that can be ignored, and “hard edits,” which require a response within the expected range

before continuing), so that interviewers could verify out-of-range responses in real time, instead of post-data collection when the respondent was no longer available. Fifth, data could be transmitted electronically to the central office upon completion of the interview.

## Survey Supplement

The NHHCS redesign provided a national agency sample for conducting the first national probability sample survey of home health aides employed by home health and hospice care agencies—the National Home Health Aide Survey (NHHAS). This supplement was sponsored by the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services. The home health aides sampled in the NHHCS agencies were contacted to participate in NHHAS, which used computer-assisted telephone interviewing. More information on this supplement can be found in the NCHS report, “Design and Operation of the National Home Health Aide Survey: 2007–2008” (11).

## Field Procedures Redesign

The final element of the survey redesign involved redesign of the procedures that guided how information was collected before and during the field period. The increased survey content, modified sampling design, NHHAS survey supplement, and CAPI instrument made it necessary to modify field procedures that had been appropriate for the much smaller paper-and-pencil-based surveys conducted in previous years. The modified procedures affected how sampled agencies were verified and recruited, how field staff were recruited, and how data were collected and submitted to the central office of the data collection contractor for coding and editing.

An important component of redesigning the field procedures was the field management system, which was uploaded on the interviewers’ laptops to track all recruitment efforts and monitor the data collection activity on all sampled agencies. Before national data

collection began, sampled agencies were screened to update the information obtained from the agency sampling frame. This procedure allowed NCHS to confirm the agency name and address and to collect the current agency director’s name and title, agency hours, and days of operation before mailing out the advance packets. All changes to the agency contact information were entered into the field management system. Another feature within the field management system was the chain tracking function. Because of the increasing number of home health and hospice care chains in the industry, a strategy was developed to identify agencies belonging to chains. This included a management system for linking and tracking chain membership and contacts with corporate offices, training interviewers on handling chains when corporate approval was required, and providing an electronic form for interviewers to record chain contact information provided by the sampled agency.

Another detail about the redesigned field procedures is that many of the new survey items had an “other, specify” response option that interviewers could use to record responses that did not fit the standard response categories. These responses were evaluated by NCHS staff, who determined whether the responses could fit into existing response categories or warranted creating a new response category if there were enough cases.

After completion of each interview, the interviewers transmitted their agency interview files from their laptops to the contractor’s central office. When the central office had received all the case materials, the field management system indicated that the case was completed and officially closed.

Also important to the field procedures were the field interviewers themselves, who recruited the agencies and collected the data. Because of the new CAPI system, the NHHCS interviewers needed to have good computer skills.

Prior to national implementation of the 2007 NHHCS and its redesigned elements, the survey and procedures were pilot tested, cognitively tested, and

pretested. Below is an overview of these activities.

### Pilot test

The NHHCS pilot test, which collected agency- and person-level data on the participating agencies, had multiple purposes:

- To gain practical experience in getting home health and hospice care agencies to participate in NHHCS.
- To gain experience with, and identify any problems with, the CAPI modules and procedures in collecting data across multiple respondents within an agency.
- To test obtaining and cleaning the patient/discharge lists and the home health aide lists.
- To test the procedures for collecting contact information on the home health aides from their employers and to assess the quality of this information.

The NHHCS pilot test was administered in nine home health and hospice care agencies in May and June 2006. These agencies were located in six states.

### Cognitive testing

A number of the agency-level and patient/discharge items in the pilot test required substantial revision; a few others were deleted. Revisions were cognitively tested with a small sample of agency directors, by telephone. Additional instrument revisions were made as a result of the cognitive testing, including deleting a few more questions, making wording changes to others, adding or combining response options, and providing clearer definitions in the CAPI help screens.

### Pretest

The original goal of the pretest was to serve as a trial run for the national survey. Because the pilot test and the resulting cognitive testing resulted in many changes to the instrument, the pretest goals were modified to focus on the revised and new questions and procedures and to evaluate interviewers'

ability to complete data collection for each agency within a day's time according to the survey protocol. The NHHCS pretest was administered in 25 agencies across three states in November and December 2006.

The major outcome of the pretest was that NCHS reduced the number of sampled current home health care patients and hospice care discharges from 12 to 10 per agency. This would allow interviewers to complete each agency interview within a day. Additional survey questions were modified. A half day was added to the interviewer training to cover agency cooperation issues, chain issues, refusal aversion and conversion strategies, and appointment-setting and scheduling. Lastly, practice sampling lists from agencies with large patient populations were incorporated into the interviewer training to teach interviewers techniques for resolving issues related to cleaning patient lists, numbering patient lists, and other sampling problems.

## National Survey Methods

### Sampling Design and Selection

#### Agency eligibility criteria

The 2007 NHHCS sampled three types of agencies: home health care only, hospice care only, and mixed agencies that provided both home health and hospice care services. Sampled agencies were eligible to participate in NHHCS if they met the following criteria:

- They provided home health care services, hospice care services, or both types of services.
- They provided more services than only homemaker or housekeeping services or than only durable medical equipment and supplies.
- In the case of agencies providing home health care only, they had one or more current patients at the time of the agency interview.

- In the case of agencies providing hospice care only, they had one or more current patients or had one or more discharges during the 3-month period prior to the month of interview.
- In the case of agencies providing both home health and hospice care, they had one or more current home health or hospice care patients or had one or more hospice care discharges during the 3-month period prior to the month of interview.

Agencies that provided only homemaker or housekeeping services, assistance with instrumental activities of daily living (IADLs), or durable medical equipment and supplies were excluded from the survey.

### Sampling frame

NHHCS used a sampling frame of U.S. home health and hospice care agencies created from three sources: the National Hospice and Palliative Care Organization, Verispan, L.L.C., and the CMS Provider of Services file. Agencies affiliated with hospitals, government entities, retirement centers, or similar institutions where the agencies maintained financial and patient records independent of the larger institution were included in the frame. The combined files were matched, and identified duplicates were removed, resulting in a sampling frame of 15,488 agencies.

### Sampling design

Sampling for NHHCS used a stratified two-stage probability design. The first stage was the selection of agencies, where the primary strata of agencies were defined by agency type (i.e., home health care only, hospice care only, and mixed) and metropolitan statistical area (MSA) status. MSA status could be "metropolitan" (a county or group of contiguous counties that contain at least one urbanized area of 50,000 or more population; an MSA may contain other counties that are economically and socially integrated with the central county, as measured by commuting), "micropolitan" (a

nonmetropolitan county or group of contiguous nonmetropolitan counties that contains an urban cluster of 10,000–49,999 persons; surrounding counties with strong economic ties, measured by commuting patterns, may also be included), or “other,” according to information available on the sampling frame. For more information, visit: [http://www.whitehouse.gov/omb/inforeg\\_statpolicy/](http://www.whitehouse.gov/omb/inforeg_statpolicy/).

Within primary strata, facilities were sorted by the following characteristics: census region (Northeast, Midwest, South, or West), ownership (proprietary, nonprofit, government, or unknown), certification status (Medicare, Medicaid, or both), state, county, and ZIP Code. Agencies were then selected by using systematic sampling with probability proportional to agency size, using the number of employees to estimate size. This stage consisted of a two-phase sampling selection that yielded the final sample of 1,545 agencies that was fielded for the 2007 NHHCS.

The second stage was the selection of current patients for home health care-only agencies, discharges for hospice care-only agencies, and current home health care patients and hospice care discharges for mixed agencies. This stage was carried out by the interviewers during the agency interview, with the aid of an algorithm programmed into CAPI. The interviewer first collected the census list(s), usually from the agency director or designee. The census list of current home health care patients was the total number of patients on the agency rolls as of midnight on the day before the agency interview. The census list of hospice care discharges was the total number of hospice care patients discharged during a 3-month period starting 4 months before the agency interview. For example, if the agency interview was conducted in October 2007, then the census of hospice care discharges would include all discharges (e.g., deaths or patients terminating hospice services) for June, July, and August 2007. A hospice care patient could appear more than once on a list if the patient had been discharged, readmitted, and discharged again during the 3-month

sample period. After collecting these lists, the interviewer reviewed them to ensure there were no duplicates and that no current home health care patients had been discharged since the census was printed. The interviewer entered the total number of patients/discharges into the CAPI system, which randomly and systematically selected 10 numbers from the list of patients/discharges.

The target for patient sampling was 10 patients/discharges from every agency. A sample of 10 current home health care patients or hospice care discharges was selected per agency that had 10 or more current patients/discharges. If a sampled home health care-only agency or a sample hospice care-only agency had fewer than 10 patients or discharges, respectively, then all of the agency’s patients/discharges were selected for the sample. In mixed agencies, the sample of 10 was split evenly to include 5 patients and 5 discharges. In mixed agencies with fewer than 5 of one type (i.e., either current home health care patient or hospice care discharge), the full sample of 10 was augmented with the other type.

Home health aides employed by the participating agencies were also sampled during the agency interviews, using a process similar to the sampling of current home health care patients and hospice care discharges. Further information on the NHHAS is available from: <http://www.cdc.gov/nchs/nhhas.htm>.

## Interviewer Training

The 2007 NHHCS was launched in August 2007, immediately following the 5-day interviewer training. Eighty-six interviewers successfully completed the training and received their assignments. Seven additional interviewers were hired and trained for the survey in September 2007, using identical training methods. Both training sessions consisted of a home study that the interviewers completed prior to in-person training. The in-person training consisted of interactive lectures and exercises, scripted role plays, and self-administered exercises. The major topics covered in the training were as follows:

- Overview of the agency questionnaire.
- Agency cooperation issues.
- Current home health care patient and hospice care discharge sampling.
- Overview of the patient health questionnaire.
- Coding of medical conditions, procedures, and medications.
- Sources of payment and home health and hospice care financing.
- NHHAS sampling.
- SAQ.
- Overview of the field management system that tracked the status of each case (i.e., agency).
- Data quality control.
- Sampling errors.
- Finalizing cases.
- Ethics, data security, and confidentiality.

The field interviewer staff was divided into six regions, each managed by a field supervisor.

## Agency Recruitment

The agency recruitment process for NHHCS followed a logical progression from agency verification to agency interview. In June 2007, specially trained staff verified the name and address of each sampled agency, its hours of operation, and the name of its director, using the Advance Mail Screener script ([Appendix IV](#)). After the screener calls were completed and the eligibility of the sampled agencies was confirmed, an advance package (see [Appendix V](#)) was sent to each agency director. The package included materials that explained the survey and encouraged participation: an NHHCS folder, NHHCS brochure, advance letter from the NCHS director, Ethics Review Board (ERB) approval letter, ERB waiver of authorization, letters of support, an NCHS publication using 2000 NHHCS data, and an NCHS confidentiality brochure. The package also included a DVD with a video about NHHAS (viewable at: <http://www.cdc.gov/nchs/nhhas.htm>).

A similar package was created for use when two or more sampled agencies were part of the same chain. Experience

with chain affiliations during the 2004 NNHS guided NCHS' approach for tracking chains and their affiliate agencies in NHHCS. This corporate advance package (see [Appendix VI](#)) contained a corporate advance letter, an ERB approval letter and ERB waiver of authorization, letters of support, and an NHHCS video on DVD (viewable at: <http://www.cdc.gov/nchs/nhhcs.htm>). Additionally, the package enabled interviewers to let agency directors know that their parent organizations had been notified about NHHCS.

The mailings of agency and corporate advance packages were timed to occur a short time before the national interviewer training in late July. The trained field interviewers followed up on the agency advance packages, generally within 1 week of the mailing, using the Set an Appointment script ([Appendix VII](#)). During the appointment-setting calls, the interviewers confirmed receipt of the advance package, verified agency eligibility, addressed any questions or concerns expressed by the director, and attempted to schedule an agency interview. An appointment confirmation package (see [Appendix VIII](#)) was shipped overnight to the director of each appointed agency approximately 2 weeks before the interview. The confirmation package included an appointment confirmation letter and a list of key items for data collection, as well as the SAQ. The list of key items detailed the types of information (e.g., Medicare agency provider number and number of admissions and discharges for 2006) that would be collected during the agency interview and the type of staff needed to assist with data collection.

A week before the scheduled interview, the interviewer placed an appointment confirmation call to the agency director or the director's designee, using the Appointment Confirmation script ([Appendix IX](#)). During this call, the interviewer reviewed the items in the appointment confirmation package that had been sent to the director a few days earlier. The interviewer also discussed how to effectively prepare for the agency interview, verified the agency's address,

and answered any of the director's remaining questions.

Two business days before the scheduled appointment, the interviewer placed a reminder call to the agency director, using the Reminder Call script ([Appendix X](#)). If the director was not available, the interviewer was instructed to leave a message for the director as the final contact before the interview.

## Information for Survey Participants

In addition to the advance packages that were mailed to the agency directors (and corporate offices, when necessary), NCHS provided online information for survey participants that included an overview of NHHCS and its importance in providing data about the home health and hospice care industry. The Web page also had a list of frequently asked questions:

- What is the National Home and Hospice Care Survey?
- Why should my agency participate?
- How are home health and hospice care agencies selected?
- Is information given confidential?
- Does the HIPAA Privacy Rule allow my agency to participate in this survey?
- What is involved in participating?
- Whom can I contact if I have additional questions?

A link to the NHHCS DVD was also made available for survey participants.

## Refusal Conversion

Achieving a high response rate was an important goal of the NHHCS data collection. NCHS' experience with refusals in the 2004 NNHS was a key factor in developing and implementing a comprehensive NHHCS refusal conversion protocol early in the data collection period. The strategy was designed to provide interviewers with tools, including a distance learning program, to help them gain cooperation from agency directors who were initially reluctant or refused to participate in NHHCS. The strategy had six basic elements:

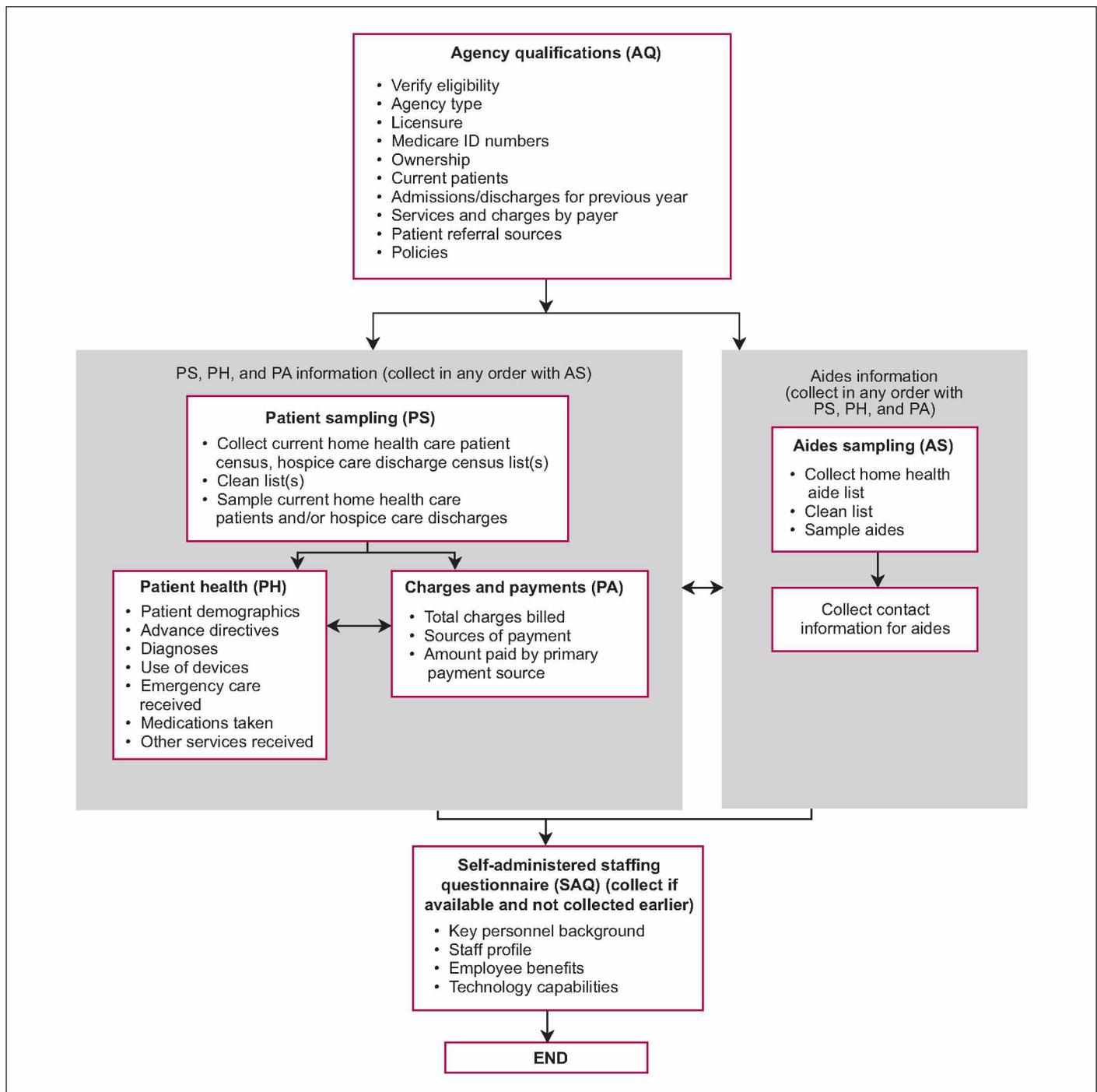
- Identifying reluctant agency directors early in the data collection period.
- Training a core of refusal converters, within 3 weeks of national training, who were successful in gaining cooperation quickly.
- Mailing a customized letter to reluctant directors within 1–14 days of initial contact with a field interviewer.
- Visiting reluctant agency directors in person within 15–30 days after the agency was identified as an initial refusal.
- Coordinating refusal conversion activities with the corporate offices of chain-affiliated agencies requiring corporate approval.
- Monitoring the progress of the NHHCS refusal conversion strategy.

A total of 32 interviewers were trained in refusal conversion. The converters completed a home study that included reading materials and two DVDs on gaining cooperation from chains, instructions on how to use the chain tracking system, related exercises, and five sets of case materials documenting various cooperation problems. The post-workshop component consisted of four conversion role plays conducted in pairs, by telephone.

## Survey Instrument and Data Collection

### CAPI System

One of the most significant changes to NHHCS was the shift from paper-and-pencil administration to computer administration. The NHHCS CAPI system was similar in form and function to that used in the 2004 NNHS. The CAPI system was loaded onto each interviewer's laptop, enabling the interviewer to enter data into the laptop during the agency interview. The CAPI instrument comprised five modules, as illustrated in the flow chart in [Figure 2](#): an agency qualifications module, two



**Figure 2. Flow chart of data collection during the National Home and Hospice Care Survey agency interview**

patient sampling modules to select current home health care patients and/or hospice care discharges and home health aides, and two person-level modules to collect patient health information and patient information on charges and sources of payment for care.

### **Agency Qualifications and Characteristics (AQ) module**

Although the CAPI system was flexible and allowed interviewers to administer the survey based on the availability of designated agency staff, the AQ module had to be administered first in

order to enable the other survey modules (see Figure 2.) After the AQ was completed, the patient sampling (PS) module was available in the CAPI system. It was necessary for interviewers to complete the PS module before collecting health and charges or billing information on the sampled patients. AQ survey items are provided in Appendix XI.

## Patient Health (PH) module

The PH module collected the same information on sampled current home health care patients as on sampled hospice discharges. Respondents for current home health care patients were asked if CMS' OASIS had been completed on the patient, and the most recent assessment date. Beginning in 1999, the federal government required that all Medicare-certified home health care agencies collect and submit health data on their patients to the (then) Health Care Financing Administration, as part of a quality improvement initiative (12). For several patient health questions, CAPI displayed the corresponding OASIS number, making it easier for the respondent to find the information in the sampled patient's OASIS, if available. Although the PH module asked similar questions about the health status of hospice care discharges, the collection of this information is not required by CMS. Respondents for current home health care patients were also asked about hospitalizations and life expectancy. For hospice care discharges, the PH module collected additional information on status at discharge (i.e., deceased or not), level of hospice care, symptoms at last visit, formal care or treatments at the last visit, and discharge reason and destination. PH survey items for the current home health care patients and hospice care discharges are provided in [Appendix XII](#).

## Charges and Payment (PA) module

The PA module collected information on charges and sources of payment for the care received by the sampled patients/discharges. For current home health care patients, the reference period was the most recent complete billing period, or the time since admission if the patient had not been there for a complete billing period. For hospice care discharges, the reference period was from admission to the sampled discharge date. PA survey items for the current home health care patients and hospice care discharges are provided in [Appendix XIII](#).

## SAQ

The SAQ was included in the appointment confirmation packages mailed to agency directors approximately 2 weeks before their scheduled agency interviews. The questionnaire collected information on the education and experience of agency management, turnover and tenure of nursing staff, employee benefits, information technology capabilities, and patient care revenue sources. The directors were asked to fill out the paper-and-pencil SAQ by the day of the in-person agency interview. This approach allowed the director time to obtain the necessary information prior to the in-person interview and enabled the interviewer to collect the completed SAQ before leaving the agency. The SAQ is provided in [Appendix VIII](#).

## Data Quality Assurance

The quality assurance (QA) measures for the redesigned NHHCS were multifaceted and included coded audio recordings, interviewer observations, interviewer debriefing calls, data collection monitoring, conference calls between NCHS and the contractor, and field memos. These measures were implemented to ensure that data were collected consistently and reliably across the sampled agencies.

## Audio Recording

The contractor developed a data QA software tool to audiorecord a subset of items through the interviewer's laptop during the in-person agency interview without interrupting the interview process. The QA tool recorded and coded a subset of agency interviews during the first 8 weeks of data collection. These audio recordings made it possible for the contractor to identify interviewers who needed additional coaching. Moreover, the recordings, which were done on a screen-by-screen basis, helped the contractor identify which survey items proved problematic for interviewers or respondents. A group

of core items were recorded in all interviews, and a set of predetermined items were recorded with varying frequencies across the interviews. By the end of the 8 weeks, the contractor had collected recordings from 402 interviews. Interviewer performance issues identified by the coded audio recordings were shared with interviewers through direct and verbatim feedback to improve interviewer performance. In addition, the coding identified four survey questions that were problematic and led to additional instructions to field interviewers on how to ask those questions during the interview.

## Observations

In addition to the audio recordings, NCHS and the contractor observed some of the early interviews. Observers noted module timings, problematic questions, and respondents' reactions to the instrument and procedures. When necessary, observers also provided technical assistance and advice during the interview.

## Debriefing Calls

Another data QA measure was the debriefing calls, focused on gaining cooperation and conducting the agency visits, that were held during the first 3 weeks of data collection. These calls were moderated by the field supervisor in each region, with mandatory participation by all field interviewers. During the debriefings, the interviewers shared their early successes and challenges in scheduling agency interviews, as well as their experiences in completing their first agency interviews. The agenda and discussion guides used by the moderators are given in [Appendixes XIV](#) and [XV](#). Upon completion of the debriefings, a list of helpful points was compiled into a field memo and distributed to all field interviewers.

## Data Collection Monitoring

Another QA measure was the weekly production reports generated by the contractor. These reports, which

informed NCHS on various aspects of the survey and its progress, included detailed information on the following:

- The status of the sampled agencies (i.e., contacted, appointed, or refused) by agency type and chain status, including weekly trends.
- The disposition of the survey modules (not started, refused, completed, or ran out of time).
- The number and eligibility of sampled current home health care patients and hospice care discharges.
- The number of started, appointed, and completed cases by region.
- The number of SAQs received by the contractor’s central office.
- A listing of scheduled agency interviews by date and assigned interviewer.
- A summary report of the time required to administer each survey module, for completed interviews.
- Response rates by agency type.

These production reports were reviewed by NCHS staff and discussed during the weekly conference calls with the contractor. These calls allowed NCHS to raise data collection issues based on information found in the production reports. The calls also allowed the contractor to inform NCHS about survey developments that required NCHS’ input. Solutions to issues or concerns were discussed during the conference calls and were summarized in a field memo, which was then distributed to the field staff.

## Data Processing

Data processing during the data collection period involved both manual and automated systems. One manual system involved SAQs, which were collected by the interviewers on the day of the agency interview. Before leaving an agency with a SAQ, the interviewer checked the questionnaire to ensure that the skip instructions had been followed appropriately and the questionnaire had been completed.

An example of the automated systems used during data collection was the automatic check within CAPI for out-of-range responses. Hard and soft edit checks and skip patterns were programmed

into CAPI based on the expected range of responses for given questions. Hard edit checks guided the interviewers to correct unlikely responses (i.e., require a response within the expected range before continuing, such as the one for the month of a patient’s admission to an agency, which was prompted if a response greater than 12 was entered). Soft edit checks prompted the interviewers to verify or correct other unlikely, but possible, responses (i.e., issue a warning that can be ignored, such as the one for the number of current home health care patients being served by the sampled agency, which was prompted if a response greater than 1,000 was entered) before moving on to the next survey item.

Data processing following data collection involved, among other things, the coding of “other, specify” data. For example, medication data that were entered into the “other, specify” fields and did not have an existing drug code were coded by the contractor and NCHS. Medication names that were entered as text strings into the “other, specify” fields and that did not have a code in the drug database were assigned new drug codes. A similar process was used to code the medication data collected in the 2004 NNHS (for detailed information on how new codes were assigned, refer to the NCHS report “Collecting Medication Data in the 2004 National Nursing Home Survey,” available at: [http://www.cdc.gov/nchs/mnhs/mnhs\\_products.htm](http://www.cdc.gov/nchs/mnhs/mnhs_products.htm)). Also, medical diagnoses and medical procedures not previously coded were assigned an appropriate code in the 2007 NHHCS.

In addition to medication data, many other items in NHHCS allowed an “other,

specify” response, where the interviewer entered responses that did not fit neatly into one of the preexisting categories. Where appropriate, “other, specify” responses were back-coded and new categories were created. “Other, specify” responses that revealed the identity or geographic location of agencies were edited to prevent unintended disclosure.

## Disclosure Risk Review

NHHCS data files intended for public-use release underwent extensive disclosure risk review to prevent the identity of any agencies, patients, or persons who participated in the survey from being made known to the public. For unusual characteristics and continuous variables, NCHS checked for clustering of responses within facilities. Furthermore, NCHS checked to see if these clustered attributes varied by geography and were represented in the universe file. When there was disclosure risk, NCHS perturbed the data and then ensured that the perturbation did not affect the estimates.

## Response Rates and Module Timings

Of the 1,545 sampled agencies selected for NHHCS, 84 were ineligible because they did not meet the survey criteria, were out of business, were duplicates, or had merged with another entity (Table A). Interviews were completed

**Table A. Agency response rates**

Response category	Number	Percent
Total sampled agencies . . . . .	1,545	100
Total agencies out of scope . . . . .	84	5
Ineligible . . . . .	43	3
Out of business . . . . .	15	1
Duplicate . . . . .	17	1
Merged . . . . .	9	1
Total agencies in scope . . . . .	1,461	100
Total refusal . . . . .	425	29
Final agency refusal . . . . .	235	16
Final corporate refusal . . . . .	190	13
Total complete . . . . .	1,036	71

NOTE: Percentages may not add up to 100 due to rounding.  
SOURCE: CDC/NCHS, National Home and Hospice Care Survey, 2007.

**Table B. Number and percent distribution of in-scope sampled home health and hospice care agencies, by agency response status and selected characteristics: National Home and Hospice Care Survey, 2007**

Agency characteristics	Number of sampled in-scope agencies <sup>1</sup>	Total sample percent distribution (weighted by the inverse of the probability of selection)	Responding agency percent distribution (weighted by the inverse of the probability of selection)	Nonresponding agency percent distribution (weighted by the inverse of the probability of selection)	Response rate <sup>2</sup> (weighted by the inverse of the probability of selection)	Unweighted response rate	Responding agency percent distribution (weighted by the inverse of the probability of selection and adjusted for nonresponse) <sup>3</sup>
All agencies . . . . .	1,461	100	100	100	59	71	100
Agency type <sup>4</sup>							
Home health care only . . . . .	577	78	74	44	56	64	75
Hospice care only . . . . .	471	14	16	32	68	78	15
Mixed . . . . .	413	8	9	28	72	73	10
Ownership <sup>4,5,6</sup>							
For-profit . . . . .	334	46	42	51	54	58	65
Voluntary nonprofit . . . . .	670	30	34	24	67	80	28
Government/other . . . . .	288	13	13	13	58	68	7
Unknown . . . . .	169	11	11	12	58	67	0
Census region <sup>4</sup>							
Northeast . . . . .	230	13	11	16	50	65	13
Midwest . . . . .	368	21	21	21	59	76	21
South . . . . .	638	53	51	56	56	68	52
West . . . . .	225	13	17	7	77	77	14
MSA status <sup>4,7</sup>							
Metropolitan . . . . .	610	74	67	84	53	62	73
Micropolitan . . . . .	455	14	17	9	74	76	14
Other . . . . .	396	13	16	8	75	79	12
Affiliation <sup>5</sup>							
Chain . . . . .	287	28	28	27	60	73	30
Independent . . . . .	1,174	73	72	73	58	64	70
Medicare certification status <sup>4,8</sup>							
Certified . . . . .	396	45	50	39	64	70	84
Not certified . . . . .	942	35	36	35	59	73	16
Unknown . . . . .	123	20	15	26	44	54	0
Medicaid certification status <sup>4,5,8</sup>							
Certified . . . . .	357	35	36	32	62	68	82
Not certified . . . . .	981	46	49	42	63	74	18
Unknown . . . . .	123	20	15	26	44	54	1

<sup>1</sup>In-scope agencies are agencies that provided home health or hospice care services to patients at the time of the survey or recently before the survey.

<sup>2</sup>Numerator is the number of sampled in-scope agencies that participated in NHHCS; denominator is all sampled in-scope agencies.

<sup>3</sup>Final estimates include adjustment for the inverse of the probability of selection, adjustment for nonresponse, ratio adjustment to the sampling frame based on region and Medicare status, and calibration to correct for over- or undersampling in the sampling frame.

<sup>4</sup>Chi-square test of association is significant ( $p > 0.0001$ ) between responding versus nonresponding distribution and indicated agency characteristic.

<sup>5</sup>Not used for nonresponse adjustment.

<sup>6</sup>Percent distribution comparable to ownership data from the Home Health Compare files from the Centers for Medicare & Medicaid Services, available at: <http://www.medicare.gov/Download/downloaddb.asp>.

<sup>7</sup>Metropolitan statistical areas (MSAs) and micropolitan statistical areas are geographic entities defined by the U.S. Office of Management and Budget for use by federal statistical agencies in collecting, tabulating, and publishing federal statistics. An MSA contains a core urban area of 50,000 or more population; a micropolitan statistical area contains an urban core of at least 10,000 (but less than 50,000) population.

<sup>8</sup>Percent distribution comparable to 2000 NHHCS.

NOTES: NHHCS is National Home and Hospice Care Survey. Percentages may not add up to 100 due to rounding.

SOURCE: CDC/NCHS, National Home and Hospice Care Survey, 2007.

with 1,036 of the 1,461 in-scope agencies, for a first-stage agency unweighted response rate of 71% and a weighted (for differential probabilities of selection) response rate of 59% (Table B). The

second-stage patient/discharge unweighted response rate was 95% and the weighted response rate was 96% (not shown).

The average time per completed case was 30 hours. This includes the

time the interviewer spent recruiting the agency to participate in the survey, conducting the agency interview, and submitting all data to the contractor's central office.

## Issues Affecting Response Rates

Refusal to participate was largely due to the perceived burden of data collection among the agency directors and corporate officers. Many directors explained that the demands of patient care precluded them from devoting a full day of staffing resources to the agency interview. Another important reason was chain cooperation issues. Although time and resources were devoted before and during data collection to identifying chain-affiliated agencies and to mailing corporate advance packages, many agency directors still resisted participating in the survey. These refusals among corporate-affiliated agencies were followed by refusal conversion activities that were similar to those for the stand-alone agencies. By the end of data collection, 95 chains had refused to participate in NHHCS, which represented 220 agencies that had been identified as chain affiliated. The data collection end date was extended from January 6, 2008, to February 29, 2008, to enable completion of 181 more interviews, which included 96 converted cases.

## Nonresponse Bias Analysis

The response rate for the 2007 NHHCS, weighted by the inverse of the probability of selection, was 59%. **Table B** presents the percent distribution of selected agency characteristics among responding and nonresponding agencies. Responding and nonresponding agencies were not significantly different by chain affiliation but were significantly different by the following agency characteristics: agency type (home health care only, hospice care only, mixed), ownership type (for-profit, voluntary nonprofit (i.e., operated under voluntary or nonprofit auspices, including church-related organizations), government/other, or unknown), census region, MSA status (metropolitan, micropolitan, other), Medicare certification status (certified, not certified, unknown), and Medicaid certification status (certified, not

certified, unknown). Metropolitan and micropolitan statistical areas are geographic entities defined by the Office of Management and Budget for use by federal statistical agencies in collecting, tabulating, and publishing federal statistics.

**Table B** also presents the unweighted response rates and the response rates weighted by the inverse of the probability of selection among agencies with different characteristics. Higher cooperation was gained among agencies with voluntary nonprofit ownership, located in the West and Midwest, in nonmetropolitan areas, with known certification status (i.e., known to be certified by Medicare and Medicaid or not certified, versus unknown), affiliated with a chain, and which provided only hospice care services or both home health care and hospice care services. The effect of this differential response is minimized by using a nonresponse adjustment factor that takes into account census region, MSA status, Medicare certification status, and agency type. These variables were selected for nonresponse adjustment because they were deemed most important for analysis and for providing estimates. To evaluate the effect of nonresponse adjustments on selected survey estimates, the last column of **Table B** shows estimates weighted by the inverse of the probability of selection and adjusted for nonresponse. Except for Medicare certification status, all other estimates among responding agencies that were adjusted for nonresponse (i.e., census region, MSA status, and agency type) came closer to the distribution in the sample, which in turn represents the distribution in the frame or universe of agencies. The higher proportion of agencies that are Medicare-certified among responding agencies relative to their proportion in the sample is likely to have resulted from a combination of misclassifications in the frame that were corrected at the time of interview, changes in certification status between the time of frame construction and interview, and the low response rate of noncertified agencies that limited the ability to effectively adjust for nonresponse. Among variables that were not used to adjust for nonresponse,

estimates for ownership and Medicaid certification status were also affected by “unknown” status at the time of interview, changes between the time of frame construction and interview, and misclassifications in the frame that were corrected at the time of interview. The percent distribution of ownership status was comparable to the ownership data from CMS, and the percent distribution categories for Medicare and Medicaid certification status was comparable to the 2000 NHHCS.

## Estimation Procedures

Because the statistics from NHHCS are based on a sample, they will differ somewhat from the data that would have been obtained if a complete census had been taken using the same definitions, instructions, and procedures. However, the probability design of NHHCS permits the calculation of sampling errors. The standard error of a statistic is primarily a measure of sampling variability that occurs by chance because only a sample, rather than the entire population, is surveyed. The standard error also reflects part of the variation that arises in the measurement process but does not include any systematic bias that may be in the data, or any other nonsampling error. The chances are about 95 in 100 that an estimate from the sample differs by less than twice the standard error from the value that would be obtained from a complete census.

Standard errors can be calculated for agency, patient/discharge, and medication estimates by using any statistical software package, as long as clustering within agencies and other aspects of the complex sampling design are taken into account. Software products such as SAS (13), Stata (14), and SPSS (15) have these capabilities. Statistics presented in NCHS publications are computed using SUDAAN software (16), which produces standard error estimates for statistics from complex sample surveys. SUDAAN employs a first-order Taylor series approximation of the deviation of estimates from their expected values. All

three of the NHHCS public-use files (agency, patient/discharge, and medication) include design variables that designate each record's stratum marker and the first-stage unit (or cluster) to which the record belongs. The design variables used to estimate characteristics in the patient/discharge public-use file are the same design variables that should be used for the medication data, which were collected at the patient/discharge level. (The patient/discharge public-use file contains data on both the current home health care patients and the hospice care discharges.)

In the agency public-use file, the variable STRATUM indicates one of the subpopulations used in the stratified sampling, and the agency indicated by the variable AGENCYID is the primary sampling unit. POPAGY represents the total number of agencies in a stratum for the finite population correction. There are two survey weights: SAMAGYWT for estimates not correlated with agency size and SIZAGYWT for estimates correlated with agency size (e.g., estimates of total staff across all agencies). The data dictionary for the agency public-use file has a Technical Notes section that provides an example of the syntax for using these design variables to describe the sampling design in SUDAAN. The NHHCS data dictionary for the agency public-use file is available on the NHHCS website at: [ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Dataset\\_Documentation/NHHCS/2007](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHHCS/2007).

The patient/discharge public-use file has two stages. The stratum in the first stage is indicated by the variable PSTRATA, in which the primary sampling unit is the agency indicated by the variable PTAGYNUM. The variable for the finite population correction in the first stage is POPAGN. In the second stage, the stratum is the variable PHTYPE, and the secondary sampling unit is the observation (i.e., patient or discharge) indicated by the variable PATNUM. There is no finite population correction in the second stage with the patient/discharge public-use file; therefore, the second stage is treated as sampling with replacement. In SUDAAN, to treat the second stage as sampling with replacement, the variable

POPPAT is used and has a value of  $-1$ . In many other statistical packages, failure to designate a variable for finite population correction at the second stage results in sampling with replacement. The survey weight is SAMWT. The data dictionary for the patient/discharge public-use file has a Technical Notes section that provides an example of the syntax for using these design variables to describe the sampling design in SUDAAN. The NHHCS data dictionary for the patient/discharge public-use file is available on the NHHCS website at: [ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Dataset\\_Documentation/NHHCS/2007](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHHCS/2007).

The current home health care patient sample describes individuals receiving home health care on the night before data collection began and represents home health care utilization on any given day between August 2007 and February 2008. The hospice care discharge sample describes the annual number of discharges from hospice care. This sampling design requires the data user to always conduct separate analyses of current home health care patients and hospice care discharges, using the PHTYPE variable. For current home health care patients, PHTYPE = 1, and for annual hospice care discharges, PHTYPE = 2. To properly account for the sampling design in the calculation of standard errors, both current home health care patients and hospice care discharges must be used in all analyses. All analyses should be conducted using the subpopulation command in the statistical software package.

Because NHHCS is a sample survey and is designed to produce national estimates for agencies and current home health care patients and hospice care discharges, data analyses must include survey weights, to inflate the sample numbers to national estimates. Each record in the public-use files has a weight for this purpose. By aggregating the weights, national counts can be estimated.

NHHCS estimators take into account the selection procedures of the complete survey design to develop the final survey weight for each sampled agency and each sampled patient/discharge. An estimator  $\hat{X}$  for any given

population total  $X$  can be expressed as a weighted sum over all sampled units, defined as

$$\hat{X} = \sum_u x(u)W(u)$$

where  $u$  represents a sampled unit,  $x(u)$  is the characteristic or response of interest for unit  $u$ , and  $W(u)$  is the final survey weight for sampled unit  $u$ . The final weight  $W(u)$  for each sampled unit is the product of up to three components:

1. Inverse of the probability of selection.
2. Nonresponse adjustment.
3. Ratio adjustment.

The first component of the weight for each sampled unit (agency, home health care patient, or hospice care discharge) is the inverse of the unit's selection probability. For the current home health care patient or hospice care discharge, the selection probability is the product of two selection probabilities: the probability of selecting the agency to the NHHCS sample and the probability of selecting the current home health care patient or hospice care discharge within the sampled NHHCS agency. The inverse of the product of these probabilities is used for weighting.

The first component was modified for sampled agencies found to have multiple listings in the sampling frame after the agency sample was selected. For each agency found to be duplicated in the sampling frame, the weights of all sampled listings for the agency were summed and divided by the total number of times the agency was found in the sampling frame. To the extent that all listings of each sampled agency are identified in the sampling frame, the resulting weights produce unbiased estimates (i.e., estimates that would be obtained if there were no duplicates in the sampling frame).

The second component for calculating the weight is adjustment for nonresponse. This adjustment is made for three types of nonresponse. The first two types are agency level, and the third is person level (patient/discharge). The first type occurs when in-scope agencies do not respond to NHHCS. In NHHCS, the second type occurs when an

in-scope agency does not provide the number of current home health care patients or hospice care discharges within the respective agency. The third type occurs when the administrative and medical records of the sampled current home health care patients or hospice care discharges are not made available to complete the survey.

The third component applies only to weights used to estimate numbers of agencies. This component involves ratio adjustments that are made within groups defined by census region and agency type to account for use of probability proportional to size when selecting the agency sample. The numerator of the ratio was the number of agencies in the sampling frame within each group, and the denominator was the estimated number of agencies for that same group. No ratio adjustment was made to other weights (i.e., agency weights for agency-level estimates for parameters other than numbers of agencies and weights for patients/discharges). Finally, the weights described above were smoothed within groups defined by census region and agency type if there were outlier sampling units whose survey weights were somewhat larger than those for the remaining sample in the same group. In smoothing, total estimates for each group were preserved.

## Reliability of Survey Estimates

Estimates published by NCHS must meet reliability criteria based on the relative standard error (RSE or coefficient of variation) of the estimate and on the number of sampled records on which the estimate is based. The RSE is a measure of variability and is calculated by dividing the standard error of an estimate by the estimate itself. The result is then converted to a percentage by multiplying by 100. Guidelines used by NCHS authors to determine whether estimates should be presented in tables of NCHS published data reports include the following:

- If the estimate is based on fewer than 30 sampled cases, the value of the estimate is not reported. This is usually indicated with an asterisk (\*).
- If the estimate is based on 60 or more sampled cases and the RSE is less than 30%, the estimate is reported and is considered reliable.
- All other reported estimates should not be assumed to be reliable. These include estimates with an RSE of 30% or more and estimates based on 30–59 cases, regardless of RSE.

## Confidentiality

Participation in NCHS surveys is strictly voluntary, and information collected on agencies and individuals is confidential. The Health Insurance Portability and Accountability Act allows health establishments to disclose protected health information without patient authorization for public health purposes and for research that has been approved by an institutional review board with a waiver of patient authorization. NCHS enforces strict procedures to prevent the disclosure of confidential data in survey operations and data dissemination. In accordance with NCHS' confidentiality mandate (Section 308(d) of the Public Health Service Act (42 U.S.C. 242m)), no information collected in NHHCS 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 consent to do so has been obtained in writing from the sampled individual or establishment. The NHHCS protocol was approved by the NCHS Research Ethics Review Board. The information provided by the agencies sampled in NHHCS is used for statistical research and reporting purposes only.

## Data Dissemination

The 2007 NHHCS data are available in public-use files on the NHHCS website at: [ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Datasets/NHHCS/2007](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Datasets/NHHCS/2007). Three NHHCS files have

been released: agency, patient/discharge, and medication. Technical notes that include a summary of the survey, data dictionaries, and input statements are also available on the website. Questions about these data may be directed to the NCHS Office of Information Services, Information Dissemination Staff, at 1-800-232-4363 or [NCHSquery@cdc.gov](mailto:NCHSquery@cdc.gov), or to the Long-term Care Statistics Branch at 301-458-4747.

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# Appendix I. Recommendations From the Hospice Care Survey Technical Advisory Group Working Meeting

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**February 8, 2001, Bethesda, MD**

## **Attendees**

Irma E. Arispe, Ph.D., National Center for Health Statistics  
Amy Bernstein, Sc.D., National Center for Health Statistics  
Stephen R. Connor, Ph.D., National Hospice and Palliative Care Organization  
Linda Demlo, Ph.D., National Center for Health Statistics  
Marilyn J. Field, Ph.D., Institute of Medicine  
Barbara Haupt, D.V.M., National Center for Health Statistics  
Esther Hing, National Center for Health Statistics  
Keith Hoffman, National Center for Health Statistics  
Thomas Hoyer, Health Care Financing Administration  
Timothy J. Keay, M.D., M.A.-TH., University of Maryland School of Medicine  
Judith Lund Person, Carolinas Center for Hospice and End-of-Life Care  
Dale Lupu, Ph.D., American Board of Hospice and Palliative Care  
Jennifer Madans, Ph.D., National Center for Health Statistics  
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R. Sean Morrison, M.D., Mount Sinai School of Medicine  
Janet Neigh, National Association for Home Care-Hospice Association of America  
Robin E. Remsburg, Ph.D., National Center for Health Statistics  
Julia H. Rowland, Ph.D., National Cancer Institute  
William D. Spector, Ph.D., Agency for Healthcare Research and Quality  
Genevieve Strahan, National Center for Health Statistics  
Joan M. Teno, M.D., Brown University  
Jonathan VanGeest, Ph.D., American Medical Association

## **Discussion leader**

Amy Bernstein, Sc.D., National Center for Health Statistics

## **Recommendations**

### **Rationale and most important research/policy questions related to hospice care**

- Learn as much as possible about hospice and palliative care providers across all settings, how they provide services, and service payment, because tax dollars pay for Medicare and Medicaid services.
- Begin to examine the needs of patients and families/caregivers served by existing programs, as well as gaps in services.
- Understand where and how people are cared for and supported at the end of life, and how resources are being used.
- Obtain empirical data on the volume of hospice care provided in this country and the outcomes of hospice care (e.g., good death experience).
- Understand how vulnerable populations are being cared for in this era of cost control (e.g., the degree of difficulty in getting care and what needs are unmet).
- Examine unplanned transfers from hospice to the nursing home care and the hospital.
- Examine the quality of hospice care in nursing homes.
- Better understand end-of-life care in all settings and for all persons with a terminal illness, e.g., in children and the elderly, in persons with cancer and Alzheimer's disease (i.e., where and by whom the care is provided).
- Monitor changes in access to and quality and cost of hospice care, with a focus on staffing (staff versus volunteers, contracting arrangements, fringe benefits, training).
- Better understand the types of providers involved in hospice/end-of-life care.
- Determine who is choosing hospice care, why they delay entry into hospice care, why physicians do or do not refer patients to hospice care, and the paths through which patients enter hospice care.
- Estimate the numbers of patients and family members receiving hospice services.
- Clarify the definition of hospice care and distinguish hospice from other kinds of treatment.
- Elucidate the treatments provided, standards of practice/performance, medical management, role of medical directors, and needs of hospice providers.

- Benchmark quality-of-care indicators.
- Examine longitudinal trends in the provision of hospice care, patterns of utilization among physicians, and the geographic penetration of hospice care.
- Look at how the NHHCS can be integrated with other surveys.
- Identify the costs of care, especially drug costs.
- Determine how well hospices implement advance directives, e.g., what are they and how are they followed.

### **Hospice variables that should/can be collected**

#### *Facility-level variables*

##### **Provider organization:**

- Existence of formal contracts with other providers (e.g., nursing homes, assisted living facilities).
- Affiliations with nursing homes, hospitals, or other providers.
- Whether the organization is part of a non-profit/for-profit/proprietary organization.
- Whether the organization is part of a provider chain or managed care system.
- Inpatient arrangements (number of hospice beds in different settings).
- Percentage of hospice beds.
- Inpatient occupancy rate.
- Availability of special services (e.g., for AIDS patients).
- Service delivery area by ZIP code or county (could be linked to number of patients who died).

##### **Staffing:**

- Disciplines available in the setting: whether a particular service is on call, provided in house, or contracted.
- Number of full-time equivalents (FTEs) per patient served.
- Number of visits by discipline and FTE.
- Use of volunteers and number of hours they provide.
- Gender and ethnicity of care providers.
- Preparation/special training of providers.
- Staff turnover and stability rate.
- Level of staff support.
- Cultural competence (language, sensitivity to death traditions).

##### **Services/quality of care:**

- Admission criteria, including exclusion criteria (e.g., does not accept children, patients without insurance, patients desiring chemotherapy or radiation).
- Admission and death data by county (to match with county death certificates).
- Case mix.
- Average length of stay.
- Days of care by level of care and payer source.
- Number of patients served by discipline.
- Medicare certification.
- Accreditation.
- Number of citations in surveys (to examine the issue of fraud in chart documentation).
- Patient satisfaction.
- Number of bereavement encounters per family (limit to visits or telephone calls).
- Types and extent of services provided to family members pre-death and post-death.
- Diagnoses in relation to National Hospice Organization (NHO) guidelines.
- Presence of a drug formulary and composition of the formulary (classifying drugs would be easier than costing out of drugs, but still would be difficult).
- Number of nursing home patients on service at any given time or per year.
- Number or percent of revocations and non-death discharges.
- Location of deaths.
- Movement of patients into inpatient facilities.
- Percent of admissions to inpatient beds (e.g., during the last 48 hours of life).
- Whether continuous care is actually provided to patients (e.g., days of care by level of care).

**Costs/expenditures:**

- How operating funds are expended (cost report by category).
- Cost of drugs in relation to services or cost of prescriptions per day (drug data could be compared with that of other providers, as captured in other surveys).
- Barriers to medication access because of cost.
- Source of the provider organization's income, including the extent to which operations and capital expenditures are supported by charitable contributions.
- Fiscal viability scale to identify institutions at risk in a geographic area.

***Patient-level variables***

**Service delivery/continuity of care:**

- Services delivered (as documented in the patient record) versus services offered.
- Which disciplines delivered the services (as documented in the patient record).
- Number of different types of health care providers serving the patient.
- Continuity of care of various types of health care provider (e.g., number of different RNs seeing patient in the home).
- Discharges to skilled nursing facility.
- Number of hours of care provided by the primary caregiver and nature of the care.
- Location of care.
- Amount of time spent in patient visits/contacts.
- Number of "unplanned" hospital admissions.
- Number of emergent pain calls to staff.
- Number of rescue or emergency department (ambulance/EMS) calls made by patient or family.
- Number of unanticipated initiations of CPR.

**Patient and family/caregiver support and comfort:**

- Assessment of patient pain, depression, and agitation.
- Whether or not a pain scale is used (and other process measures).
- Level of pain at specified time points (e.g., admission, 24 or 48 hours after admission, just before death).
- Place of death and whether it was the patient's preferred place of death.
- Presence of patient preference documentation in the medical record.
- Personal trade-offs required for the patient to enter hospice care.
- Patient satisfaction with care.
- Level of training in self-care.
- Performance scale score (need to use a consistent scale).
- Medications administered.
- Assessment of family/primary caregiver function.
- Amount/type of backup provided to primary caregiver.

**Demographics:**

- Age.
- Gender.
- Marital status.
- Race/ethnicity.
- Education.
- Street address for patient at home, including ZIP Code.
- Diagnosis.
- Venue of care prior to admission.
- Social support status (e.g., living at home, number of children 18 and younger living at home).

## Appendix II. Content Wish List for the Redesigned National Nursing Home Survey

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### \*Items or related items found on current survey

#### PATIENT-LEVEL ITEMS:

- Sociodemographics
  - Age\*
  - Race\*
  - Ethnicity\*
  - Gender\*
  - Education
  - Income (how much detail?)
  - Marital status\*
  - Other?
- Health and functional status
  - Activities of daily living (ADLs)/instrumental activities of daily living (IADLs) at admission
  - ADLs/IADLs current resident\*
  - ADLs/IADLs at discharge for discharge resident\*
  - ADLs/IADLs at some other point?
  - Cognitive status (how many points in time?)
  - Conditions\* (International Classification of Diseases (ICD) and/or checklists) (how many points in time?)
  - Depression scale?
  - Pain scale?
  - Quality-related indicators (pressure sores, pain management, urinary catheters,\* falls, hospitalizations, tube feedings, restraints, psychotropic drugs, etc.)
  - Other?
  - Social Support/Family Involvement
  - Palliative Care/End-of-life Care/ Hospice care
- Services/care received
  - Therapies\*
  - Drugs
  - Devices\*
  - Tests
  - Immunizations/preventive services\*
  - Quality-of-life-related activities (involvement in nursing home activities, e.g., crafts, church, etc.)
  - Other?
- Costs/payment
  - Source of payment\*
  - Out of pocket
  - Spend-down history
  - Other?
- Reason for admission to the facility, why admitted to the nursing home versus another facility, whether they could be cared for in other less-intensive settings, other options available in the geographic area

#### FACILITY-LEVEL ITEMS:

- Units (type\*, beds\*, criteria for admission or exclusion?)
- Services offered\*
- Staffing-
  - Full-time\*
  - Part-time\*
  - Vacancies

- Agency use
- Absenteeism
- Turnover/retention (bedside staff, director of nursing (DON), administrator, medical doctor (MD))
- Expertise/Training
  - Training of medical director
    - American Medical Directors Association (AMDA)
    - Gerontologist
  - Training of Nursing Staff
    - Certified Nurses
    - Clinical Nurse Specialist
- Involvement in educational programs (nursing assistants (NAs), nurses, other)
- Specialty programs\*
  - Dementia
  - Ventilator weaning
    - Rehab?
    - Spinal cord injuries
    - HIV/AIDS
    - Mental retardation (MR)
- Payment streams
- History (years in business)
- Ownership\*
- Contracts/carve-outs
- Integration with other providers and services (part of a life-care community? A chain?\* A health care system? A managed care system?)
- Formulary/practice-based research network (PBRN)
- Guidelines/protocols required (Do they profile providers? How? Do they require use of specific pain scales?) Best Practices, e.g., implementation of protocols/programs that have been demonstrated to improve outcomes (toileting programs, skin care programs, screening/treatment of depression, etc.)
- Volunteer Programs\*
  - Types-augmentation/enhancement of services, or replacement of services
- Staff Questions (if there is a special staffing supplement)
  - Satisfaction
  - Length of service in facility
  - Length of stay (LOS) in LTC
  - Length of service in general
  - Hours worked
  - Education
  - Training
  - Continuing education
  - Work-related injuries
  - Safety (perceptions)
  - Other?
- Family/Caregiver/Next-of-Kin Questions (if there is a supplement)
  - Informed consent
  - Satisfaction with facility (care)
  - Burden:
    - Emotional
    - Financial
  - Health status of patient prior to institutionalization
  - Health services used by patient immediately prior to institutionalization
  - Services (if any) received by family (e.g., financial counseling, spiritual counseling)
  - Services family provides for patient not included in institutional costs (e.g., laundry)

SAMPLING/DESIGN ISSUES:

- *Whom to sample? Discharges? Residents? If we sample residents, how much retrospective info should we collect?*
- *Can we get all of the care a person receives over a time period, including hospitalizations, admissions and discharges, etc.? How?*
- What should the time frame be?
- What is the reference date?
- Can we survey at multiple points in time?
- Can we do a family/caregiver supplement?
- Can we do a staffing supplement?
- Can we do special unit supplements?
- How can we incorporate state information? Could we make estimates for some states?

# Appendix III. Recommendations From the Home Health Care Survey Technical Advisory Group Working Meeting

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**January 28, 2002**

## **Attendees**

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Linda K. Demlo, Ph.D., National Center for Health Statistics  
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Vicki Freedman, Ph.D., Polisher Research Institute at Philadelphia Geriatric Center  
Wil Gehne, Centers for Medicare and Medicaid Services  
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Julia Holmes, Ph.D., National Center for Health Statistics  
Ed Hunter, National Center for Health Statistics  
Carrie Jones, National Center for Health Statistics  
Enid Kassner, AARP Public Policy Institute  
Harriet Komisar, Ph.D., Georgetown University  
Bruce Leff, M.D., Johns Hopkins School of Medicine  
James Lubitz, National Center for Health Statistics  
Thomas McLemore, National Center for Health Statistics  
Christopher Murtaugh, Ph.D., Visiting Nurse Service of New York  
D.E.B. Potter, Agency for Healthcare Research and Quality  
Robin Remsburg, Ph.D., National Center for Health Statistics  
Patricia A. Rusca, Visiting Nurse Association of Central New Jersey  
Linda Scott, Johns Hopkins Home Care Group  
Al Sirrocco, National Center for Health Statistics  
William D. Spector, Ph.D., Agency for Healthcare Research and Quality  
Mary St. Pierre, National Association for Home Care  
Genevieve Strahan, National Center for Health Statistics  
Virginia Tritschler, Visiting Nurse Association of Boston  
Bob Wardwell, Visiting Nurse Association of America  
Mary Weakland, Centers for Medicare and Medicaid Services

## **Discussion Leader**

Amy Bernstein, Sc.D., National Center for Health Statistics

## **Recommendations**

### **Rationale and most important research/policy questions related to home health care**

- Effects of the Medicare Home Health Agency Prospective Payment System (PPS) on home health providers and their patients.
- Post-PPS changes in patterns of services offered by home health agencies and received by patients.
- Changes in services received for specific patient populations of varying disability levels and how the cost of these services changed/ as well as the payment sources used to pay for care.
- Favorable and unfavorable outcomes of care (quality of care).
- Information on volume of services provided by agencies, including number of visits patients received per episode of care, number of readmissions during a year.
- Trends on number of providers, patients served, size measures.
- Characteristics of non-certified home health agencies.
- Limitations in access to care as measured by existence of wait lists for admission to program, or not accepting new admissions.
- Safety and appropriateness of care received by patients.

- Existence of informal caregivers while patient receives home health services.
- Post-PPS true cost of services versus amount reimbursed by various reimbursement sources.
- Impact of all reimbursement sources on type of care received.
- Levels of care provided by home health agencies and comparability of these services with other long-term care settings.
- Comparable information on agencies and patients across all payers.
- Home health staffing information such as: number of employees, temporary employees and contract staff, hours worked, wages, availability of fringe benefits, recruitment and retention measures.
- Impact of staff shortage (where it exists) on patient care provided.
- Expand the survey to cover “home care” providers in addition to home health providers.
- Linked claims data from Medicare files for sampled patients.
- Variation in staffing practices and impact on patients, particularly minority and other subpopulations.
- Services that differentiate “home care” versus “home health” patients.
- Factors correlated with re-hospitalization.
- How use of Medicaid and Medicare for payment affects type of care/services received.
- Level of computerized records in the industry: Are medical records computerized? Are management data computerized? Do agencies have any data from customer satisfaction survey that they conducted?
- Efficiency measures introduced by agencies to lower operating cost, such as telemedicine.
- Linkage data that would permit matching provider (market) context variables such as percentage elderly in local area, to the data set.
- Trends in special needs of non-elderly home health patients, such as use of special equipment and home modification.

### **Priority home health data items for the NHHCS**

#### *Patient data items:*

- Readmissions to home health agency within a given time period.
- Emergent care while in a home health program.
- Outcome and Assessment Information Set (OASIS) outcome measures for Medicare and non-Medicare patients, including its 4-point severity scale.
- Severity/illness measures including: weight loss or anorexia, inability to walk, hand grip strength.
- Prognosis.
- Homebound status as recorded on OASIS and using other definitions (I can't get out of my house/ I won't get out of my house).
- Length of episode of care, including time care paid for all payers.
- Development of new problems during the episode of care.
- Self-care independence.
- ADLs, IADLs, cognitive impairments (all on OASIS).
- Presence of caregiver at home.
- Information on changes in use of assistive devices during episode of care (also on OASIS).
- English as a second language; patient's preferred language; How does staff communicate with patient? Are teaching materials in patient's language?
- Patient's payment sources, including whether has long-term care insurance.
- Patient income/poverty status.
- Diagnosis specific (e.g., cardiac) services provided.

#### *Facility data items:*

- Home health staffing information such as: number of employees or FTE staff, temporary employees and contract staff, hours worked, wages, availability of fringe benefits, recruitment and retention measures, FTE staff by staff type.
- Staffing satisfaction.
- Is agency hospital based or free-standing?
- Provider ID or linkage variables needed for linkage to other files such as the Area Resource File.
- Number of visits made by staff type (registered nurse (RN), licensed practical nurse (LPN), physical therapist, etc.) during the year.
- Types of services provided, including new innovations, such as telemedicine.
- Accreditation information.
- Are services provided under a physician's plan of care? Are your physicians proactive or passive?
- Is agency making a profit (revenues, expenses, cost)?
- Revenue payer mix at agency level (% Medicare revenues, % Medicaid revenues, % health maintenance organization (HMO), etc.).
- Whether agency had certified ICD9 coders or coding software.

- Staff training.
- Average cost per visit by staff type (skilled nursing, home health aide, etc.).
- Services provided to assisted living facilities; # of contracts with assisted living facilities and other organizations.
- Number of staff with laptop computers, existence of computerized records system.
- Measures of outcome at the facility level; resources used to meet needs.
- Did agency refuse, cut-off admissions and why?
- Any patients transferred to another home health agency?
- Any agency outsourcing?
- Any website marketing?

### **Research priorities**

**Participants were asked to prioritize areas that the next NHHCS should cover. The following areas were identified:**

- Cost/expenditures/charges/payment sources/revenues.
- OASIS-type outcome measures.
- Caregiver at home.
- Staffing.
- Readmissions and emergent care.
- Facility structure.
- Services, including telemedicine and palliative care.
- Volume of services.
- New technologies or new services added in past year.
- Changes agencies made in response to PPS.
- Expanding the survey to cover home care agencies.

### **Areas where developmental work is needed before NHHCS can be changed**

- Developing a home care agency sampling frame.
- Identifying classification methods (for the sampling frame) that differentiate between home care and home health agencies.
- How to improve matching rates when linking with the OASIS.
- Developing methods for linkages with Medicare/Medicare claims data, Provider of Service file, other claims data sets.
- Contractual relationships between home health branches/health systems/managed care organizations.
- Homebound definition.

# Appendix IV. Advance Mail Screener Script

SCREENER FINAL RESULT: \_\_\_\_\_

## National Home and Hospice Care Survey (NHHCS) Advance Mail Screener

AFFIX AGENCY LABEL HERE

1. Hello, my name is \_\_\_\_\_. I'm working on the National Home and Hospice Care Survey sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics. I'm calling to confirm the mailing address and the name of the agency director.

Is this [SAMPLED AGENCY NAME PREPRINTED ABOVE] at [ADDRESS PREPRINTED ABOVE]?

YES ..... 1 (GO TO Q11)  
NO ..... 2

2. [What is the name/address of this agency/place?] RECORD NAME AND/OR ADDRESS CHANGES.

AGENCY NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

PHONE: \_\_\_\_\_

3. INTERVIEWER: IS THIS AGENCY'S NAME DIFFERENT THAN THE SAMPLED AGENCY NAME PREPRINTED ABOVE (OTHER THAN MINOR MISSPELLING)?

YES, AGENCY NAME CHANGED ..... 1  
YES, SOME OTHER AGENCY ..... 2 (GO TO Q5)  
YES, NOT A HOME HEALTH/HOSPICE AGENCY ..... 3 (GO TO Q5)  
NO ..... 4

4. INTERVIEWER: IS THE ADDRESS DIFFERENT THAN THE SAMPLED AGENCY ADDRESS PREPRINTED ABOVE (OTHER THAN MINOR MISSPELLING, ZIP CODE, OR AREA CODE CHANGE)?

YES ..... 1 (GO TO Q9)  
NO & Q3=1 'AGENCY NAME CHANGED' .... 2 (GO TO Q4a)  
NO & Q3=4 'NO' ..... 3 (GO TO Q11)

4a. Was this agency previously called [SAMPLED AGENCY NAME]?

- YES ..... 1 (GO TO Q11)
- NO ..... 2 (GO TO Q7)
- DON'T KNOW..... -8 (GO TO Q7)

5. Can I reach [SAMPLED AGENCY NAME] at some other telephone number or address?

- YES ..... 1 (GO TO Q6)
- NO ..... 2 (GO TO Q7)
- DON'T KNOW..... -8 (GO CLOSING 1)

6. What is that address and phone number?

ADDRESS:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

PHONE: \_\_\_\_\_

DON'T KNOW ..... -8

7. Is this (agency/place) associated with [SAMPLED AGENCY NAME]?

- YES ..... 1
- NO ..... 2 (GO TO CLOSING 1)
- R HAS NO INFORMATION ABOUT  
SAMPLED AGENCY..... 3 (GO TO CLOSING 1)

8. Can you tell me how they are associated? CIRCLE ASSOCIATION/RELATIONSHIP.

- HOSPITAL CONTACTED, SAMPLED AGENCY WITHIN THIS HOSPITAL 1
- CORPORATE/CENTRAL OFFICE CONTACTED, SAMPLED AGENCY  
IS AFFILIATED WITH THIS CORPORATE/CENTRAL OFFICE..... 2
- OTHER, SPECIFY ..... 3

\_\_\_\_\_

\_\_\_\_\_

GO TO CLOSING 1

9. Was this agency previously located at [THE ADDRESS ON THE LABEL]?

- YES ..... 1 (GO TO Q11)
- NO ..... 2
- DON'T KNOW ..... -8



- CHECK BOX IF AGENCY MERGED WITH ANOTHER AGENCY (**Q10=1**). DISPOSITION CODE = C4 – AGENCY MERGED, NCHS REVIEW REQUIRED. RECORD FINAL CODE ON FRONT PAGE OF SCREENER.
- CHECK BOX IF NO HOME HEALTH OR HOSPICE AGENCY AT THIS TELEPHONE NUMBER, CALL DA FOR A BETTER NUMBER AND RE-ADMINISTER SCREENER. DISPOSITION CODE = C3 – AGENCY FOUND AT DIFFERENT LOCATION, NCHS REVIEW REQUIRED. RECORD FINAL CODE ON FRONT PAGE OF SCREENER.
- IF NO GOOD TELEPHONE NUMBER OBTAINED, DISPOSITION CODE 10 = TRACING REQUIRED.
- CHECK BOX IF AGENCY FOUND AT DIFFERENT LOCATION, READMINISTER SCREENER. DISPOSITION CODE = C3 – AGENCY FOUND AT DIFFERENT LOCATION, NCHS REVIEW REQUIRED. RECORD FINAL CODE ON FRONT PAGE OF SCREENER.
- NOTE: FOR CODES C2, C3, C4, SEND A COPY OF COMPLETED ADVANCE MAIL SCREENER TO NCHS FOR REVIEW.

# Appendix V. Agency Advance Package Materials

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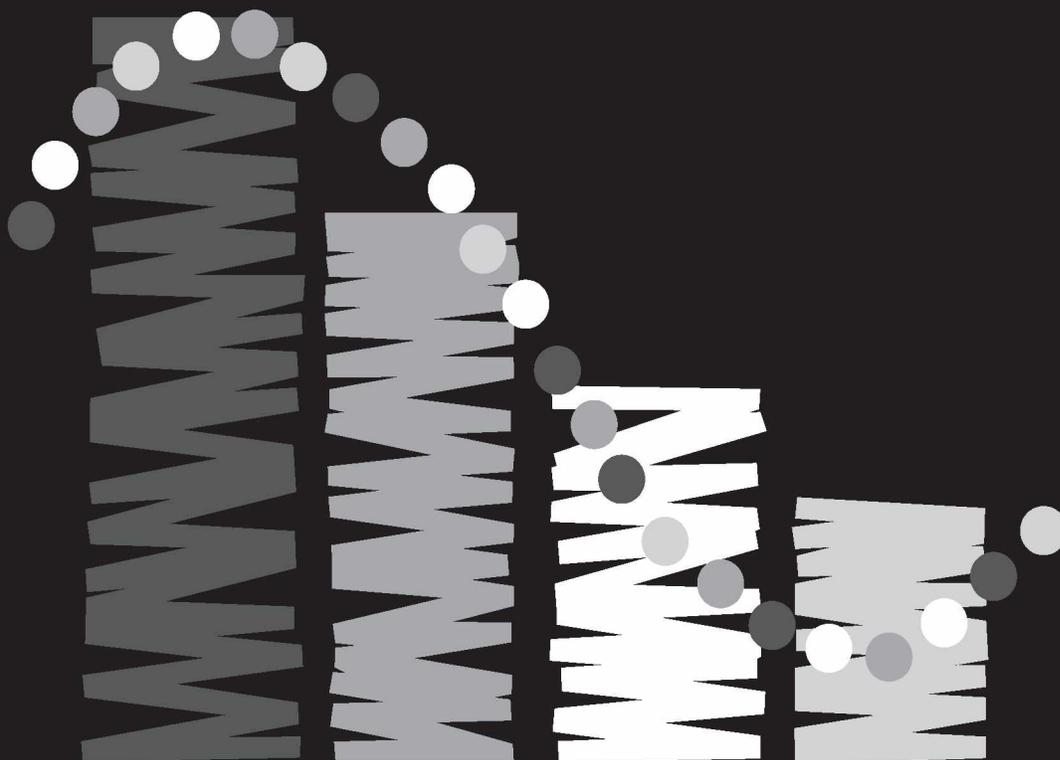
NHHCS folder (front)



SAFER • HEALTHIER • PEOPLE™

## National Home and Hospice Care Survey

National Health Care Survey



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

**NHHCS folder (back)**

NCHS data are released in printed reports, CD-ROMs, diskettes, and through the NCHS home page on the World Wide Web.

For further information and to access NCHS products, visit the NCHS home page at [www.cdc.gov/nchs/](http://www.cdc.gov/nchs/).

To obtain additional information about the National Home and Hospice Care Survey, visit the Web site: [www.cdc.gov/nchs/nhhcs.htm](http://www.cdc.gov/nchs/nhhcs.htm).

NHHCS brochure (front cover)

# National Home and Hospice Care Survey



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U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention  
National Center for Health Statistics  
Long-Term Care Statistics Branch



**Advance Letter From NCHS Director (front)**



**DEPARTMENT OF HEALTH & HUMAN SERVICES**

Public Health Service  
Centers for Disease Control and Prevention

National Center for Health Statistics  
3311 Toledo Road, room 3418  
Hyattsville, Maryland 20782

Dear Administrator:

The National Center for Health Statistics of the Centers for Disease Control and Prevention is conducting a nationwide survey of home health and hospice agencies. The purpose of the National Home and Hospice Care Survey (NHHCS) is to collect data on the characteristics of home health and hospice agencies and their patients, discharges, and staff. The survey is used by researchers, policy analysts, and practitioners to track changes in home health and hospice care utilization, costs, agency characteristics, staffing, and services provided, and to project future long-term health care needs. For more information, please visit the NHHCS website at [www.cdc.gov/nchs/nhhcs.htm](http://www.cdc.gov/nchs/nhhcs.htm) and see a short video about the NHHCS.

The purpose of this letter is to invite you to participate in the NHHCS. This survey includes a randomly selected nationwide sample of home health and hospice agencies, each of which represents a number of similar agencies. It is essential that we obtain data from all sample agencies in order to achieve accurate and complete statistics. Information is collected primarily by personal interview with administrators or their staff. No patient will be contacted at any time. A small sample of home health aides will be selected to participate in a voluntary offsite telephone interview. Your participation is voluntary, there are no penalties for refusing to answer any questions, and you may stop at any time. You may be asked to take part in other government surveys sometime in the future. Taking part in any other survey is also voluntary.

As part of this survey, the name, Social Security Number, Medicare Number, and Medicaid Number will be collected for each sampled patient and discharge. This information will be used only for statistical purposes, which will include obtaining Outcome and Assessment Information Set (OASIS) data about the home health patients from the Centers for Medicare and Medicaid Services and matching against the vital statistics records of the National Center for Health Statistics. Data collection for the NHHCS is authorized by the Public Health Service Act (Title 42, United States Code, Section 242k). All information collected is held in the strictest confidence, and will be used only to prepare statistical summaries. Please be assured that there are several ways that the Privacy Rule (as mandated by the Health Insurance Portability and Accountability Act [HIPAA]) allows you to participate. In particular, disclosures of patient data are permitted for public health purposes and for research that has been approved by an Ethics Review Board – both of which apply to this survey.

I want to emphasize further that the information you and your staff supply will be used solely for statistical research and reporting purposes. The only parties that can receive such data are those we've told you about on the back of this letter. In accordance with Section 308(d) (42 U.S.C. 242m) of the Public Health Service Act and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)], 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 such release. A report with information from the last survey is enclosed to illustrate how the data will be presented.

Within the next few weeks, a representative from Westat, the contractor conducting the survey on our behalf, will contact you for an appointment. If you have any questions, please call a NHHCS representative at **1-888-798-6678**. I greatly appreciate your cooperation.

Sincerely,  
/Edward J. Sondik, Ph.D./  
Director, National Center for Health Statistics

Enclosures

<b>Advance Letter From NCHS Director (back)</b>
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**National Home and Hospice Care Survey (NHHCS)**  
**Frequently Asked Questions**

**I'm asked to participate in studies all the time. What makes this one any different?**

The NHHCS is a large national study that, because of its size and design, can provide information that is representative of all home health and hospice agencies in the United States. Since the NHHCS is a periodic survey, the results can be used to track changes that are taking place in these types of agencies over time. The survey has been developed collaboratively by several government agencies. The survey is endorsed by industry associations, including the National Association for Home Care and Hospice and the National Hospice and Palliative Care Organization. **For more information about the survey visit [www.cdc.gov/nchs/nhhcs.htm](http://www.cdc.gov/nchs/nhhcs.htm)**

**What other home health and hospice agencies are you going to visit?**

This is a random national sample and we do not release the names of these agencies to anyone. This is to protect individual agencies and the patients they serve.

**Why can't some other agency take our place?**

If you do not participate, the unique qualities of your agency will be lost. The survey will be used by Congress and decision makers who will formulate policy for the next decade. You represent other agencies like yours. If you don't participate, there is no guarantee that home health agencies and/or hospices like yours will be adequately represented. We don't want industry decisions based on this survey to be made without all types of agencies, including those like yours, represented.

**Will the data be held confidential?**

The NHHCS is authorized by Congress in Section 306 of the Public Health Service Act (42 USC 242K). All information collected in this survey will be held in strict confidence according to law [Section 308(d) of the Public Health Service Act (42 United States Code 242m (d) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)]. Aside from NCHS employees, the only parties that can receive information that would directly identify the agency, patients, or staff are: (1) WESTAT – hired to conduct this survey, and (2) our collaborators – persons who have worked as our full partners from the earliest stages of this survey.

These parties, who will use your information for statistical research only and to carry out this survey, are bound by strong restrictions designed to guarantee your privacy. By law we cannot release information that could identify your agency, patients, or staff to anyone else without your consent. If any federal employee or contractor gives out confidential information not authorized by law, he or she can be fired, fined, and/or imprisoned.

**My staff is incredibly overworked right now. I need to know how much of their time will be required for this survey. How long will this take?**

We will need about 30 minutes with you or someone you designate to answer questions about your agency. We will also collect information about a sample of 10 current home health patients and/or hospice discharges that will take approximately 25 minutes for each person sampled. In addition, in order to conduct a telephone survey during non-working with a sample of your home health aides, we will need a list of the home health aides employed by your agency. The interviewer will accommodate the schedules of your staff members to complete these tasks as quickly as possible.

**Ethics Review Board Approval Letter**



**DEPARTMENT OF HEALTH & HUMAN SERVICES**

Public Health Service  
Centers for Disease Control and Prevention

National Center for Health Statistics  
3311 Toledo Road, Room 1209  
Hyattsville, Maryland 20782

**MEMORANDUM**

May 2, 2007

From: Stephen Blumberg, Ph.D.  
Chair, NCHS Research ERB  
Anjani Chandra, Ph.D.  
Vice Chair, NCHS Research ERB

Continuation of Protocol #2006-05 National Home and Hospice Care Survey

To: Genevieve Strahan,  
Lisa Dwyer,

The NCHS Research ERB reviewed the request for approval of Continuation of Protocol #2006-05 National Home and Hospice Care Survey on April 18, 2007. Continuation of Protocol #2006-05 is approved for the maximum allowable period of one year.

IRB approval of protocol #2006-05 will expire on **05/12/2008**.

If it is necessary to continue the study beyond the expiration date, **a request for continuation approval should be submitted about 6 weeks prior to 05/12/2008.**

Any problems of a serious nature should be brought to the immediate attention of the Research ERB, and any proposed changes should be submitted for Research ERB approval before they are implemented.

Please submit "clean" copies of the revised protocol or consents and any other revised forms to this office for the official protocol file.

Please call or e-mail me or Dewey LaRochelle if you have any questions.

/Stephen Blumberg, Ph.D./  
Chair, NCHS Research ERB

/Anjani Chandra, Ph.D./  
Vice Chair, NCHS Research ERB

<b>Ethics Review Board Waiver of Authorization Letter</b>
---

**DEPARTMENT OF HEALTH & HUMAN SERVICES**

Public Health Service  
Centers for Disease Control and Prevention

National Center for Health Statistics  
3311 Toledo Road,  
Hyattsville, Maryland 20782

May 2, 2007

From: Stephen Blumberg, Ph.D.  
Chair, NCHS Research ERB  
Anjani Chandra, Ph.D.  
Vice Chair, NCHS Research ERB

Protocol #2006-05 National Home and Hospice Care Survey

To: Genevieve W. Strahan, BS

The NCHS Research Ethics Review Board reviewed and granted the request for continuation of approval of Protocol #2006-05 National Home and Hospice Care Survey, which included a request for Waiver of Authorization for Use or Disclosure of Protected Health Information based on 45 CFR 46, as allowed in the Health Insurance Portability and Accountability Act of 1996 (HIPAA), 164.512(i)(2)(iv)(C). Approval of Protocol #2006-05 will expire on 05/12/2008.

The Board granted the following waiver of Protocol #2006-05 National Home and Hospice Care Survey based on 45 CFR 46.116, as allowed in the Health Insurance Portability and Accountability Act of 1996 (HIPAA), 164.512(i)(2)(iv)(C):

In accordance with 45 CFR 46.116(d) the Board voted (10-0) to approve the request for waiver of informed consent for the patients. The Board found that the research involves no more than minimal risk to the subjects, that the waiver will not adversely affect the rights or welfare of the subjects, and that the research could not practicably be carried out without the waiver or alteration.

In accordance with 45 CFR 46.117(c) the Board voted (10-0) to approve the request for waiver of documentation of informed consent for the facility administrators. The Board found that the research involves no more than minimal risk of harm to the subjects and involves no procedures for which written informed consent is normally required outside the research context.

In accordance with 45 CFR 46.117(c) the Board voted (10-0) to approve the request for waiver of documentation of informed consent for the home health care aides. The Board found that the research involves no more than minimal risk of harm to the subjects and involves no procedures for which written informed consent is normally required outside the research context.

Any problems of a serious nature resulting from implementation of this amendment should be brought to the attention of the Research ERB, and any proposed changes should be submitted for Research ERB approval before they are implemented.

/Stephen Blumberg, Ph.D./  
Chair, NCHS Research ERB

/Anjani Chandra, Ph.D./  
Vice Chair, NCHS Research ERB

**Letter of Support From the National Hospice and Palliative Care Organization (NHPCO)**

**National Hospice and Palliative Care  
Organization**



Dear Hospice Administrator:

I am writing to encourage your participation in the 2007 National Home and Hospice Care Survey to be conducted by the Center for Disease Control's National Center for Health Statistics (NCHS). This survey collects baseline and trend information from a sample of both home health agencies and hospices throughout the United States.

NHPCO has worked in collaboration with NCHS on a number of projects to help improve our understanding of hospice care in the US. Recently the NCHS has redesigned their survey with input from NHPCO. We are confident that data from our own annual National Data Set can be used collaboratively with the periodic NCHS survey to improve our understanding of hospice trends in the country.

Strict confidentiality is maintained in the conduct of this survey and only summary data will be published and made available to health planners, researchers, health professionals, NHPCO, and the public. Your participation assures that the reporting of hospice trends will be based on the input of industry professionals. We appreciate your cooperation in this effort.

Sincerely,

/J. Donald Schumacher, PsyD/  
President and CEO

**Letter of Support From the National Association for Home Care and Hospice (NAHC)**



**Ruth L. Constant**  
*Chairman of the Board*

NATIONAL ASSOCIATION FOR HOME CARE & HOSPICE  
228 Seventh Street, SE, Washington, DC 20003 • 202/547-7424 • 202/547-3540 fax

**Val J. Halamandaris**  
*President*

August 2006

Dear Administrator:

I am writing to encourage you to participate in the 2007 National Home and Hospice Care Survey (NHHCS) that will be administered by the Centers for Disease Control and Prevention and the National Center for Health Statistics (NCHS). The survey, conducted periodically since 1992, is designed to collect data on home health and hospice agencies, their services and staff, and their patients. These data provide useful information about our industry to agency owners, their suppliers, and health care planners.

The NHHCS allows timely and convenient data collection through its new computer-assisted data collection system. The survey will collect information on important topics such as immunization policies and practices, family and caregiver services, staff training, and patient health status and medications. As with all NCHS surveys, strict confidentiality will be maintained and only summary data will be published and made available to the public.

Some agencies sampled to participate in the 2007 NHHCS will also be asked to help in a first-ever national survey of home health aides—the National Home Health Aide Survey. This survey, which will be conducted by telephone during non-working hours, will ask sampled home health aides to share their experiences as direct care workers in the home health industry. Their feedback will help to inform policy changes and work practices that can promote retention of home health aides in, and attract others to, this field. If your agency is selected for this supplemental survey, I hope we can count on your cooperation.

Your participation in the 2007 National Home and Hospice Care Survey ensures that agencies like yours will be represented in the survey. Furthermore, your participation gives the home health industry greater information to address critical issues that affect fragile and chronically ill children and older adults who receive care through your agencies.

Again, I cannot over-emphasize the importance of this survey and your valuable input. I hope we can count on your support in this effort.

Sincerely,

/Val J. Halamandaris/  
President



SAFER • HEALTHIER • PEOPLE™

Vital and Health Statistics

Series 13, Number 161

June 2006

# Use of Computerized Medical Records in Home Health and Hospice Agencies: United States, 2000



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

## *Other safeguards for your privacy*

- Any item that could be used, either directly or indirectly, to identify health care providers or their patients is removed from public-use data files. Names, addresses, dates of birth, dates of service, and location of the health care establishment are never released to the public.
- NCHS withholds statistical totals if they represent a location so small that the numbers might identify someone.
- Information security procedures, including use of coded passwords and physical security of computers, prevent unauthorized access to the data.
- No authority — not even law enforcement officials, the Internal Revenue Service, or the Immigration and Naturalization Service — may obtain identifiable information from NCHS without your permission. Your survey responses are also protected from the Freedom of Information Act as well as court subpoenas.
- All published summaries are presented in such a way that no respondent can be identified.

We believe that our procedures for safeguarding information and our record of protecting the privacy of respondents are reasons why so many providers readily participate and provide reliable, high quality information. As a result, ample representative and accurate statistical information on health care utilization is made available every year to the American public, health care providers, the U.S. government, and the research community.

## *For further information*

NCHS data are released in printed reports, CD-ROMs, and on the NCHS website,

<http://www.cdc.gov/nchs/>  
or

For more information about how NCHS protects the information you provide, see:

<http://www.cdc.gov/nchs/about/policy/confidentiality.htm>

or contact:

Information Dissemination Staff  
3311 Toledo Road, Room 5412  
Hyattsville, MD 20782

For specific questions about how NCHS protects the information you provide, contact:

Confidentiality Officer  
Peter Meyer  
3311 Toledo Road, Room 4113  
Hyattsville, MD 20782

**Telephone:** (301) 458-4375  
**E-mail:** [prm7@cdc.gov](mailto:prm7@cdc.gov)



# **How the National Health Care Surveys Keep Your Information**

## *Strictly Confidential*

National Ambulatory Medical Care Survey  
National Hospital Ambulatory Medical Care Survey  
National Survey of Ambulatory Surgery  
National Hospital Discharge Survey  
National Survey of Residential Care Facilities  
National Nursing Home Survey  
National Home and Hospice Care Survey



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



## *There is safety in numbers, especially our numbers!*

### *The law . . .*

Information collected in the National Health Care Survey (NHCS) is used for research and statistical purposes. No information that could identify a person or establishment can be released to anyone — including the President, Congress, or any court—without the consent of the provider.

### *The affidavit . . .*

Anyone working for the National Center for Health Statistics (NCHS) **must** sign an affidavit — a legal document making them subject to the Privacy Act, the Public Health Service Act, and other laws.

### *The penalties . . .*

Disclosures of confidential statistical information are considered a class E felony that is punishable by imprisonment for up to 5 years, a fine of \$250,000, or both.

### *The record . . .*

Since its first survey in 1957, NCHS has maintained an outstanding record in protecting the privacy of individuals and businesses participating in its surveys.

## *A message from the Director of NCHS*

NCHS is well known for the high quality statistical information it provides. Maintaining that level of quality is not possible unless those who provide us with this information can be guaranteed confidentiality.

The confidentiality of records is of primary concern to NCHS. This principle is firmly grounded in federal laws, including the Privacy Act, the Public Health Service Act, the E-Government Act of 2002, and Title 18 of the United States Code. NCHS staff must sign a pledge to obey these laws and associated regulations to prevent disclosure of information, and they must follow strict procedures concerning data access, physical protection of records, avoidance of disclosure, and maintenance of confidentiality.

## *Unblemished record for maintaining privacy during data collection and processing*

NCHS collaborates with other organizations (for example, the U.S. Census Bureau and private research companies) to collect and process data for NHCS. These groups have an impeccable record of protecting the privacy of survey respondents.

## *HIPAA Privacy Rule on health information and survey participation*

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule permits you to make disclosures of protected health

information without patient authorization for public health purposes and for research that has been approved by an institutional review board (IRB) with a waiver of patient authorization. The NHCS meets both of these criteria. As part of the IRB approval process, reviews were conducted of the surveys' procedures for handling protected health information, and practices were determined to be appropriate for safeguarding respondent confidentiality. Additionally, disclosures may be made under a data-use agreement with NCHS for some surveys that do not collect directly identifiable data.

Copies of IRB approval letters and other related materials, such as data-use agreements, are available upon request for each component survey of the NHCS. There are several things that you must do to assure compliance with the Privacy Rule when participating in the survey. First, the privacy notice that you generally provide to your patients must indicate that patient information may be disclosed for either research or public health purposes. Second, you may need to keep a record of the disclosure that shows that some data from the patient's medical record were disclosed to CDC for NHCS (we will provide forms to assist you in record keeping). If you do not transmit health information electronically (such as claims data), you are not subject to the Privacy Rule or the requirements described above.

For additional information on the HIPAA Privacy Rule, see:

<http://www.hhs.gov/ocr/hipaa>

## Appendix VI. Corporate Advance Package Materials

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### Corporate Advance Letter (front)

#### DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service  
Centers for Disease Control and Prevention

National Center for Health Statistics  
3311 Toledo Road, room 3418  
Hyattsville, Maryland 20782

Dear Administrator:

The National Center for Health Statistics of the Centers for Disease Control and Prevention is conducting a nationwide survey of home health and hospice agencies. The purpose of the National Home and Hospice Care Survey (NHHCS) is to collect data on the characteristics of home health and hospice agencies and their patients, discharges, and staff. The survey is used by researchers, policy analysts, and practitioners to track changes in home health and hospice care utilization, costs, agency characteristics, staffing, and services provided, and to project future long-term health care needs. Visit the NHHCS website at [www.cdc.gov/nchs/nhhcs.htm](http://www.cdc.gov/nchs/nhhcs.htm) for additional information about the survey.

This letter is to inform you that some of the agencies in your organization may be invited to participate in the NHHCS. This survey includes a randomly selected nationwide sample of home health and hospice agencies, each of which represents a number of similar agencies. It is essential that we obtain data from all sample agencies in order to achieve accurate and complete statistics. Information is collected primarily by personal interview with administrators or their staff. No patient will be contacted at any time. A small sample of home health aides will be selected to participate in a voluntary offsite telephone interview. Although the agency's participation is voluntary, there are no penalties for refusing to answer any questions. It is important that we obtain data from all sample home health and hospice agencies in order to achieve accurate and complete statistics.

As part of this survey, the name, Social Security Number, Medicare Number, and Medicaid Number will be collected for each sampled patient and discharge. This information will be used only for statistical purposes, which will include obtaining Outcome and Assessment Information Set (OASIS) data about the home health patients from the Centers for Medicare and Medicaid Services and matching against the vital statistics records of the National Center for Health Statistics. Data collection for the NHHCS is authorized by the Public Health Service Act (Title 42, United States Code, Section 242k). All information collected is held in the strictest confidence, and will be used only to prepare statistical summaries. Please be assured that there are several ways that the Privacy Rule (as mandated by the Health Insurance Portability and Accountability Act [HIPAA]) allows you to participate. In particular, disclosures of patient data are permitted for public health purposes and for research that has been approved by an Ethics Review Board – both of which apply to this survey.

I want to emphasize further that the information that the staff of your agencies supply will be used solely for statistical research and reporting purposes. The only parties that can receive such data are those we've told you about on the back of this letter. In accordance with Section 308(d) (42 U.S.C. 242m) of the Public Health Service Act and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)], 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 such release. A report with information from the last survey is enclosed to illustrate how the data will be presented.

Within the next few weeks, a representative from Westat, the contractor conducting the survey on our behalf, will contact the agencies for an appointment. If you have any questions, please call an NHHCS representative at **1-888-798-6674**. I greatly appreciate your cooperation.

Sincerely,  
/Edward J. Sondik, Ph.D./  
Director, National Center for Health Statistics

Enclosures

**Corporate Advance Letter (back)**

**National Home and Hospice Care Survey (NHHCS)**  
**Frequently Asked Questions**

**Our agencies are asked to participate in studies all the time. What makes this one any different?**

The NHHCS is a large national study that, because of its size and design, can provide information that is representative of all home health and hospice agencies in the United States. Since the NHHCS is a periodic survey, the results can be used to track changes that are taking place in these types of agencies over time. The survey has been developed collaboratively by several government agencies. The survey is endorsed by industry associations, including the National Association for Home Care and Hospice and the National Hospice and Palliative Care Organization. **For more information about the survey, visit [www.cdc.gov/nchs/nhhcs.htm](http://www.cdc.gov/nchs/nhhcs.htm).**

**What other home health and hospice agencies are you going to visit?**

This is a random national sample and we do not release the names of these agencies to anyone. This is to protect individual agencies and the patients they serve.

**Why can't other agencies besides ours participate?**

If your agencies do not participate, the unique qualities of your agencies will be lost. The survey will be used by Congress and decision makers who will formulate policy for the next decade. Your agencies represent other similar agencies. If your agencies don't participate, there is no guarantee that home health agencies and/or hospices like yours will be adequately represented. We don't want industry decisions based on this survey to be made without all types of agencies, including those like your agencies, represented.

**Will the data be held confidential?**

The NHHCS is authorized by Congress in Section 306 of the Public Health Service Act (42 United States Code 242K). All information collected in this survey will be held in strict confidence according to law [Section 308(d) of the Public Health Service Act [42 United States Code 242m(d)] and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)]. Aside from NCHS employees, the only parties that can receive information that would directly identify the agency, patients, or staff are: (1) Westat – hired to conduct this survey, and (2) our collaborators – persons who have worked as our full partners from the earliest stages of this survey.

These parties, who will use your information for statistical research only and to carry out this survey, are bound by strong restrictions designed to guarantee your privacy. By law we cannot release information that could identify your agencies, patients, or staff to anyone else without your consent. If any federal employee or contractor gives out confidential information not authorized by law, he or she can be fired, fined, and/or imprisoned.

**Staff in my agencies is incredibly overworked right now. I need to know how much of their time will be required for this survey. How long will this take?**

We will need about 30 minutes with the agency director or someone he or she designates to answer questions about the agency. We will also collect information about a sample of 10 current home health patients and hospice discharges that will take approximately 25 minutes for each person sampled. In addition, in order to conduct a telephone survey during non-working hours with a sample of home health aides, we will need a list of all home health aides employed by the agency. The interviewer will accommodate the schedules of the agency staff members to complete these tasks as quickly as possible.

<b>Letter of Support From the Paraprofessional Healthcare Institute (front)</b>
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349 East 149th Street, 10th Floor • Bronx, New York 10451  
 Telephone: 718-402-7766 • Fax: 718-585-6852 • info@paraprofessional.org

17 August 2006

Dear Director:

On behalf of the Board of Directors of the Paraprofessional Healthcare Institute (PHI), I am writing to urge you to participate in the National Home and Hospice Care Survey, conducted by the U.S. Centers for Disease Control and Prevention's National Center for Health Statistics.

For the first time in its history, the National Home and Hospice Care Survey will gather information directly from **home health aides** working for home health and hospice agencies, which is crucial to helping industry leaders such as yourself recruit and retain a highly-qualified, direct-care staff.

PHI is a national healthcare institute that focuses exclusively on the recruitment and retention of paraprofessional workers in long-term care – home health aides, certified nursing assistants and personal care attendants. For this reason, PHI is highly supportive of the new *National Home Health Aide Survey*, and I hope you in turn will urge the staff at your agency to participate.

From this special survey, the long-term care field will learn from home health aides about:

- Φ How and why they became home health aides;
- Φ Their work history and experiences;
- Φ What they like about being home health aides;
- Φ How the demands of the job affect them individually; and
- Φ If they are thinking of leaving the field, what opportunities and changes might keep them working in long-term care.

The entire field will share in the findings of the survey, which will help providers and policymakers develop new programs and public policies to address the growing "care gap" across the nation – many more individuals needing care with too few workers able and willing to provide that care.

*Quality Care through Quality Jobs*



Letter of Support From the Paraprofessional Healthcare Institute (back)

We have been assured that names of participating home health aides from your agency, and where they work, will be kept private; the original data will be used for statistical purposes only. Therefore, strict provisions of confidentiality are maintained. Only summary data will be published and made available to health professionals such as yourself, health planners, researchers, and the public.

The willingness of the home health aides selected from your agency to participate will be essential to ensure that the survey is an accurate representation from across the country. *Please* encourage the home health aides selected from your agency to take part in the *National Home Health Aide Survey*. We at PHI believe you will find the information from this survey worthy of your help, and worthy of the participation of the home health aides within your agency.

Sincerely,  
/Steven L. Dawson/  
President

## National Association of Health Care Assistants

National Headquarters: 1201 L Street NW, Washington, DC 20005  
Operations Center: 2709 W 13th Street, Joplin, MO 64801  
800.784.6049 [www.nahcacares.org](http://www.nahcacares.org)

Dear Director:

I encourage you to participate in the National Home and Hospice Care Survey conducted by the U.S. Centers for Disease Control and Prevention's National Center for Health Statistics. Your agency was chosen to be part of a nationally representative sample of home and hospice agencies and your participation is important to the success of the overall national study.

There is an important new component in the home and hospice care survey—a feature not part of previous surveys conducted by the National Center for Health Statistics. Included this time is a survey of home health aides who care for patients in home health and hospice agencies—The National Home Health Aide Survey.

Today the nation is facing a critical shortage of home health aides, nursing assistants, and other direct-care workers in long-term care as the generation of “baby boomers” ages. We need today—probably more than ever before—to hear from home health aides about their work history, their experiences, and the challenges they encounter in their work to better inform discussions on changes in policy and practice that can help attract people to join long-term care as home health aides.

Any personal information in the survey will be kept confidential, including names of participating home health aides and the name of your agency. The data will be used for research purposes only where rules of confidentiality are followed. Only aggregate research results will be made public and available.

Again, please participate in the National Home and Hospice Care Survey. And encourage the home health aides selected from your agency to be part of The National Home Health Aide Survey.

I thank you for your cooperation and assistance.

Your partner in caring,

/Lori J. Porter/  
Co-founder & CEO

Letter of Support From the Visiting Nurse Associations of America



*the voice of home healthcare*

December 6, 2007

Dear VNA CEO:

I am writing to encourage your participation in the 2007 National Home and Hospice Care Survey being conducted by the Federal Center for Disease Control's National Center for Health Statistics (NCHS). This survey collects baseline and trend information from a sample of home health agencies and hospices across the United States.

It is important for you to participate in the survey if you are selected as part of the sample. If you do not participate, your agency's information will not be included and thus the survey will prove less representative of VNAs. The data collected in this survey is used by researchers and policy makers to assess the current adequacy of home health and hospice care as well as influencing future policy decisions.

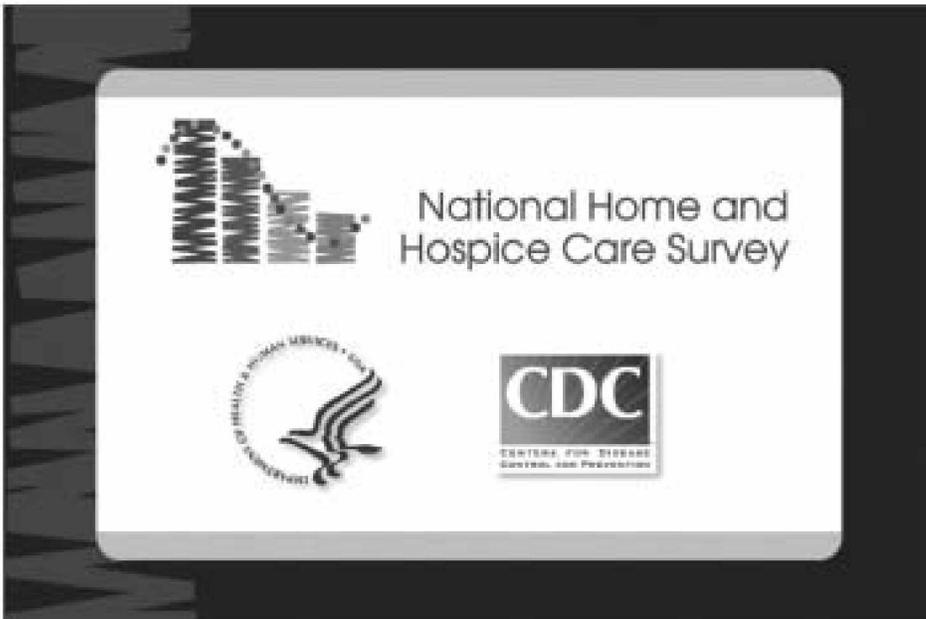
The information collected in the survey is kept strictly confidential and only summary data, not identifying your VNA, will be published or made available to the public. The survey protocol has been approved under both HIPPA and Privacy Act Standards.

Thank you for your cooperation in assuring that this survey includes VNA data and is thus fully representative of the entire home health and hospice community.

Sincerely,

/Andy Carter/  
CEO

NHHCS DVD Slide Presentation



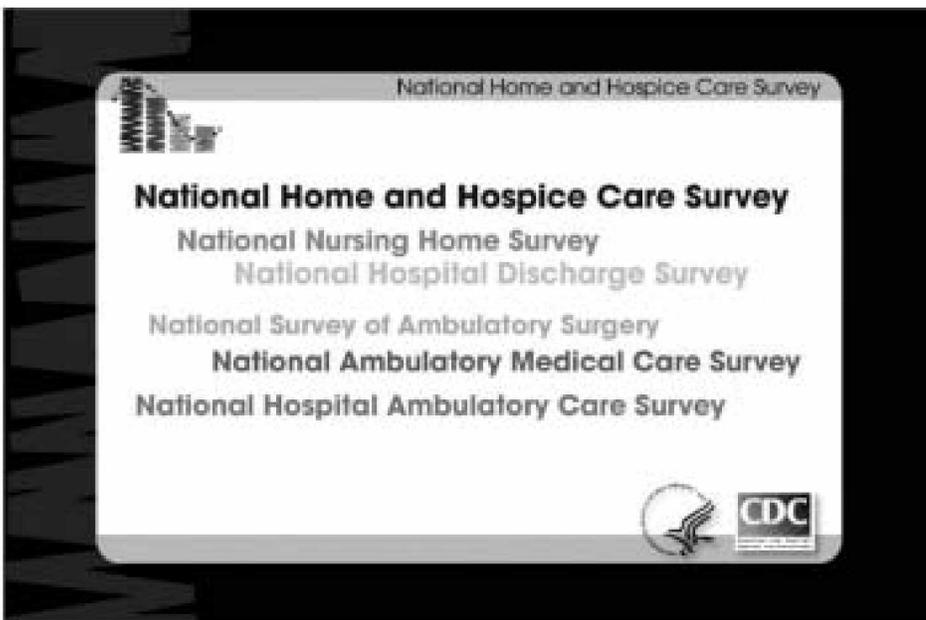
Slide 1. Music plays. National Home and Hospice Care Survey logo appears with Department of Health and Human Services and CDC logos below.



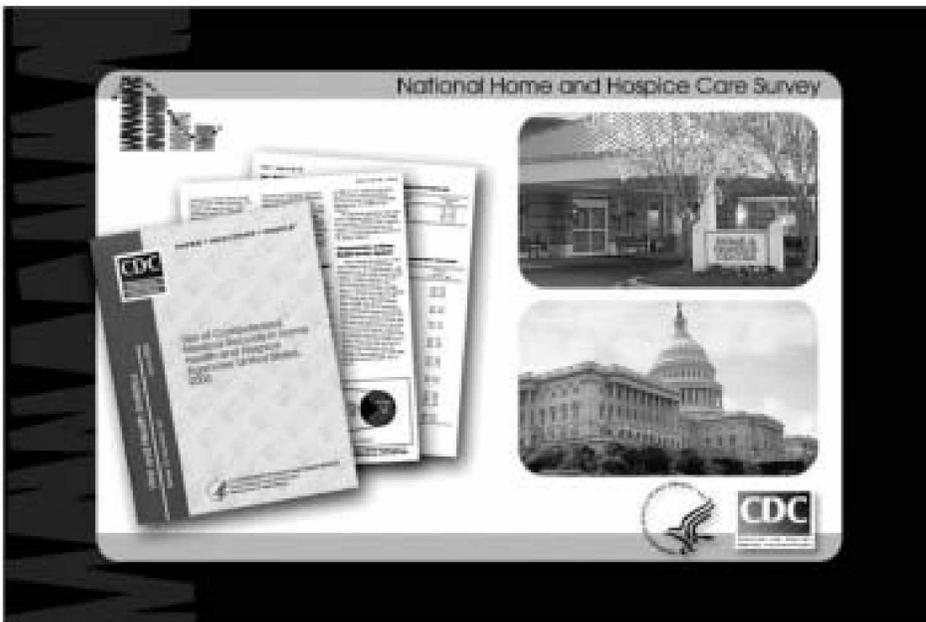
Slide 2. Welcome to the National Home and Hospice Care Survey.



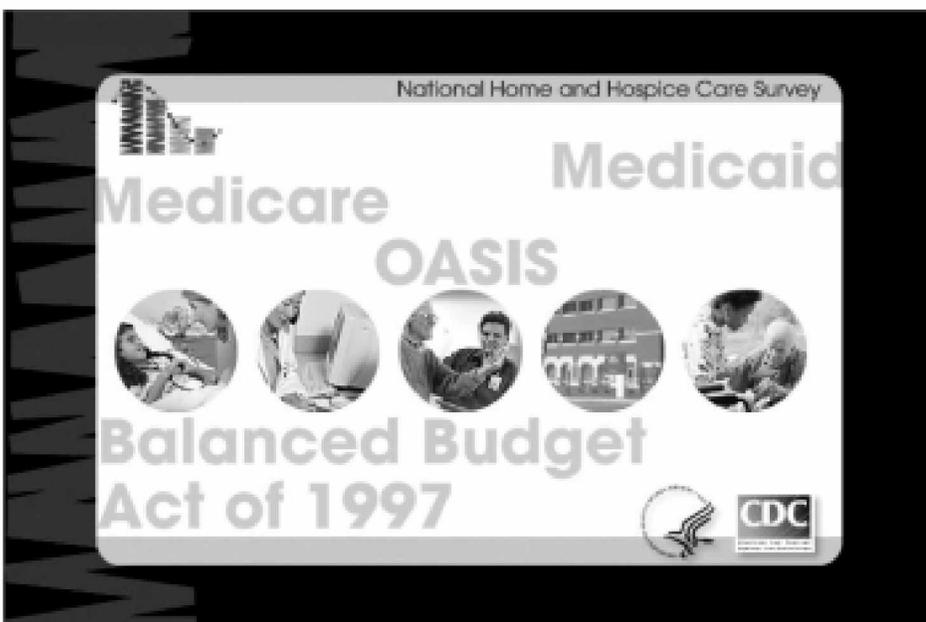
Slide 3. The National Home and Hospice Care Survey (also known as NHHCS) gathers data from a nationally representative sample to describe the nation's home health and hospice care agencies and the health status of their patients.



Slide 4. This survey is part of a family of health care establishment and provider-based surveys conducted by the National Center for Health Statistics (or NCHS).



Slide 5. The data from the National Home and Hospice Care Survey and other NCHS surveys provide critical information to answer important questions and policy issues that are part of the national debate on health care.



Slide 6. Over the past several years, the home health and hospice industry as a whole has witnessed many changes in the kinds of services and care it offers.



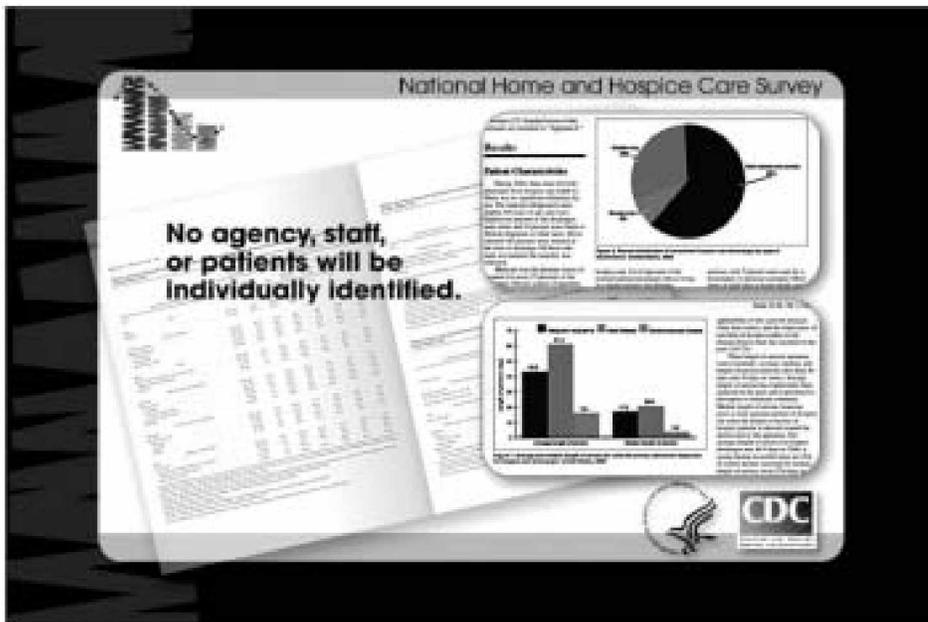
Slide 7. As part of the 2007 National Home and Hospice Care Survey, 1,500 (fifteen hundred) home and hospice care agencies around the country will be randomly selected and asked to participate by providing data that will be used to address current and proposed home health and hospice care policy.



Slide 8. These randomly selected agencies will represent the more than 10,000 home health and hospice care agencies in the United States that provide care and support to more than 2.2 million elderly, disabled, and chronically ill people.

Your participation guarantees that home health and/or hospice agencies like yours will be adequately represented.



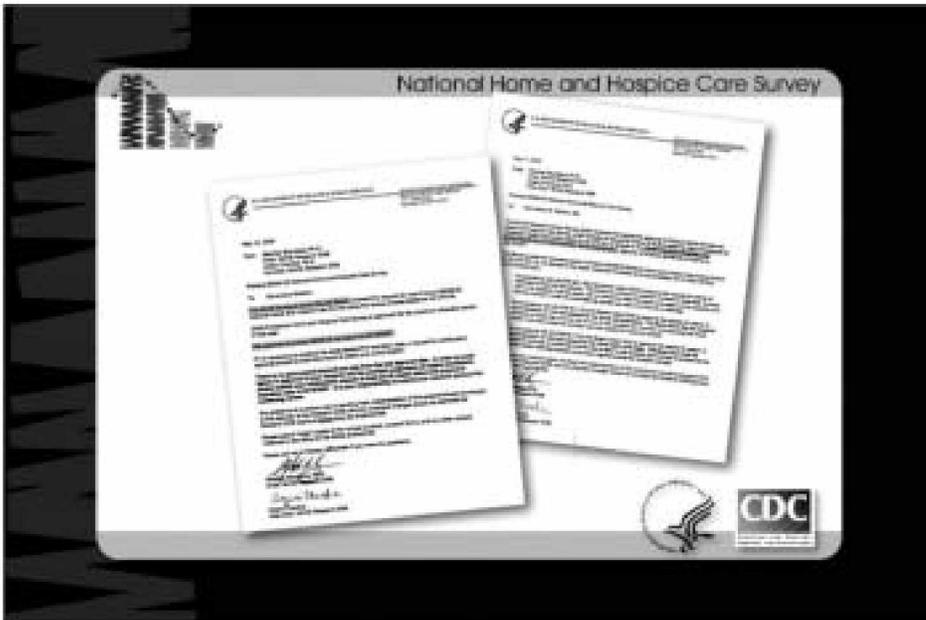


Slide 11. Data from each participating agency will be combined and released only in summary form in reports and tables.

No agency, staff, or patients will be individually identified.



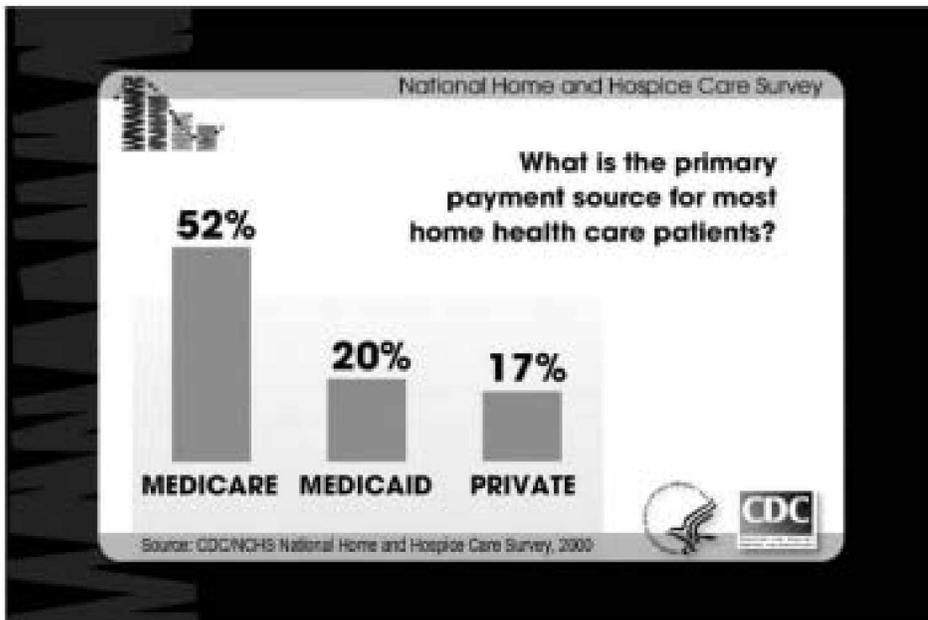
Slide 12. Data collection for the National Home and Hospice Care Survey is allowed by the Health Insurance Portability and Accountability Act (HIPAA) and has been approved by the NCHS Ethics Review Board.



Slide 13. HIPAA permits the disclosure of patient data for public health purposes and for research that has been approved by an Ethics Review Board—both of which apply to this survey.

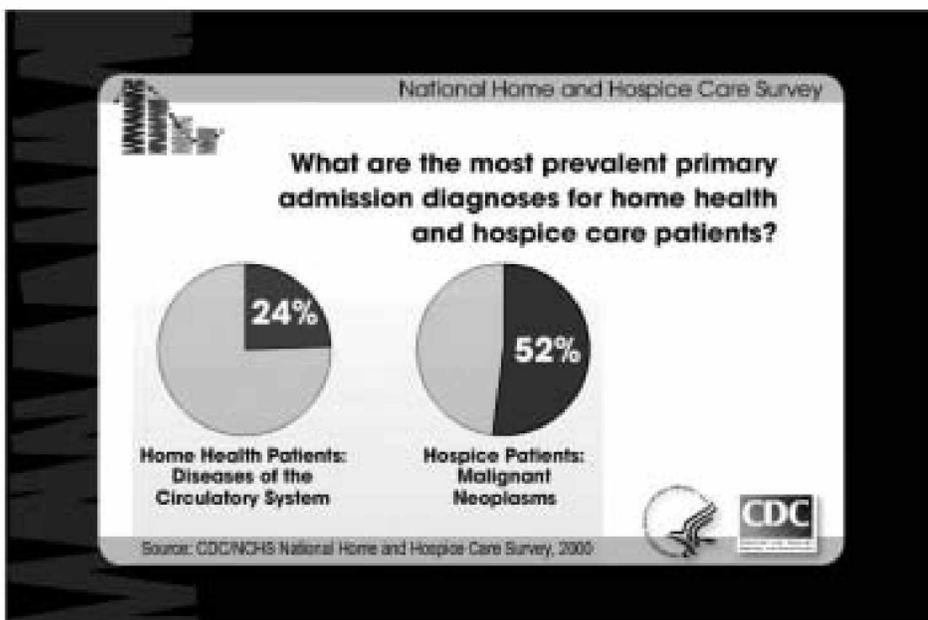


Slide 14. Every home health and hospice care agency that participates in the survey will contribute important information that will help to describe and improve home health and hospice care throughout the country. Here are a few examples of questions that were answered when the last National Home and Hospice Care Survey was conducted in 2000.



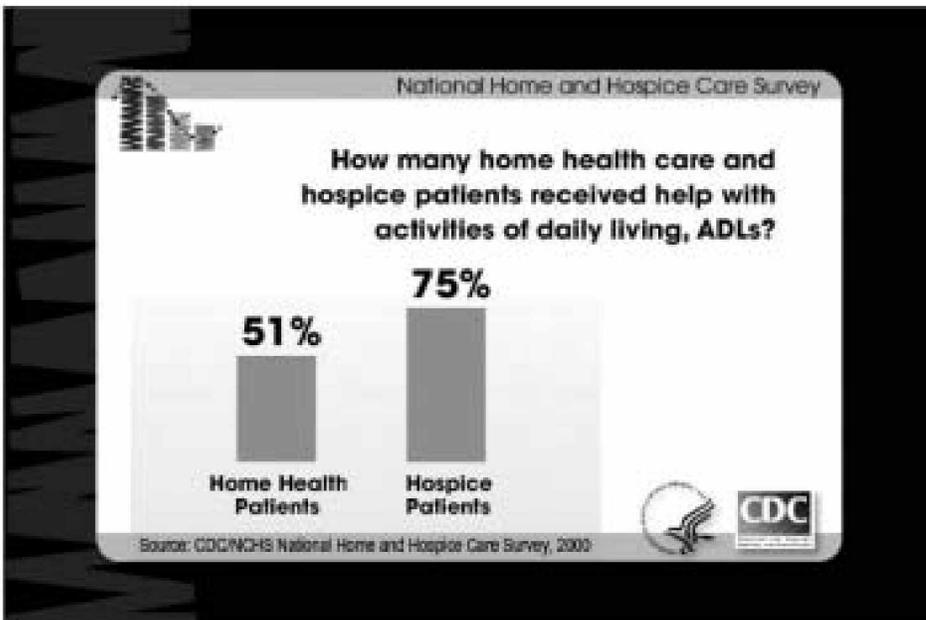
Slide 15. What is the primary payment source for most home health care patients?

Medicare was the primary payment source for the majority of home health care patients at 52%, followed by Medicaid at 20%, and private sources at 17%.



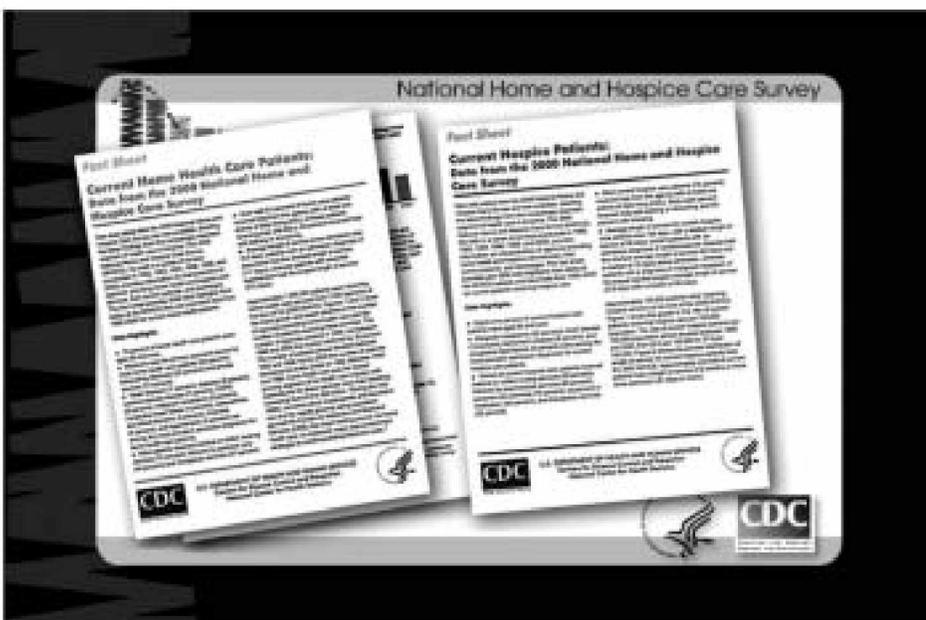
Slide 16. What are the most prevalent primary admission diagnoses for home health patients and hospice care patients?

The most common diagnoses for home health care patients were diseases of the circulatory system and for hospice care patients, malignant neoplasms.

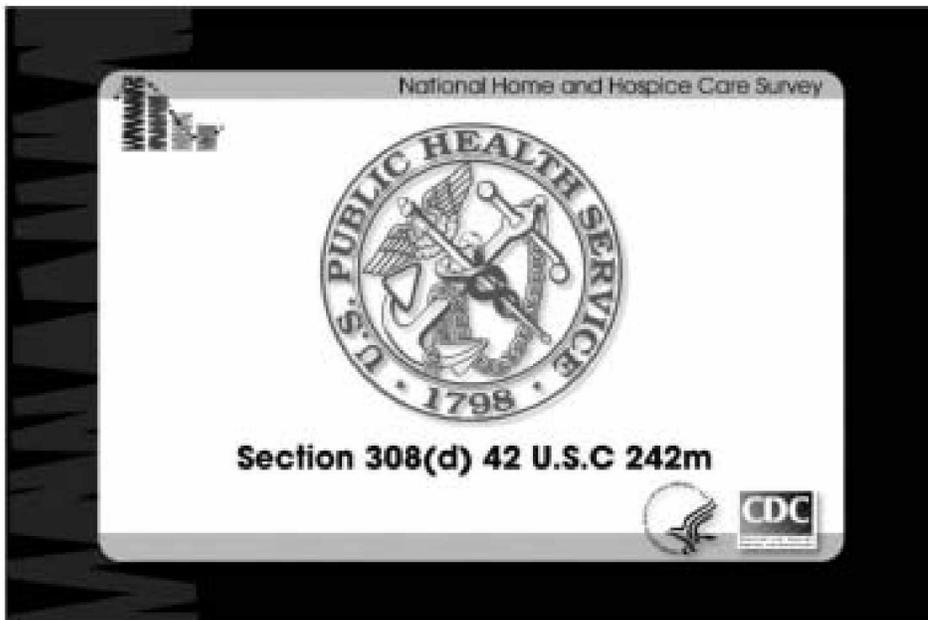


Slide 17. How many home health care and hospice patients received help with activities of daily living (ADLs)?

Over half of home health care patients and three-fourths of hospice patients received help from the agency with at least one ADL.



Slide 18. These, and other important data, are provided through the National Home and Hospice Care Survey.



Slide 19. The survey is authorized by the Public Health Service Act, which mandates and authorizes the collection of these data.

The law also states that all information collected is held in the strictest confidence and is to be used only for statistical research and reporting purposes.



Slide 20. The National Home and Hospice Care Survey is endorsed by industry associations, including the National Association for Home Care and Hospice and the National Hospice and Palliative Care Organization.



**Slide 21. The survey will help the home health and hospice industry develop more effective ways of meeting the needs of current and future home health and hospice patients.**



**Slide 22. The survey uses trained interviewers to gather information directly from agency directors and staff during an in-person visit at your agency.**



Slide 23. The interviewers will use a computer-assisted interviewing instrument to collect data on home health and hospice agencies, their services, their staff, and their patients and discharges, using agency and medical records.

Patients are not contacted directly to collect information.

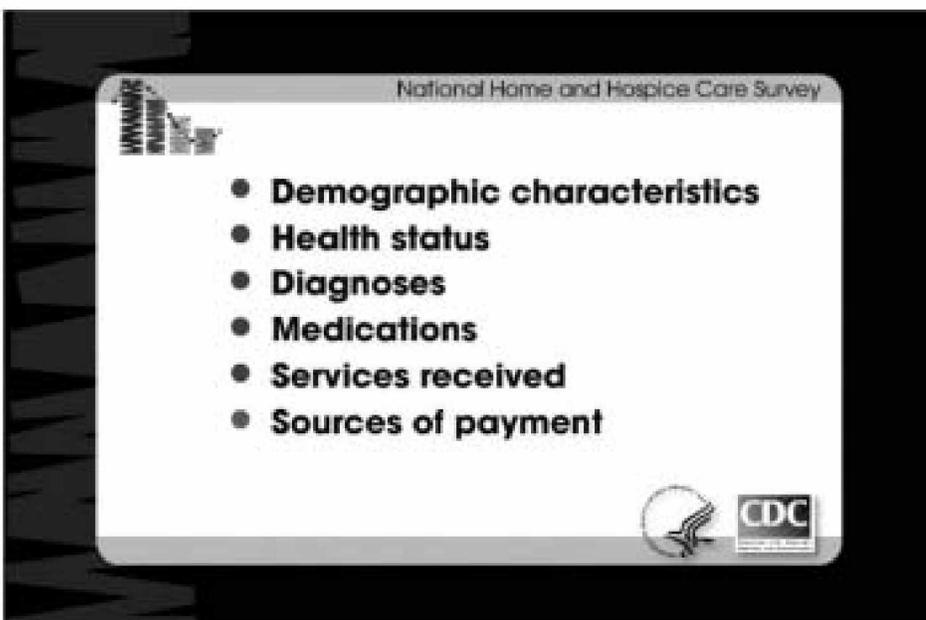


Slide 24. The information collected about each agency will include: size, ownership, certification status, types of services and care provided, basic service charges, staffing, and policies.

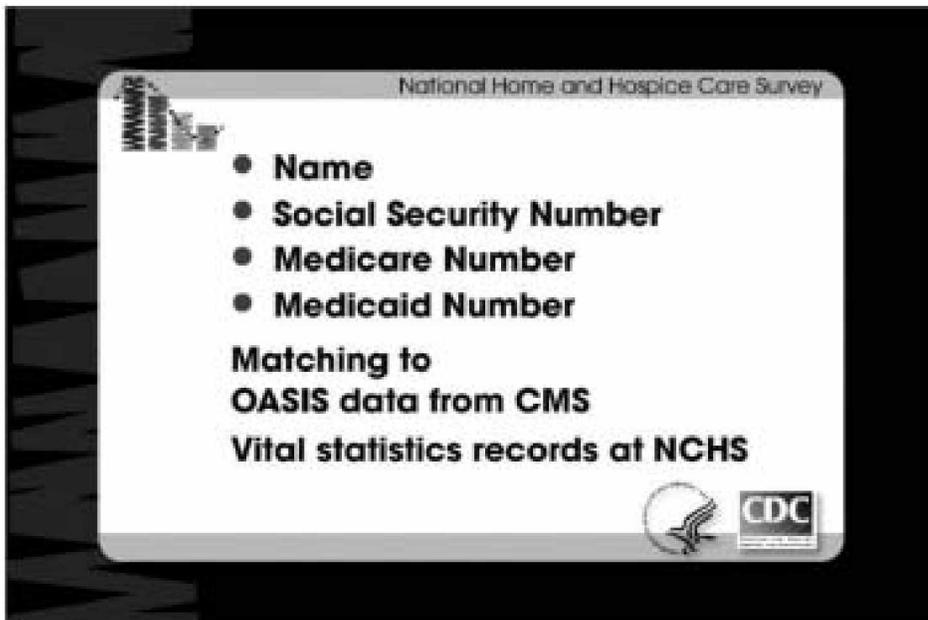


Slide 25. During the visit, a small sample of current home health patients and hospice discharges will be randomly selected.

Agency staff who are familiar with patient records will be asked to use these records to provide information about the selected patients.



Slide 26. The patient data collected will include: demographic characteristics, functional and health status, diagnoses, medications, services received, and sources of payment for their home health and hospice care.



Slide 27. The survey will also collect the name, social security number, Medicare number, and Medicaid number for each sampled home health patient and hospice discharge.

NCHS will use this information to match to the Outcome and Assessment Information Set, or OASIS, data from the Centers for Medicare & Medicaid Services for home health patients.

NCHS also plans to use the patient and discharge names and social security numbers for future followup studies, such as matching against vital statistics records at NCHS.

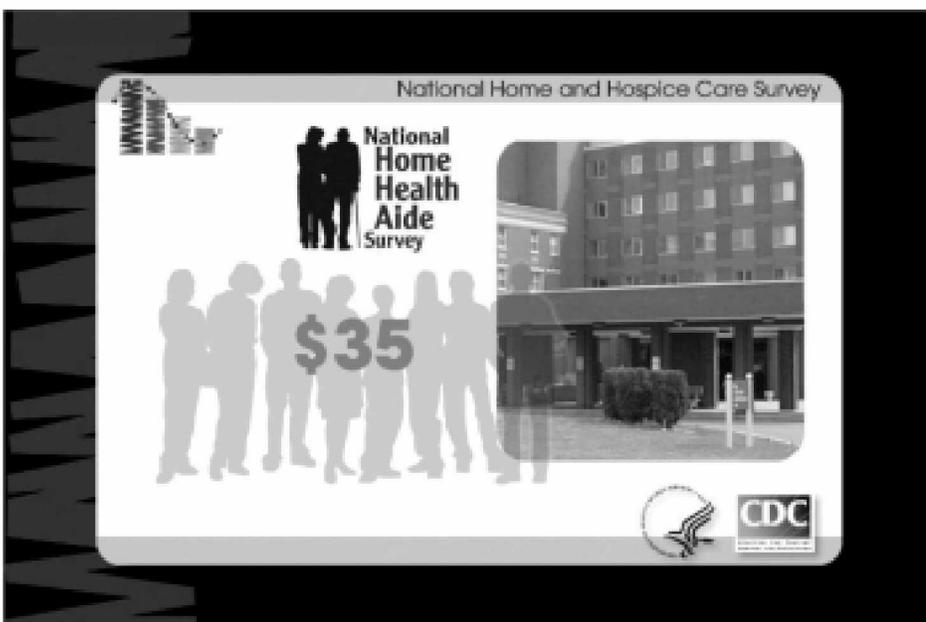


Slide 28. This year, home health and hospice agencies will also be asked to participate in a first-ever nationwide survey of home health aides.

Home health aides provide the majority of direct care to people receiving home health and hospice care services.



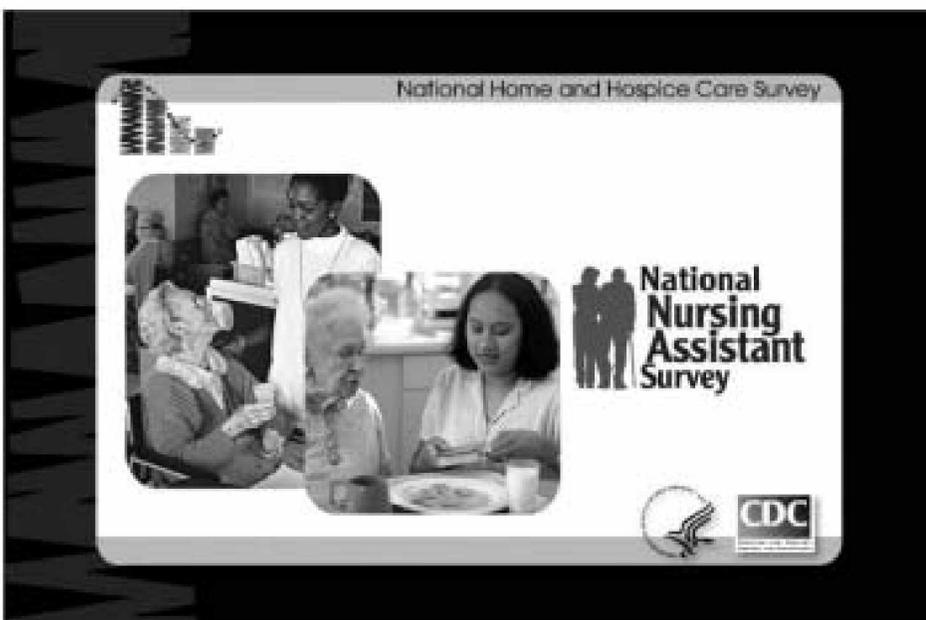
Slide 29. For the National Home Health Aide Survey (also referred to as the NHHAS), a sample of 6,000 home health aides will be selected to participate in a telephone interview during non-working hours.



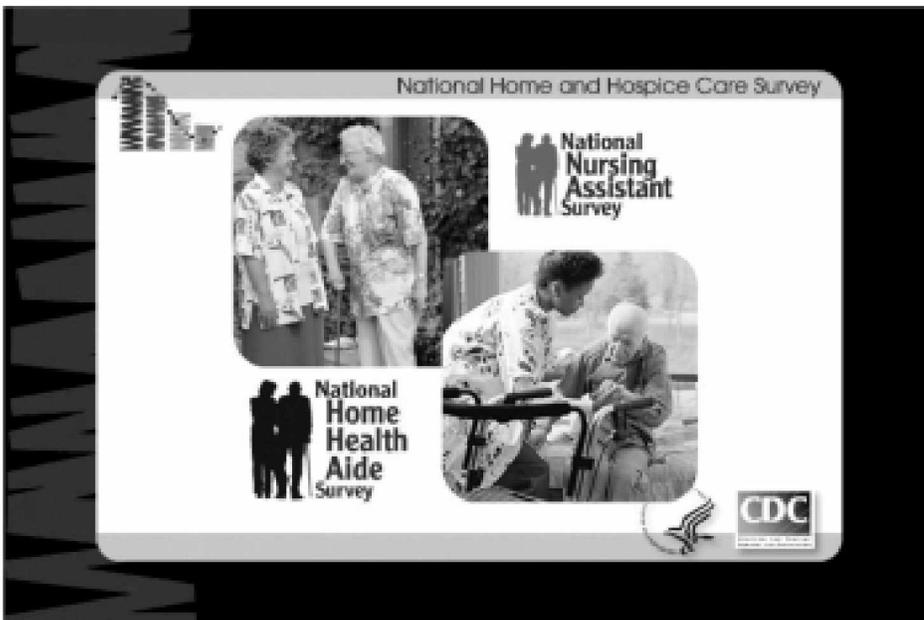
Slide 30. Home health aides employed to assist patients with activities of daily living will be selected from each agency at the time of the agency visit. Each home health aide who participates in the survey will receive \$35.



Slide 31. The National Home Health Aide Survey is sponsored by the Department of Health and Human Services, which has made the long-term care workforce a major focus of its policy research agenda.



Slide 32. In 2004, the Department of Health and Human Services also sponsored the National Nursing Assistant Survey (the NNAS), the first-ever national survey of nursing assistants working in nursing homes.

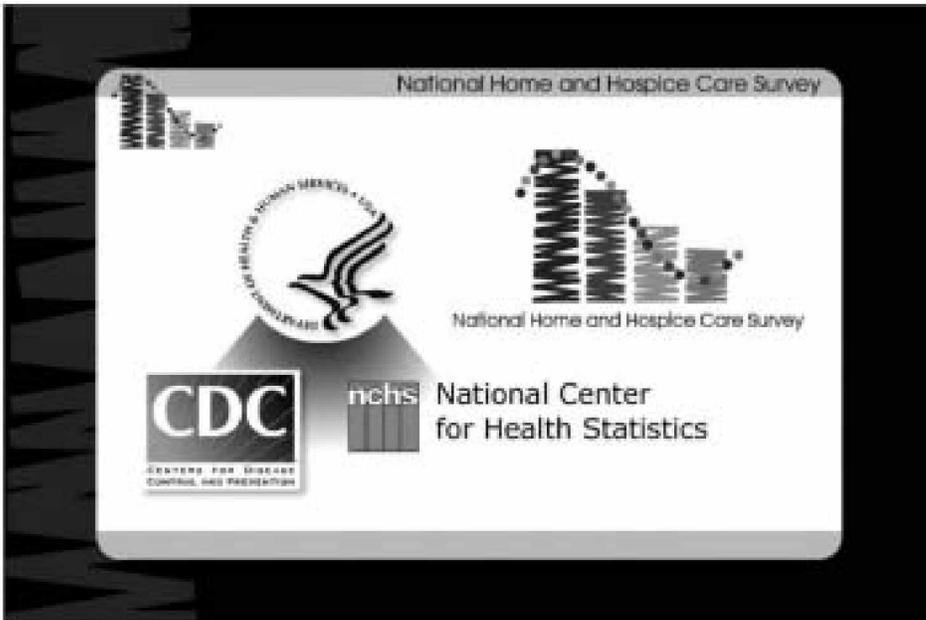


Slide 33. Together, the National Home Health Aide Survey and the National Nursing Assistant Survey will improve our understanding of the direct care workforce.

These surveys will provide data to help address the pending shortage in the long-term care workforce and the challenges long-term care providers face in ensuring there are enough experienced home health aides to provide high-quality care.

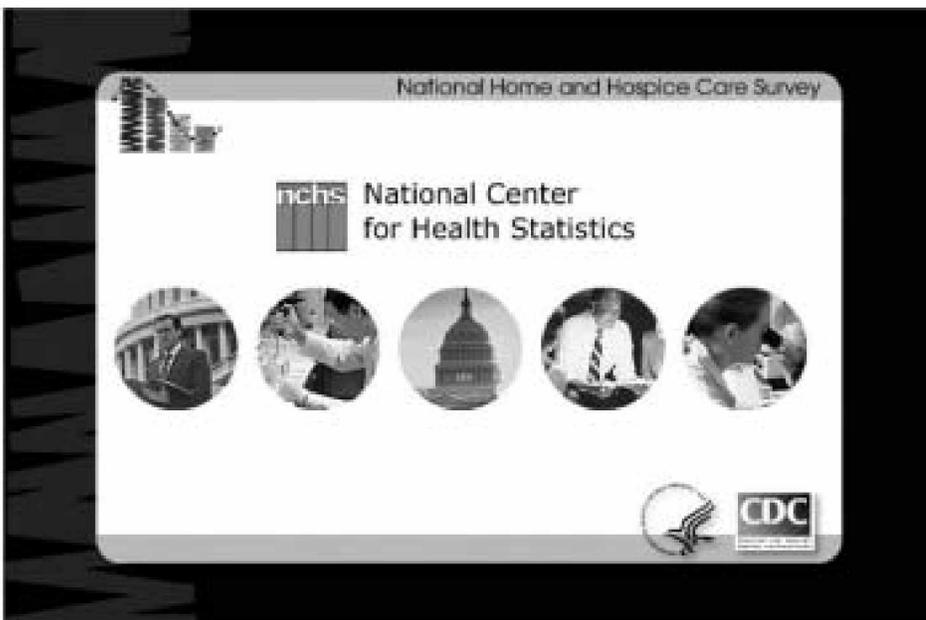


Slide 34. Westat, a nationally known survey research organization with headquarters in the Washington, D.C., area will collect the National Home and Hospice Care Survey and the National Home Health Aide Survey data under contract with NCHS.



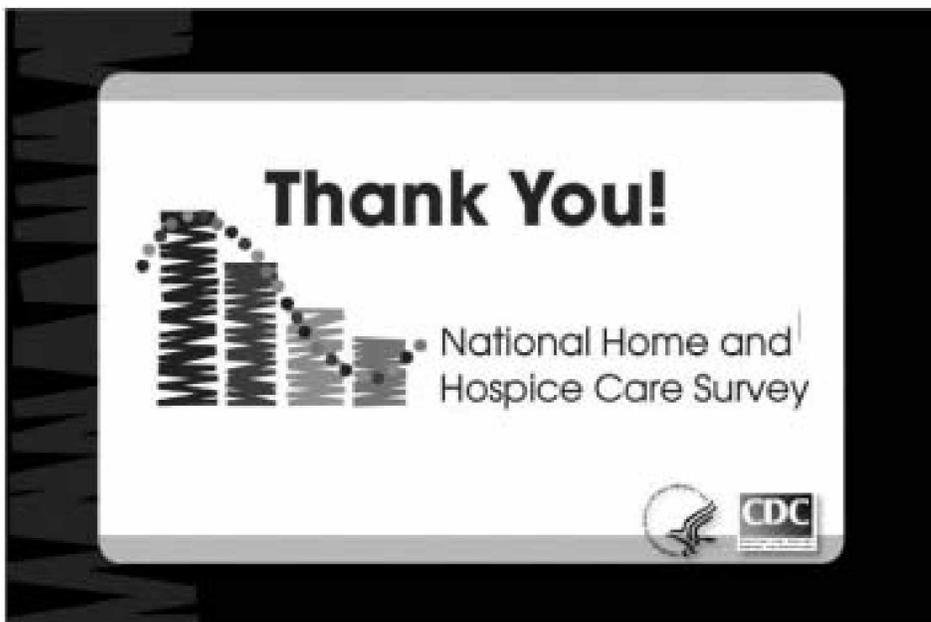
Slide 35. The National Home and Hospice Care Survey is sponsored by the Centers for Disease Control and Prevention's National Center for Health Statistics.

Both CDC and NCHS are part of the U.S. Department of Health and Human Services.



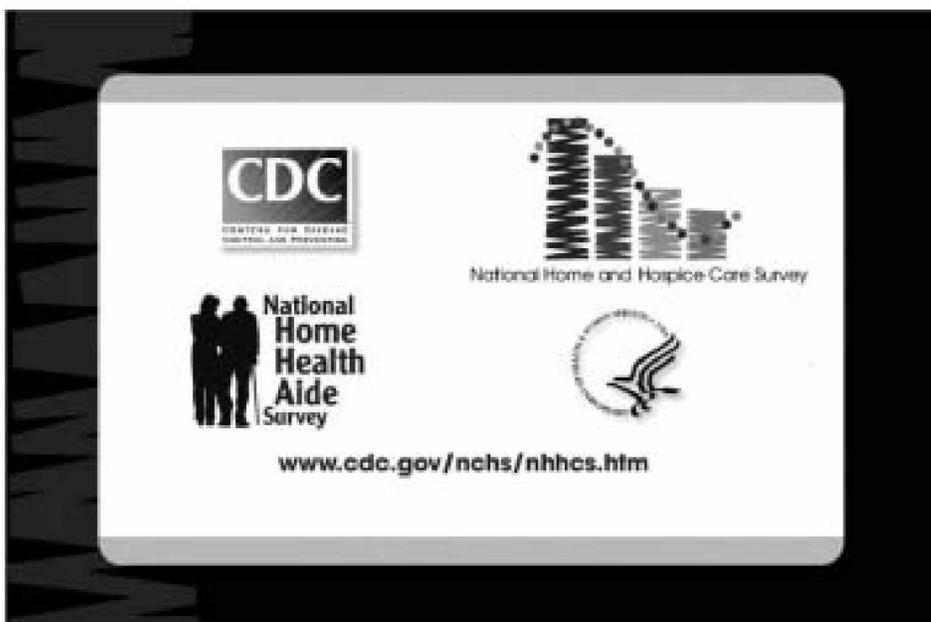
Slide 36. NCHS, as the nation's principal health statistics agency, provides accurate, relevant, and timely data to identify and address health issues.

NCHS' statistical data help to guide our country's public health and health policy decisions.



Slide 37. Thank you for taking the time to learn about this important national health care survey conducted by NCHS.

We look forward to your participation!



Slide 38. For more information about uses of the National Home and Hospice Care Survey and the National Home Health Aide Survey data, or for access to the data for your own research, navigate on this website when the video has ended. [www.cdc.gov/nchs/nhhcs.htm](http://www.cdc.gov/nchs/nhhcs.htm)

# Appendix VII. Set an Appointment Script

## National Home and Hospice Care Survey (NHHCS) Set an Appointment Script

AFFIX AGENCY LABEL HERE

1. Hello, may I please speak to [AGENCY DIRECTOR] regarding some materials that we sent (a few days ago)? My name is \_\_\_\_\_ and I'm working on the National Home and Hospice Care Survey sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS).

YES ..... 1 (GO TO Q3)  
 NO ..... 2

2. Is there a better time for me to speak to (Mr./Ms.) [AGENCY DIRECTOR]?

PREFERRED DATE: \_\_\_\_\_ TIME: \_\_\_\_\_ AM/PM  
 DON'T KNOW -8  
 REFUSED -7

GO TO CLOSING 2

3. (Hello, my name is \_\_\_\_\_, and I am calling about the National Home and Hospice Care Survey sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS).)

First, is [HOME HEALTH/HOSPICE AGENCY NAME] a (home health/home care) agency, a hospice agency, **or** both a (home health/home care) **and** hospice agency?

HOME HEALTH ONLY ..... 1  
 HOSPICE ONLY ..... 2  
 BOTH HOSPICE AND HOME HEALTH ..... 3  
NOT A HOME HEALTH OR HOSPICE AGENCY ..... 4

GO TO Q5

4. What type of business/company is this?

\_\_\_\_\_  
 \_\_\_\_\_

Those are all of the questions I have for now. Thank you very much for your time. END THE CALL. GO TO BOX 1.

BOX 1 INTERVIEWER: AGENCY IS INELIGIBLE - NOT A HOME HEALTH OR HOSPICE AGENCY. ENTER AN EROC WITH A DISPOSITION CODE OF 41-INELIGIBLE NOT A HOME HEALTH OR HOSPICE AGENCY. COMPLETE THE NIRF AND INCLUDE INFORMATION FROM Q4.

5. Some home health and hospice agencies only serve as a central office and do not provide services to patients from the central office. Does this agency location provide services to patients?

YES, AGENCY PROVIDES PATIENT SERVICES ..... 1 (GO TO Q7)  
 AGENCY DOES NOT PROVIDE PATIENT SERVICES .. 2

6. I'll have to contact my supervisor to find out how to proceed. I may be contacting you again. Thank you very much for your time. END THE CALL. GO TO BOX 2.

BOX 2 INTERVIEWER: AGENCY IS INELIGIBLE - NO ELIGIBLE CURRENT HOME HEALTH PATIENTS OR HOSPICE DISCHARGES. ENTER AN EROC WITH A DISPOSITION CODE OF 42-NO ELIGIBLE CURRENT HOME HEALTH PATIENTS OR HOSPICE DISCHARGES. COMPLETE THE NIRF AND INCLUDE INFORMATION FROM Q5. FEDEX COPY OF THIS SCRIPT TO WESTAT.

7. Did you receive the package of materials that we sent (a few days ago)?

YES ..... 1  
 NO ..... 2 (GO TO Q9)

8. Have you had a chance to review the material?

YES ..... 1 (GO TO Q15)  
 NO ..... 2

9. Shall I describe the survey to you now or would you prefer that I call you back after you have reviewed the materials? (I'll re-send them.)

DESCRIBE SURVEY ..... 1 (GO TO Q14)  
 CALL BACK ..... 2

10. Is this a good time of day to call or is there a better time?

PREFERRED DATE: \_\_\_\_\_ TIME: \_\_\_\_\_ AM/PM

11. INTERVIEWER: DO THE MATERIALS NEED TO BE REMAILED? (Q7=2 "NO")

YES ..... 1 (GO TO Q12)  
 NO ..... 2 (GO TO CLOSING 2)

12. I would like to confirm that we have your correct address to re-mail the package. According to my records, you are located at (AGENCY ADDRESS). Is this correct?

YES..... 1 (GO TO Q13)  
NO..... 2

RECORD CORRECT ADDRESS:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

13. I will put this package in the mail today.

GO TO CLOSING 2

14. INTERVIEWER: PROVIDE SUMMARY DESCRIPTION OF SURVEY AS NEEDED, THEN GO TO Q15.

The National Home and Hospice Care Survey is a nationally representative sample of agencies that provide home health and hospice care.

Its purpose is to collect information on home health and hospice agencies, services provided, their staff, and their patients' health, demographics, and sources of payment.

- [HOME HEALTH/HOSPICE AGENCY NAME] was randomly selected.
- Short interview with the director.
- The survey requires an interviewer to visit your agency:
  - to collect information about your agency and staff;
  - to collect medical and billing information about a sample of current patients/hospice discharges; and
  - to select a sample of home health aides and their home addresses and telephone numbers from all aides employed by your agency. The selected aides will be contacted at home during non-working hours for the National Home Health Aide Survey.
- Confidentiality is ensured by federal law.
- A sample of home health and hospice agencies is intended to produce estimates for United States home health and hospice agencies.
- The findings will provide critical input to national issues on home health and hospice care.

15. Do you have any questions about (the material you received/the information I just provided to you)?

YES ..... 1 (GO TO BOX 3)  
NO ..... 2 (GO TO Q16)



19. According to my records, you are located at (AGENCY ADDRESS). Is this correct?

RECORD CORRECT ADDRESS:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

20. We will send out an appointment confirmation letter as a reminder of the appointment we just scheduled. To whom should this letter be addressed please? What is (your/his/her) title? ASK IF NECESSARY: Is that Mr or Ms (DIRECTOR'S LAST NAME)?

DIRECTOR NAME: \_\_\_\_\_

DIRECTOR TITLE: \_\_\_\_\_

DIRECTOR PREFIX (CIRCLE ONE):      MR      MS      DR      SR

21. And where should we come when we arrive at your agency?

WRITE LOCATION: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

GO TO CLOSING 2

22. What is the name of your parent corporation/chain?

CORPORATE/CHAIN NAME: \_\_\_\_\_

\_\_\_\_\_

REFUSED ..... -7 (CLOSING 2)

23. Who would we need to contact at your corporate/chain office for the 2007 National Home and Hospice Care Survey? What is (his/her) name and title? IF AGENCY DIRECTOR OFFERS TO CONTACT CORPORATE/CHAIN OFFICE, SAY: Thank you very much for offering to contact your corporate office. I would like this information in case we need to followup with the corporate office to send additional information about the survey.

CONTACT PERSON NAME: \_\_\_\_\_

CONTACT PERSON TITLE: \_\_\_\_\_

DON'T KNOW/NOT AVAILABLE..... -8

REFUSED ..... -7

24. What is the mailing address and phone number for [CORPORATE/CHAIN CONTACT]?

RECORD MAILING ADDRESS:

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

CORPORATE/CHAIN CONTACT PHONE: \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

DON'T KNOW/NOT AVAILABLE ..... -8  
 REFUSED ..... -7

CLOSING 1 Thank you very much for your time. END CALL. THEN GO TO Q25.

25. AGENCY DIRECTOR INDICATED CORPORATE/CHAIN APPROVAL IS NEEDED. INDICATE WHETHER THE AGENCY DIRECTOR OFFERED TO FOLLOWUP WITH CORPORATE/CHAIN OFFICE.

DIRECTOR OFFERED TO FOLLOWUP ..... 1  
 DIRECTOR DID NOT OFFER TO FOLLOWUP ..... 2  
 CORPORATE/CHAIN NAME REFUSED ..... -7

CLOSING 2 Thank you very much for your time.

BOX 5

INTERVIEWER:

- UPDATE AGENCY NAME AND ADDRESS INFORMATION, DIRECTOR'S NAME, AND TITLE AND THE NUMBER OF HOME HEALTH AIDES AS APPROPRIATE USING THE AGENCY INFO BUTTON.
- RECORD APPOINTMENT INFORMATION ON CALENDAR AND EROC AS APPROPRIATE.
- UPDATE CASE DISPOSITION IN IFMS BY ENTERING EROC & APPOINTMENT DATE AS APPROPRIATE.
- IF CORPORATE CONTACT/CHAIN APPROVAL REQUIRED, ENTER AN EROC WITH AN INTERIM CODE OF 36-CO APPROVAL REQUIRED.
- IF AGENCY LOCATION IS A CENTRAL OFFICE AND PATIENT SERVICES NOT PROVIDED AT LOCATION (Q5=2), ENTER AN EROC WITH AN INTERIM CODE OF 42-NO ELIGIBLE HOME HEALTH PATIENTS OR HOSPICE DISCHARGES. CONTACT SUPERVISOR IMMEDIATELY. FEDEX COPY OF THIS SCRIPT TO WESTAT.
- IF ADDRESS OR NAME CHANGE (OTHER THAN MINOR MISSPELLING, ZIP CODE, OR AREA CODE CHANGE), ENTER AN EROC WITH AN INTERIM CODE OF 52-NAME/ADDRESS CHANGE, NCHS REVIEW REQUIRED. CONTACT SUPERVISOR IMMEDIATELY.
- CONNECT TO WESTAT AND TRANSMIT.

## Appendix VIII. Appointment Confirmation Package Materials, Including Self-administered Staffing Questionnaire (SAQ)

### Appointment Confirmation Letter



An Employee-Owned  
Research Corporation

1600 Research Boulevard  
Rockville, MD 20850-3129  
tel: 301-251-1500  
fax: 301-294-2040  
www.westat.com

Stuckeyville, MD 15432

Dear Ms. Collins:

Thank you for agreeing to participate in the National Home and Hospice Care Survey (NHHCS) sponsored by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics. This is to confirm an appointment with a Westat field representative that is scheduled at **Collins Home Care on Tuesday, August 21, 2007, at 10 a.m.** We have enclosed a "Summary of Key Items for Data Collection" to give you an overview of the data collection process and the information we will need.

Please have available a daily census of all home health patients (exclude patients who only receive homemaker services and/or durable medical equipment/supplies) as of midnight **Monday, August 20, 2007** if your agency serves home health patients, and/or a separate list of all hospice discharges with their discharge month, day, and year for **3 months** beginning with **April 2007** if your agency serves hospice patients.

Also, our representative will need a list of all home health aides who are currently employed and paid by your agency and who provide assistance with eating, transferring, toileting, dressing, and bathing to patients. This list should include the names (or other identifiers) of all home health aides. Having this information readily available will help to shorten the visit.

After the interviewer selects the sample of (up to 6) home health aides from this list for the National Home Health Aide Survey (NHHAS), he/she will also need someone from your staff to provide some contact information for the selected home health aides (full name, home address, and home phone).

Enclosed are NHHAS flyers for you to post in prominent locations to inform home health aides in your agency about the survey. In addition, copies of a letter about the NHHAS are enclosed and can be distributed to each home health aide in your agency. We also have enclosed a video about the NHHAS for you to share with your home health aides. NHHAS endorsement letters from the National Association of Health Care Assistants (NAHCA) and the Paraprofessional Healthcare Institute (PHI) encouraging you to participate in the survey are also enclosed.

An important part of the NHHCS is to obtain information about the people who manage the agency and the people who provide home and hospice care. To conserve your time during our visit, this information about your agency will be collected through a self-administered questionnaire. Please complete the enclosed staffing questionnaire at your convenience. The interviewer will collect the completed questionnaire during the visit to your agency. Again, thank you for your help in this important survey. If you have any questions, please call me at 1-888-798-6674 or email me at [laurabranden@westat.com](mailto:laurabranden@westat.com).

Sincerely,  
/Laura Branden/  
Associate Project Director

Enclosures  
(90002)

<b>List of Key Items for Data Collection</b>
--

### Summary of Key Items for Data Collection

#### Agency Visit Activities

Approximately 30 minutes of the director's (or designee's) time will be needed to answer questions about the agency, patients, its services and practices, and staff. Access to the following information will help to shorten the visit.

- Service rates for Medicaid and private pay patients
- Medicare agency provider number
- Number of admissions and discharges for 2006
- If your agency provides home health care, a list of all current patients served by this agency as of midnight Monday, August 20, 2007. Exclude patients who only receive homemaker services and/or durable medical equipment/supplies.
- If your agency provides hospice care, a list of all hospice discharges with their discharge month, day, and year for **3 months, April 2007 to June 2007**.

#### Sampled Patient Information

The survey collects information about the sampled patients and discharges. To collect this medical and billing information, we will meet with staff who are familiar with the medical and billing records. Agency staff will answer specific questions about the sampled patients and discharges; the interviewer will not obtain the information directly from the medical records.

Approximately 25 minutes per patient is required to collect the following information:

- Health status information for home health patients obtained from OASIS data and medical records
- Health status information for hospice discharges obtained from medical records
- Services received from the agency
- Medications taken
- Expenditure information including: total charges, sources of payment, and amount paid by patient/discharge for most recent billing period for home health patients and the most recent episode of care for hospice patients

#### Home Health Aide Sampling Information

We will also need a list of all home health aides who assist patients with ADLs and who are employed and paid by the agency as of midnight Monday, August 20, 2007. The list should include employee names (or other identifiers).

For the home health aides (up to 6) selected for the National Home Health Aide Survey (NHHAS), their home address and phone number will be needed at the time of the visit.

Approximately 20 minutes of the director's (or designee's) time will be needed for these activities.

Self-administered Staffing Questionnaire (SAQ)

OMB #: 0920-0298

Exp.: 07/31/2009

Agency Name: \_\_\_\_\_

Agency ID: \_\_\_\_\_

# 2007 National Home and Hospice Care Survey

## Staffing Questionnaire

Prepared for the  
Centers for Disease Control and Prevention  
National Center for Health Statistics

by

Westat  
1650 Research Boulevard  
Rockville, MD 20850  
1-888-798-6674



Dear Director/Administrator,

The National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) is conducting the National Home and Hospice Care Survey on a randomly selected nationwide sample of home health care and hospice agencies. This voluntary survey is authorized by Federal Law.

We would like some information about the staff of your agency, including their training, benefits, and experience. Any information you provide will be used only for research purposes and will be held in strict confidence. It will not be released to anyone, other than the agencies involved in the survey that are listed in the Dear Director letter sent to you previously, without the consent of the individual or the establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347).

If you wish to comment on any question or qualify your answers, please feel free to use space in the margins or on the inside of the final page. Your comments will be read and taken into account.

Please answer all of the questions in reference to the agency listed on the front cover.

**NOTICE** - Public reporting burden of this collection of information is estimated to average 50 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road, MS E-11, Atlanta, GA 30333, ATTN: PRA (0920-0298).

**Assurance of Confidentiality** - All information which would permit identification of an individual, a practice, or an establishment will be held confidential, will be used only by persons engaged in and for the purpose of the survey and will not be disclosed or released to other persons or used for any other purpose without the consent of the individual or the establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347).

# A Background of Director

**These first few questions ask about the background of this agency's Director/Administrator.**

**1. Does this agency currently have a Director/Administrator (or acting) on staff?**

<sup>2</sup>  No → **SKIP TO QUESTION 10.**

<sup>1</sup>  Yes

**2. Does this agency's Director/Administrator have a nursing degree?**

<sup>2</sup>  No → **SKIP TO QUESTION 4.**

<sup>1</sup>  Yes

**3. What is the highest nursing degree that the agency's Director/Administrator holds?**

Mark one box.

- <sup>1</sup>  Diploma Degree in Nursing
- <sup>2</sup>  Associates Degree in Nursing
- <sup>3</sup>  Bachelors Degree in Nursing
- <sup>4</sup>  Masters Degree in Nursing
- <sup>91</sup>  Other nursing degree (PLEASE SPECIFY)

**4. What is the highest degree of any kind that the agency's Director/Administrator holds?**

Mark one box.

- <sup>1</sup>  Diploma Degree in Nursing
- <sup>2</sup>  Associates Degree in Nursing
- <sup>3</sup>  Associates Degree in Health Care Administration
- <sup>4</sup>  Associates Degree (other health related)
- <sup>5</sup>  Associates Degree (not health related)
- <sup>6</sup>  Bachelors Degree in Nursing
- <sup>7</sup>  Bachelors Degree in Health Care Administration
- <sup>8</sup>  Bachelors Degree (other health related)
- <sup>9</sup>  Bachelors Degree (not health related)
- <sup>10</sup>  Masters Degree in Nursing
- <sup>11</sup>  Masters Degree in Health Care Administration
- <sup>12</sup>  Masters Degree (other health related)
- <sup>13</sup>  Masters Degree (not health related)
- <sup>91</sup>  Other (PLEASE SPECIFY)

**5.** Does this agency's Director/Administrator have a Certified Home or Hospice Care Executive (CHCE) certification?

<sup>2</sup>  No

<sup>1</sup>  Yes

**6.** What other medical specialty certifications does this agency's Director/Administrator have?

Mark all that apply.

<sup>0</sup>  None

<sup>1</sup>  American Nurses Credentialing Center (ANCC) certification (Nurse Practitioner, Nursing Case Management, Public/Community Health, etc.)

<sup>2</sup>  Certification from a professional health care association/organization [for example, Certified Hospice and Palliative Nurse (CHPN), Certified Rehabilitation Registered Nurse (CRRN), etc.]

**7.** About how long has he/she been the Director/Administrator at this agency?

Write number in only one box.

<sup>a</sup>  Number of weeks

OR

<sup>b</sup>  Number of months

OR

<sup>c</sup>  Number of years

**8.** Altogether, about how long has he/she worked as Director/Administrator at any home health or hospice agency, including this one?

Write number in only one box.

<sup>a</sup>  Number of weeks

OR

<sup>b</sup>  Number of months

OR

<sup>c</sup>  Number of years

**9.** Does the agency's Director/Administrator also serve as the Director of Nursing for this agency?

This person may be called the Director of Professional Services or Clinical Director or is the clinical lead manager or supervisor nurse.

<sup>2</sup>  No ➔ CONTINUE TO QUESTION 10.

<sup>1</sup>  Yes ➔ SKIP TO QUESTION 14.

## **B** Background of Director of Nursing

**10.** The following questions are about the Director of Nursing at this agency.

This person may be called the Director of Professional Services or Clinical Director or is the clinical lead manager or supervisor nurse who reports to this agency's Director/Administrator.

Does this agency currently have a Director of Nursing (or acting) on staff?

<sup>2</sup>  No → SKIP TO QUESTION 16.

<sup>1</sup>  Yes

**11.** What is the highest nursing degree the Director of Nursing holds?

Mark one box.

- <sup>1</sup>  Diploma Degree in Nursing
- <sup>2</sup>  Associates Degree in Nursing
- <sup>3</sup>  Bachelors Degree in Nursing
- <sup>4</sup>  Masters Degree in Nursing
- <sup>91</sup>  Other nursing degree (PLEASE SPECIFY)

**12.** What is the highest degree of any kind the Director of Nursing holds?

Mark one box.

- <sup>1</sup>  Diploma Degree in Nursing
- <sup>2</sup>  Associates Degree in Nursing
- <sup>3</sup>  Associates Degree in Health Care Administration
- <sup>4</sup>  Associates Degree (other health related)
- <sup>5</sup>  Associates Degree (not health related)
- <sup>6</sup>  Bachelors Degree in Nursing
- <sup>7</sup>  Bachelors Degree in Health Care Administration
- <sup>8</sup>  Bachelors Degree (other health related)
- <sup>9</sup>  Bachelors Degree (not health related)
- <sup>10</sup>  Masters Degree in Nursing
- <sup>11</sup>  Masters Degree in Health Care Administration
- <sup>12</sup>  Masters Degree (other health related)
- <sup>13</sup>  Masters Degree (not health related)
- <sup>91</sup>  Other (PLEASE SPECIFY)

## Profile of Nursing Staff **C**

**13.** What medical specialty certifications does this agency's Director of Nursing have?

Mark all that apply.

- <sup>0</sup>  None
- <sup>1</sup>  American Nurses Credentialing Center (ANCC) certification, (for example, Nurse Practitioner, Nursing Case Management, Public/Community Health, etc.)
- <sup>2</sup>  Certification from a professional health care association/organization [for example, Certified Hospice and Palliative Nurse (CHPN), Certified Rehabilitation Registered Nurse (CRRN), etc.]

**14.** About how long has he/she been the Director of Nursing at this agency?

Write number in only one box.

- a  Number of weeks  
OR
- b  Number of months  
OR
- c  Number of years

**15.** Altogether, about how long has he/she been the Director of Nursing at any home health or hospice agency, including this one?

Write number in only one box.

- a  Number of weeks  
OR
- b  Number of months  
OR
- c  Number of years

Next, we would like to know about the background and turnover of this agency's staff.

**16.** Approximately what percentages of the RNs currently on staff have the following as their highest education/training?

Write percentage on each line. If none, please enter "0." Your entries should equal 100%

Percent of RNs

- a  % Diploma
- b  % Associate Degree
- c  % BS/BSN (4 years)
- d  % MS/MSN or higher
- 
- % Total

**17.** Do any of the RNs currently on staff have any specialty certifications?

*(Examples include: palliative care, pain management, wound and ostomy care, gerontology, rehabilitation, nursing administration, medical-surgical nursing, public/community health, etc.)*

- <sup>2</sup>  No → SKIP TO QUESTION **19**.
- <sup>1</sup>  Yes → CONTINUE TO QUESTION **18**.

**18.** Do any of the RNs on staff have the following certifications?

Mark one box in each row.

<u>No</u>	<u>Yes</u>	
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Palliative Care
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Wound and Ostomy Care
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Pain Management
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Gerontology
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Public/Community Health

**19.** Does this agency have the following types of Advanced Practice Nurses on staff? Include both full-time and part-time employees

Mark one box in each row.

<u>No</u>	<u>Yes</u>	
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Clinical Nurse Specialist
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Nurse Practitioner

**20.** Does this agency ever employ or seek to employ any of the following?

*Do not include contract workers.*

Mark one box in each row.

<u>No</u>	<u>Yes</u>	
2 <input type="checkbox"/>	1 <input type="checkbox"/>	RNs
2 <input type="checkbox"/>	1 <input type="checkbox"/>	LPNs/LVNs
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Certified HHAs/CNAs
2 <input type="checkbox"/>	1 <input type="checkbox"/>	Non-certified Aides

**21.** Does this agency currently have any RN employees on staff?

*Do not include contract workers.*

2  No → SKIP TO QUESTION 23.

1  Yes

**22.** How many?

*Do not include contract workers.*

a  Number of full-time RN employees

b  Number of part-time RN employees

OR

c  Number of FTE RN employees

**23.** Does this agency currently have any LPN/LVN employees on staff?

*Do not include contract workers.*

2  No → SKIP TO QUESTION 25.

1  Yes

**24.** How many?

*Do not include contract workers.*

a  Number of full-time LPN/LVN employees

b  Number of part-time LPN/LVN employees

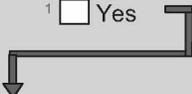
OR

c  Number of FTE LPN/LVN employees

**25.** Does this agency currently have any certified HHA/CNA employees on staff?

*Do not include contract workers.*

<sup>2</sup>  No → SKIP TO QUESTION **27**.

<sup>1</sup>  Yes 

**26.** How many?

*Do not include contract workers.*

a  Number of full-time certified HHA/CNA employees

b  Number of part-time certified HHA/CNA employees

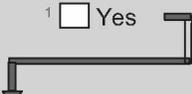
OR

c  Number of FTE certified HHA/CNA employees

**27.** Does this agency currently have any non-certified aide employees on staff?

*Do not include contract workers.*

<sup>2</sup>  No → SKIP TO QUESTION **29**.

<sup>1</sup>  Yes 

**28.** How many?

*Do not include contract workers.*

a  Number of full-time non-certified aide employees

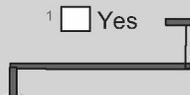
b  Number of part-time non-certified aide employees

OR

c  Number of FTE non-certified aide employees

**29.** Does this agency currently use any contract workers for ANY of the following staff: RNs, LPNs, certified HHAs/CNAs, or non-certified aides?

<sup>2</sup>  No → SKIP TO QUESTION **38**.

<sup>1</sup>  Yes 

**30.** Does this agency currently use any RN contract workers?

<sup>2</sup>  No → SKIP TO QUESTION **32**.

<sup>1</sup>  Yes 

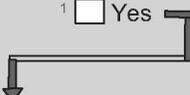
**31.** How many?

a  Number of full-time RN contract workers

b  Number of part-time RN contract workers

**32.** Does this agency currently use any LPN/LVN contract workers?

<sup>2</sup>  No → SKIP TO QUESTION **34**.

<sup>1</sup>  Yes 

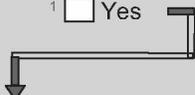
**33.** How many?

a  Number of full-time LPN/LVN contract workers

b  Number of part-time LPN/LVN contract workers

**34.** Does this agency currently use any certified HHA/CNA contract workers?

<sup>2</sup>  No → SKIP TO QUESTION **36**.

<sup>1</sup>  Yes 

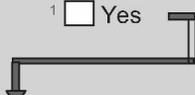
**35.** How many?

a  Number of full-time certified HHA/CNA employees

b  Number of part-time certified HHA/CNA employees

**36.** Does this agency currently use any non-certified aide contract workers?

<sup>2</sup>  No → SKIP TO QUESTION **38**.

<sup>1</sup>  Yes 

**37.** How many?

a  Number of full-time non-certified aide contract workers

b  Number of part-time non-certified aide contract workers

**38.** Does this agency currently have any vacancies for ANY of the following staff: RNs, LPNs/LVNs, certified HHAs/CNAs, or non-certified aides?

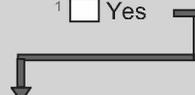
This would include vacant positions for employees for which you are actively recruiting, even if for now you are using contract workers.

<sup>2</sup>  No → SKIP TO QUESTION **47**.

<sup>1</sup>  Yes → CONTINUE TO QUESTION **39**.

**39.** Does this agency currently have any RN vacancies?

<sup>2</sup>  No → SKIP TO QUESTION **41**.

<sup>1</sup>  Yes 

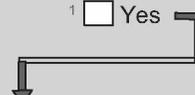
**40.** How many?

a  Number of full-time RN vacancies

b  Number of part-time RN vacancies

**41.** Does this agency currently have any LPN/LVN vacancies?

<sup>2</sup>  No → SKIP TO QUESTION **43**.

<sup>1</sup>  Yes 

**42.** How many?

a  Number of full-time LPN/LVN vacancies

b  Number of part-time LPN/LVN vacancies

**43.** Does this agency currently have any certified HHA/CNA vacancies?

<sup>2</sup>  No → SKIP TO QUESTION **45**.

<sup>1</sup>  Yes 

**44.** How many?

a  Number of full-time certified HHA/CNA vacancies

b  Number of part-time certified HHA/CNA vacancies

**45.** Does this agency currently have any non-certified aide vacancies?

<sup>2</sup>  No → SKIP TO QUESTION **47**.

<sup>1</sup>  Yes

**46.** How many?

a  Number of full-time non-certified aide vacancies

b  Number of part-time non-certified aide vacancies

**47.** Over the past 3 months, did this agency hire ANY of the following staff: RNs, LPNs/LVNs, certified HHAs/CNAs, or non-certified aides?

*Do not include contract workers.*

<sup>2</sup>  No → SKIP TO QUESTION **56**.

<sup>1</sup>  Yes

**48.** Did this agency hire any RNs in the past 3 months?

<sup>2</sup>  No → SKIP TO QUESTION **50**.

<sup>1</sup>  Yes

**49.** How many?

a  Number of full-time RNs hired

b  Number of part-time RNs hired

**50.** Did this agency hire any LPN/LVNs in the past 3 months?

<sup>2</sup>  No → SKIP TO QUESTION **52**.

<sup>1</sup>  Yes

**51.** How many?

a  Number of full-time LPN/LVNs hired

b  Number of part-time LPN/LVNs hired

**52.** Did this agency hire any certified HHAs/CNAs in the past 3 months?

<sup>2</sup>  No → SKIP TO QUESTION **54**.

<sup>1</sup>  Yes

**53.** How many?

a  Number of full-time certified HHAs/CNAs hired

b  Number of part-time certified HHAs/CNAs hired

**54.** Did this agency hire any non-certified aides in the past 3 months?

<sup>2</sup>  No → SKIP TO QUESTION **56**.

<sup>1</sup>  Yes

**55.** How many?

a  Number of full-time non-certified aides hired

b  Number of part-time non-certified aides hired

**56.** Over the past 3 months, have any of the following staff terminated employment: RNs, LPNs/LVNs, certified HHAs/CNAs, or non-certified aides?

*This would include both voluntary and involuntary terminations (retired, dismissed, resigned).*

*Do not include contract workers.*

<sup>2</sup>  No → SKIP TO QUESTION **65**.

<sup>1</sup>  Yes

**57.** Were there any RN terminations in the past 3 months?

<sup>2</sup>  No → SKIP TO QUESTION **59**.

<sup>1</sup>  Yes

**58.** How many?

a  Number of full-time RNs terminated

b  Number of part-time RNs terminated

**59.** Were there any LPN/LVN terminations in the past 3 months?

<sup>2</sup>  No → SKIP TO QUESTION **61**.

<sup>1</sup>  Yes

**60.** How many?

a  Number of full-time LPN/LVNs terminated

b  Number of part-time LPN/LVNs terminated

**61.** Were there any certified HHA/CNA terminations in the past 3 months?

<sup>2</sup>  No → SKIP TO QUESTION **63**.

<sup>1</sup>  Yes

**62.** How many?

a  Number of full-time certified HHA/CNAs terminated

b  Number of part-time certified HHA/CNAs terminated

**63.** Were there any non-certified aide terminations in the past 3 months?

<sup>2</sup>  No → SKIP TO QUESTION **65**.

<sup>1</sup>  Yes

**64.** How many?

a  Number of full-time non-certified aides terminated

b  Number of part-time non-certified aides terminated

**65.** What is the average length of orientation at this agency for the following types of newly hired nursing staff?

For each employee type, write length of orientation in appropriate box.

If no orientation, check the NONE box.

	<u>None</u>		<u>HOURS</u>		<u>DAYS</u>		<u>WEEKS</u>
RNs	0 <input type="checkbox"/> OR a	<input type="text"/>	OR b	<input type="text"/>	OR c	<input type="text"/>	
LPNs/ LVNs	0 <input type="checkbox"/> OR d	<input type="text"/>	OR e	<input type="text"/>	OR f	<input type="text"/>	
Certified HHAs/ CNAs	0 <input type="checkbox"/> OR g	<input type="text"/>	OR h	<input type="text"/>	OR i	<input type="text"/>	
Non- certified Aides	0 <input type="checkbox"/> OR j	<input type="text"/>	OR k	<input type="text"/>	OR l	<input type="text"/>	

**66.** About what percentage of this agency's current nursing staff have been employed for more than 1 year?

Write in percentage in each box. If none for a staff type, please enter "0."

Percent employed  
more than 1 year

a	<input type="text"/>	% of RNs
b	<input type="text"/>	% of LPNs/LVNs
c	<input type="text"/>	% of Certified HHAs/CNAs
d	<input type="text"/>	% of Non-certified Aides

**67.** If hired today, what would be the hourly wage of entry-level nursing staff at this agency?

Write in dollar amount in each box.

Entry-level  
Hourly Wages

\$	<input type="text"/>	RNs
\$	<input type="text"/>	LPNs/LVNs
\$	<input type="text"/>	Certified HHAs/CNAs
\$	<input type="text"/>	Non-certified Aides

PLEASE CONTINUE  
TO NEXT PAGE



## **D** Profile of Other Agency Workers

**68.** Does this agency use any volunteers to help your current patients or this agency's staff in any way?

<sup>2</sup>  No → SKIP TO QUESTION 72.

<sup>1</sup>  Yes

**69.** What kinds of services do they provide?

Mark all that apply.

- <sup>1</sup>  General office help
- <sup>2</sup>  Homemaker/household services
- <sup>3</sup>  Personal care (haircuts, nail care, massage, etc.)
- <sup>4</sup>  Transportation services
- <sup>5</sup>  Visiting with patients
- <sup>6</sup>  Bereavement/family support
- <sup>7</sup>  Recreational activities
- <sup>8</sup>  Pet therapy
- <sup>9</sup>  Religious/spiritual activities
- <sup>91</sup>  Other (PLEASE SPECIFY)

**70.** About how many volunteer workers currently provide services for this agency?

<sup>a</sup>  Number of volunteers

**71.** In total, how many of this agency's current patients receive services from any of your volunteer workers?

<sup>a</sup>  Number of current patients

OR

<sup>b</sup>  % Percent of current patients

**72.** Is this agency ever used as a clinical or training site for students?

<sup>2</sup>  No → SKIP TO QUESTION 74.

<sup>1</sup>  Yes

**73.** For what types of students?

Mark all that apply.

- <sup>1</sup>  Home Health Aide
- <sup>2</sup>  Nurse (RN, LPN)
- <sup>3</sup>  Advance Practice Nurse (NP, CNS)
- <sup>4</sup>  Physician Assistant
- <sup>5</sup>  Medical Student/Intern/Resident
- <sup>6</sup>  Therapist (Physical, Speech, Occupational)
- <sup>7</sup>  Social Worker
- <sup>91</sup>  Other (PLEASE SPECIFY)

**74. Does this agency have any of the following types of staff or contract personnel who provide services to patients served by this agency?**

Please mark "No" or "Yes" for each personnel type.

No Yes

- <sup>2</sup>  <sup>1</sup> Physicians
- <sup>2</sup>  <sup>1</sup> Dental health professionals
- <sup>2</sup>  <sup>1</sup> Psychiatrists
- <sup>2</sup>  <sup>1</sup> Psychologists
- <sup>2</sup>  <sup>1</sup> Nutritionists, Dietitians
- <sup>2</sup>  <sup>1</sup> Occupational Therapists
- <sup>2</sup>  <sup>1</sup> Occupational Therapy Assistants
- <sup>2</sup>  <sup>1</sup> Physical Therapists
- <sup>2</sup>  <sup>1</sup> Podiatrists
- <sup>2</sup>  <sup>1</sup> Respiratory Therapists
- <sup>2</sup>  <sup>1</sup> Social Workers
- <sup>2</sup>  <sup>1</sup> Speech Pathologists/Audiologists
- <sup>2</sup>  <sup>1</sup> Complementary Alternative Medicine (CAM) Providers

**75. Which of these nursing staff retention/recruitment strategies are used by this agency?**

Mark all that apply.

- <sup>1</sup> Employee recognition programs (employee of the month, staff dinners/luncheons, etc.)
- <sup>2</sup> Reimbursement for workshops/conferences
- <sup>3</sup> Sign-on bonus
- <sup>4</sup> Recruitment bonus
- <sup>5</sup> Career ladder positions for Nurses
- <sup>6</sup> Career ladder positions for HHAs/CNAs
- <sup>7</sup> Flexible scheduling or job sharing
- <sup>8</sup> Bonus/paid time off
- <sup>9</sup> Sabbatical
- <sup>10</sup> Tuition (reimbursement or direct payment for employees/new hires)
- <sup>11</sup> Payback for unused sick/vacation time
- <sup>91</sup> Other (PLEASE SPECIFY)

## **E** Employee Benefits

**76.** What types of employee benefits are offered to full-time RN and LPN/LVN staff by this agency?

Mark all that apply.

- 1  Fully paid health insurance plan for employee
- 2  Fully paid health insurance plan for employee spouse/dependents
- 3  Partially paid health insurance plan for employee
- 4  Partially paid health insurance plan for employee spouse/dependents
- 5  Other employee insurance plan (dental, vision, disability, life)
- 6  Retirement/pension
- 7  401k plan/tax-deferred annuity
- 8  Paid vacation/holidays
- 9  Paid sick days
- 10  Paid time off days for "other/personal" reasons
- 11  Other paid bonuses
- 12  Mileage reimbursement/agency car
- 13  Uniforms
- 14  Cell phones/reimbursements
- 15  Career promotion/development (workshops, conferences, certification exam, etc.)
- 16  Education reimbursement
- 91  Other (PLEASE SPECIFY)


**77.** What types of employee benefits are offered to full-time HHA/CNA staff by the agency?

Mark all that apply.

- 1  Fully paid health insurance plan for employee
- 2  Fully paid health insurance plan for employee spouse/dependents
- 3  Partially paid health insurance plan for employee
- 4  Partially paid health insurance plan for employee spouse/dependents
- 5  Other employee insurance plan (dental, vision, disability, life)
- 6  Retirement/pension
- 7  401k plan/tax-deferred annuity
- 8  Paid vacation/holidays
- 9  Paid sick days
- 10  Paid time off days for "other/personal" reasons
- 11  Other paid bonuses
- 12  Mileage reimbursement/agency car
- 13  Uniforms
- 14  Cell phones/reimbursements
- 15  Career promotion/development (workshops, conferences, certification exam, etc.)
- 16  Education reimbursement
- 91  Other (PLEASE SPECIFY)


## F Agency Information Technology Capabilities

**78.** Does this agency currently have an Electronic Medical Records system? This is a computerized version of the patient's medical information used in the management of the patient's health care.

Exclude electronic records used only for billing purposes and required documentation, such as OASIS files.

- <sup>2</sup>  No
- <sup>1</sup>  Yes → SKIP TO QUESTION 80.

**79.** Does this agency have plans to obtain an Electronic Medical Records System within the next year?

- <sup>2</sup>  No → SKIP TO QUESTION 81.
- <sup>1</sup>  Yes → SKIP TO QUESTION 81.

**80.** With this agency's current Electronic Medical Records system, please indicate for each component listed below, whether it is used, available but not used, or not available.

Mark one box on each line.

<u>Used</u>	<u>Available/ Not used</u>	<u>Not Available</u>	
<sup>1</sup> <input type="checkbox"/>	<sup>2</sup> <input type="checkbox"/>	<sup>3</sup> <input type="checkbox"/>	Computerized Physicians Order Entry (CPOE) - prescriptions, labs, tests, etc.
<sup>1</sup> <input type="checkbox"/>	<sup>2</sup> <input type="checkbox"/>	<sup>3</sup> <input type="checkbox"/>	Test results (chest x-rays, labs, etc.)
<sup>1</sup> <input type="checkbox"/>	<sup>2</sup> <input type="checkbox"/>	<sup>3</sup> <input type="checkbox"/>	Patient demographics
<sup>1</sup> <input type="checkbox"/>	<sup>2</sup> <input type="checkbox"/>	<sup>3</sup> <input type="checkbox"/>	Electronic reminders for tests (labs, imaging, etc.)
<sup>1</sup> <input type="checkbox"/>	<sup>2</sup> <input type="checkbox"/>	<sup>3</sup> <input type="checkbox"/>	Clinical Decision Support System (CDSS) contraindications, allergies, guidelines, etc.
<sup>1</sup> <input type="checkbox"/>	<sup>2</sup> <input type="checkbox"/>	<sup>3</sup> <input type="checkbox"/>	Clinical notes
<sup>1</sup> <input type="checkbox"/>	<sup>2</sup> <input type="checkbox"/>	<sup>3</sup> <input type="checkbox"/>	Public health reporting (notifiable diseases)
<sup>1</sup> <input type="checkbox"/>	<sup>2</sup> <input type="checkbox"/>	<sup>3</sup> <input type="checkbox"/>	Sharing medical records electronically with other agencies

**81.** For each item below, please indicate whether or not this agency uses any of the following Management Systems electronically?

Mark one box in each row.

<u>No</u>	<u>Yes</u>	
<sup>2</sup> <input type="checkbox"/>	<sup>1</sup> <input type="checkbox"/>	Billing system
<sup>2</sup> <input type="checkbox"/>	<sup>1</sup> <input type="checkbox"/>	Inventory control (i.e. bar coding)
<sup>2</sup> <input type="checkbox"/>	<sup>1</sup> <input type="checkbox"/>	Human Resources management (personnel records)
<sup>2</sup> <input type="checkbox"/>	<sup>1</sup> <input type="checkbox"/>	Staff management (e.g., staffing scheduling, etc.)
<sup>2</sup> <input type="checkbox"/>	<sup>1</sup> <input type="checkbox"/>	Accounting

**82.** For each item below, please indicate whether or not this agency uses any of the following Education Systems?

Mark one box in each row.

- |   | <u>No</u>                | <u>Yes</u>                 |   |
|---|--------------------------|----------------------------|---|
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | Satellite Broadcast capability (in service, training)                 |
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | Staff Internet access   |
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | Patient Internet access (web site with patient educational materials) |

**83.** Does this agency use any telemedicine capabilities? Telemedicine is the use of electronic communication and information technologies to provide or support clinical care at a distance.

2  No → SKIP TO QUESTION 86.

1  Yes

**84.** For each item below, please indicate whether or not this agency uses any of the following telemedicine capabilities?

Mark one box in each row.

- |   | <u>No</u>                | <u>Yes</u>                 |   |
|---|--------------------------|----------------------------|---|
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | Routine telephone monitoring of patients' health, involving conversation with nurse or other health care provider/monitor |
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | E-mail access to health professionals for patients/caregivers   |
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | Video consults with health care professionals   |
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | Routine video monitoring of patients' health, involving conversation with nurse or other health care provider/monitor     |
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | Routine non-video monitoring of patients' health, without conversation (e.g., regular transmission of vital signs)        |
| 2 | <input type="checkbox"/> | 1 <input type="checkbox"/> | Other telemedicine capability (PLEASE SPECIFY)  |

**85.** For about what percentage of this agency's current patients is telemedicine used?

Enter percent of current patients or mark the None box.

0  None OR a  % of patients

**86.** Does this agency's staff use any system for Electronic Point of Care Documentation?

Include PDAs (Personal Digital Assistants) Notebook PCs, or other portable handheld devices.

<sup>2</sup>  No → SKIP TO QUESTION **91**.

<sup>1</sup>  Yes

**87.** How many of your direct care staff use these?

<sup>0</sup>  None

<sup>1</sup>  Some

<sup>2</sup>  All

**88.** How many of your administrative staff use these?

<sup>0</sup>  None

<sup>1</sup>  Some

<sup>2</sup>  All

**89.** Do any other staff use these?

<sup>2</sup>  No

<sup>1</sup>  Yes (PLEASE SPECIFY)

**90.** Are these devices used for any of the following?

Mark one box in each row.

- | <u>No</u>                             | <u>Yes</u>                            |   |
|---------------------------------------|---------------------------------------|---|
| <sup>2</sup> <input type="checkbox"/> | <sup>1</sup> <input type="checkbox"/> | Computerized Physicians Order Entry (prescriptions/pharmacy, labs, tests) |
| <sup>2</sup> <input type="checkbox"/> | <sup>1</sup> <input type="checkbox"/> | Test results  |
| <sup>2</sup> <input type="checkbox"/> | <sup>1</sup> <input type="checkbox"/> | Electronic reminders for tests  |
| <sup>2</sup> <input type="checkbox"/> | <sup>1</sup> <input type="checkbox"/> | Clinical Decision Support System guidelines or reference systems          |
| <sup>2</sup> <input type="checkbox"/> | <sup>1</sup> <input type="checkbox"/> | E-mail communication with agency staff/other staff                        |
| <sup>2</sup> <input type="checkbox"/> | <sup>1</sup> <input type="checkbox"/> | Scheduling appointments/visits  |
| <sup>2</sup> <input type="checkbox"/> | <sup>1</sup> <input type="checkbox"/> | OASIS   |
| <sup>2</sup> <input type="checkbox"/> | <sup>1</sup> <input type="checkbox"/> | Other (PLEASE SPECIFY)  |

PLEASE CONTINUE  
TO NEXT PAGE

**G** Agency Information  
Other

**91.** Has this agency developed a written plan for management of patients during an influenza pandemic?

- <sup>0</sup>  No, not started
- <sup>1</sup>  Yes, in progress
- <sup>2</sup>  Yes, completed

**92.** About what percentage of this agency's patient care revenue comes from each of the following?

Write percentage on each line. If none, please enter "0." Your entries should equal 100%

Percent of revenue

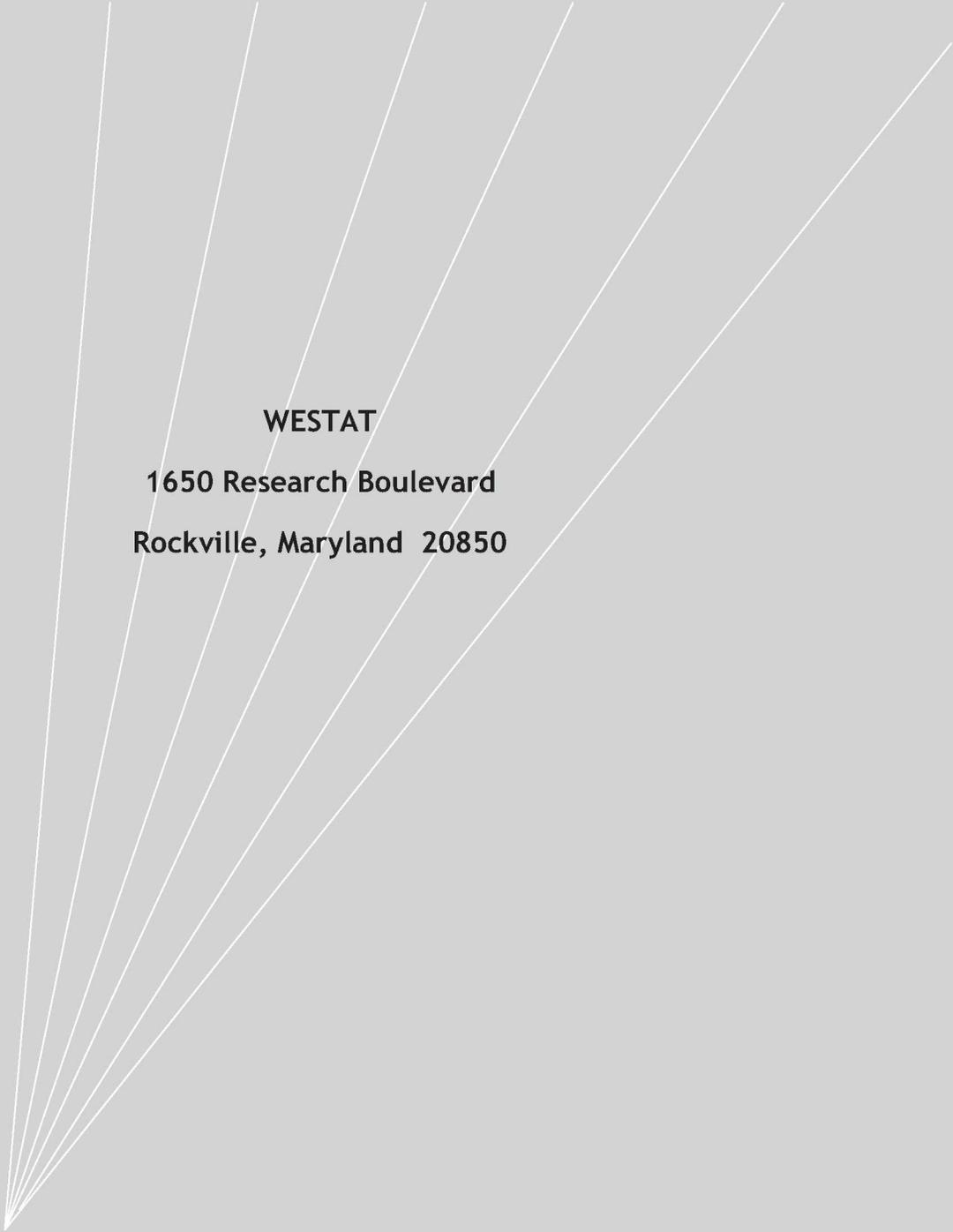
- a  % Medicare
- b  % Medicaid
- c  % Private insurance
- d  % Patient payments
- e  % Other sources

---

- % Total



Thank you  
for your cooperation.



**WESTAT**

**1650 Research Boulevard**

**Rockville, Maryland 20850**

# Appendix IX. Appointment Confirmation Script

## National Home and Hospice Care Survey (NHHCS) Appointment Confirmation Script

Interviewer Name: \_\_\_\_\_

Interviewer ID Number: NHHC \_\_\_\_\_

AFFIX AGENCY LABEL HERE

1. Hello, my name is \_\_\_\_\_, and I work for Westat on the National Home and Hospice Care Survey sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS).

May I please speak to (Mr./Ms.) [AGENCY DIRECTOR] regarding the appointment confirmation package of survey materials that we sent (a few days ago)?

YES ..... 1 (GO TO Q4)  
NO ..... 2

2. Is there a better time for me to speak to (Mr./Ms.) [AGENCY DIRECTOR]?

PREFERRED DATE: \_\_\_\_\_ TIME: \_\_\_\_\_ AM/PM  
DON'T KNOW -8  
REFUSED -7

3. Thank you very much for your time.

END THE CALL

4. Hello, my name is \_\_\_\_\_, and I work for Westat on the National Home and Hospice Care Survey sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS). Did you receive the appointment confirmation package of survey materials that we sent (a few days ago)?

YES ..... 1  
NO ..... 2 (GO TO Q6)

5. Have you had a chance to review the material?

YES ..... 1 (GO TO Q9)  
NO ..... 2

6. Shall I go over the materials with you or would you prefer that I call you back after you have reviewed the materials (I'll re-send them to you.)?

DESCRIBE MATERIALS ..... 1 (GO TO Q8)  
 CALL BACK..... 2

7. Thank you very much for your time. I'll call back in a couple of days. **END THE CALL.**

8. INTERVIEWER: PROVIDE SUMMARY DESCRIPTION OF MATERIALS AS NEEDED, THEN GO TO Q9.

The package included a letter confirming the [APPOINTMENT DATE] as the day I'll visit. It also asked if you could provide a list of all current patients as of midnight before [APPOINTMENT DATE] if your agency serves home health patients, (and/or) a list of all hospice discharges with their discharge month, day, and year for 3 months beginning with [4 FULL MONTHS BEFORE APPOINTMENT DATE MONTH AND YEAR] if your agency provides hospice care and a list of home health aides employed by the agency as of midnight before [APPOINTMENT DATE].

9. Do you have any questions about (the material you received/the information I just provided to you)?

YES ..... 1 (GO TO BOX 1)  
 NO ..... 2 (GO TO Q10)

**BOX 1 INTERVIEWER: ANSWER DIRECTOR'S QUESTIONS AS APPROPRIATE. THEN CONTINUE WITH Q10.**

10. I would like to confirm the appointment day and time: READ APPOINTMENT DAY AND TIME FROM CASE MATERIALS.

APPOINTMENT CONFIRMED ..... 1 (GO TO Q12)  
 NEED TO RESCHEDULE ..... 2 (GO TO Q11)

11. I'm sorry that doesn't work for you. In that case, I would like to come to your agency on [IDEAL APPOINTMENT DATE] at [IDEAL APPOINTMENT TIME]. Is this a convenient time for you?

**IDEAL APPOINTMENT DATE:\_\_\_\_\_ IDEAL APPOINTMENT TIME:\_\_\_\_\_ AM/PM**

YES ..... 1 (GO TO Q12)  
 NO, RESCHEDULE ..... 2 (COLLECT DATE AND TIME)

DATE:\_\_\_\_\_ TIME:\_\_\_\_\_ AM/PM THEN END CALL)

RECORD DATE ON CALENDAR AND ENTER AN EROC IN THE IMS.

NO, CALL BACK ..... 3

DATE:\_\_\_\_\_ TIME:\_\_\_\_\_ AM/PM (END THE CALL)

RECORD DATE ON CALENDAR AND ENTER AN EROC IN THE IMS.

REFUSED ..... 4 (PROBE FOR REASON AND RECORD. END THE CALL.  
 REASON FOR REFUSAL \_\_\_\_\_ COMPLETE THE NIRF.)

\_\_\_\_\_

12. We'd like to meet with the person who is most knowledgeable about the information we'll need.

13. CONFIRM ADDRESS, DIRECTIONS, AND MEETING LOCATION.

END: Thank you very much for your time.

INTERVIEWER:

- UPDATE AGENCY NAME, ADDRESS, AND DIRECTOR INFORMATION USING THE AGENCY INFO BUTTON AS APPROPRIATE.
- WRITE APPOINTMENT INFORMATION ON CALENDAR AS APPROPRIATE.
- UPDATE CASE DISPOSITION ON THE ROC AND IN THE IMS USING THE EROC.
- CONNECT TO WESTAT AND TRANSMIT.

# Appendix X. Reminder Call Script

## National Home and Hospice Care Survey (NHHCS) Reminder Call Script

AFFIX INTERVIEWER  
MINI-LABEL HERE

AFFIX AGENCY LABEL HERE

1. Hello, my name is \_\_\_\_\_ and I'm working on the National Home and Hospice Care Survey sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS).

May I please speak to (Mr./Ms.) [AGENCY DIRECTOR] regarding our upcoming appointment?

YES ..... 1 (GO TO Q4)  
NO ..... 2

2. May I be transferred to (his/her) voice mail to leave a message or may I leave a message with you?

YES ..... 1  
NO ..... 2 (GO TO Q2b)

2a. LEAVE A BRIEF MESSAGE ABOUT THE SCHEDULED APPOINTMENT, ALONG WITH EITHER YOUR HOME NUMBER OR THE NHHCS TOLL FREE NUMBER 1-888-798-6674 IN CASE THE DIRECTOR HAS ANY QUESTIONS BEFORE THE APPOINTMENT. END THE CALL.

2b. Is there a better time for me to speak to (Mr./Ms.) [AGENCY DIRECTOR] before [APPOINTMENT DATE]?

PREFERRED DATE: \_\_\_\_\_ TIME: \_\_\_\_\_ AM/PM  
DON'T KNOW -8  
REFUSED -7

3. Thank you very much for your time.

END THE CALL

4. Hello, my name is \_\_\_\_\_. I work for Westat on the National Home and Hospice Care Survey sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS).

I'm calling to confirm my appointment with you and your staff at [APPOINTMENT TIME] on [APPOINTMENT DATE] for this survey.

- APPOINTMENT CONFIRMED ..... 1 (GO TO Q6)
- NEED TO RESCHEDULE ..... 2 (GO TO Q5)

5. I'm sorry that doesn't work for you. In that case, I would like to come to your agency on [IDEAL APPOINTMENT DATE] at [IDEAL APPOINTMENT TIME]. Is this a convenient time for you?

INTERVIEWER: APPOINTMENT TIME SHOULD BE AS CLOSE AS POSSIBLE TO THE OPENING TIME FOR THE AGENCY AND NO LATER THAN 10:00 AM.

IDEAL APPOINTMENT DATE: \_\_\_\_\_ IDEAL APPOINTMENT TIME: \_\_\_\_\_ AM/PM

- YES ..... 1 (GO TO Q6)
- NO, RESCHEDULE ..... 2 (COLLECT DATE AND TIME,  
DATE: \_\_\_\_\_ TIME: \_\_\_\_\_ AM/PM THEN END CALL)

RECORD DATE ON CALENDAR AND ENTER AN EROC IN THE IMS.

- NO, CALL BACK ..... 3
- DATE: \_\_\_\_\_ TIME: \_\_\_\_\_ AM/PM (END THE CALL)

RECORD DATE ON CALENDAR AND ENTER AN EROC IN THE IMS.

- REFUSED ..... 4 (PROBE FOR REASON AND RECORD. END THE CALL. COMPLETE THE NIRF.)
- REASON FOR REFUSAL \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

6. CONFIRM AGENCY NAME, ADDRESS, AND MEETING LOCATION FROM CASE MATERIALS. REQUEST DIRECTIONS TO THE AGENCY.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

7. Do you have any questions I can answer before our visit on [APPOINTMENT DATE]?

- YES ..... 1
- NO ..... 2 (GO TO Q9)

8. INTERVIEWER: ANSWER QUESTIONS. REFER TO SUMMARY DESCRIPTION OF ITEMS NEEDED FOR THE INTERVIEW AS NEEDED, THEN GO TO Q9.

READ INFORMATION FOR THE APPROPRIATE AGENCY TYPE:

**HOME HEALTH AGENCY:**

- a list of all current patients as of midnight before [APPOINTMENT DATE]. The list should exclude patients who **only** receive homemaker services and/or durable medical equipment/supplies.
- a list of home health aides employed by the agency as of midnight before [APPOINTMENT DATE]).

**HOSPICE AGENCY:**

- a list of all hospice discharges with their discharge month, day, and year for 3 months beginning with [4 FULL MONTHS BEFORE APPOINTMENT DATE MONTH AND YEAR]
- a list of home health aides employed by the agency as of midnight before [APPOINTMENT DATE).

**MIXED AGENCY:**

- a list of all current patients as of midnight before [APPOINTMENT DATE]. The list should exclude patients who **only** receive homemaker services and/or durable medical equipment/supplies.
- a list of all hospice discharges with their discharge month, day, and year for 3 months beginning with [4 FULL MONTHS BEFORE APPOINTMENT DATE MONTH AND YEAR]).
- a list of home health aides employed by the agency as of midnight before [APPOINTMENT DATE]).

FOR ALL AGENCY TYPES:

We will be asking for the agency's Medicare Provider ID number, payment rates for Medicaid and private pay patients, and the number of admissions and discharges for 2006.

BOX 1 INTERVIEWER: ANSWER DIRECTOR'S QUESTIONS AS APPROPRIATE. THEN CONTINUE WITH Q9.

9. After speaking with you, I'd like to meet with the person who is most knowledgeable about the information I'll need about patient records and billing information.

END: I'm looking forward to meeting you and your staff . Thank you very much for your time.

INTERVIEWER:

- UPDATE AGENCY NAME, ADDRESS, AND DIRECTOR INFORMATION IN THE AGENCY INFO TASK OF THE IMS AS NEEDED.
- WRITE ANY MODIFIED APPOINTMENT INFORMATION ON YOUR CALENDAR.
- UPDATE RECORD OF CALLS AND EROC TO REFLECT ALL CONTACT ATTEMPTS MADE WITH THE AGENCY AND ANY CHANGES TO THE APPOINTMENT TIME OR DATE.

## Appendix XI. CAPI: Agency Qualifications and Characteristics (AQ) Questionnaire

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### AQPRE Help Screens

Form Approved OMB No. 0920-0298 Exp. Date 07/31/2009

**NOTICE** – Public reporting burden of this collection of information is estimated to average 30 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road, MS E-11, Atlanta, GA 30333, ATTN: PRA (0920-0298).

**Assurance of Confidentiality** – All information which would permit identification of an individual, a practice, or an establishment will be held confidential, will be used only by persons engaged in and for the purpose of the survey and will not be disclosed or released to other persons or used for any other purpose without the consent of the individual or the establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m).

AQ5 - A **chain** is defined as having two or more agencies under one ownership or operation.

AQ13- The year recorded should reflect the year the sampled hospice agency, under its current ownership, began delivering services.

AQ14 -The year recorded should reflect the year the sampled home health care agency, under its current ownership, began delivering services.

AQ15- The agency is **for profit** if it is owned by an individual, a partnership, or a corporation.

The agency is **private nonprofit** if it is owned by a religious group or a nonprofit corporation, etc.

AQ16A - Referral services provide information about services available from public and private providers. They may also order or arrange services but they do not provide the services directly.

AQ17/18 - Pending refers to the fact that the paperwork for Medicare certification of the agency has been submitted to CMS but the final approval and certification number have not been sent or issued to the agency.

AQ25 B - The agency type according to the Medicare certification on file:

- 81=Hospice (non-hospital based)
- 82=Hospice (hospital-based) which includes 32X, 33X, 34X

AQ20/21 - Pending refers to the fact that the paperwork for Medicaid certification of the agency has been submitted to CMS but the final approval and certification number have not been sent or issued to the agency.

AQ28 - "**Hospital**" is a broad concept. It includes the following:

- acute care hospitals;
- private psychiatric hospitals;
- state or county hospitals for the mentally ill;
- Department of Veterans Affairs hospitals and medical centers;
- state hospitals for the mentally retarded;
- chronic disease, rehabilitation, geriatric, and other long-term hospitals; and,
- other places that are commonly called hospitals.

"**Health care system**" is an organized system that provides medical care, including inpatient, emergency, ambulatory care, and diagnostic procedures to a population. Many times, the system will have satellite facilities where some or all services may be offered.

AQ29 - Formal contracts- The parties to an arrangement have attempted to spell out all terms in a legal contract or letter of agreement. A preferred provider agreement is considered a formal contract.

AQ 34/35 - Complementary and Alternative Medicine (CAM) is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. Examples include acupuncture, dietary supplements, and homeopathic medicine.

AQ36 - Pharmacy services (also referred to as Pharmaceutical Services) refer to the system of appropriate methods and procedures for the dispensing and administering of drugs and biologicals under the direction of a qualified pharmacist. This includes evaluation of patients' responses to the medication therapy, identification of adverse drug reactions, and taking appropriate corrective action. Drugs and biologicals must be obtained from community or institutional pharmacists or stocked by the agency. The agency must furnish the drugs and biologicals for each patient, as specified in each patient's care plan. The use of drugs and biologicals must be provided in accordance with accepted professional principles and appropriate Federal, State, and local laws.

AQ37 - Ethical issues- Regarding what is in accordance with law and accepted principles of right and wrong in the profession/industry.

AQ46 - Open Access means the hospice accepts anyone who meets the eligibility requirements for hospice. (Eligibility requirement is that individual must have a medical prognosis that his or her life expectancy is 6 months or less if the illness runs its normal course.) The patients may continue their current treatment or start new treatments.

AQ5

Is AGENCY part of a chain?

PRESS F1 FOR HELP SCREEN.

1 YES  
 2 NO  
 RF  
 DK

AQ5A

What is the name of the chain?

Enter Chain Name.

\_\_\_\_\_

AQ6

Is AGENCY a (home health/home care) agency, a hospice agency or does this agency serve both (home health/home care) and hospice patients?

1 HOME HEALTH/HOME CARE AGENCY ONLY  
 2 HOSPICE AGENCY ONLY  
 3 BOTH HOME HEALTH/HOME CARE AND HOSPICE AGENCY  
 91 NONE OF THE ABOVE

AQ6A

What type of service do you provide?

\_\_\_\_\_

Refused  
 Don't know

AQ6B

Does this agency provide its patients with ONLY homemaker services and durable medical equipment and supplies or are OTHER types of services to patients also provided?

0 ONLY HOMEMAKER SERVICES AND/OR EQUIPMENT/SUPPLIES  
 1 OTHER SERVICES (ALSO) PROVIDED  
 2 REFUSED  
 DON'T KNOW

AQ7

How many (home health/home care) admissions did AGENCY have during calendar year?

Only include this agency's home health patients for this location.

NUMBER OF ADMISSIONS.

\_\_\_\_\_

REFUSED  
DON'T KNOW

AQ8

How many (home health/home care) discharges did AGENCY have during calendar Year?

Only include this agency's home health discharges for this location.

NUMBER OF DISCHARGES

\_\_\_\_\_

REFUSED  
DON'T KNOW

AQ9

What is the number of (home health/home care) patients currently being served by {AGENCY} at this location?

ENTER NUMBER OF CURRENT PATIENTS.

\_\_\_\_\_

REFUSED  
DON'T KNOW

AQ10

How many hospice admissions did (AGENCY) have during calendar year ?

Only include this agency's hospice admissions for this location.

ENTER NUMBER OF ADMISSIONS.

\_\_\_\_\_

REFUSED  
DON'T KNOW

AQ11

How many hospice discharges did {AGENCY} have during calendar year?  
Only include this agency's hospice discharges for this location.

ENTER NUMBER OF DISCHARGES.

\_\_\_\_\_

REFUSED  
DON'T KNOW

AQ11A

Did this agency have any hospice patients discharged in {BEGMONTH} through  
{ENDMONTH} of 2007?

1 YES  
2 NO

REFUSED  
DON'T KNOW

AQ12

What is the number of hospice patients currently being served by {AGENCY} at this  
location?

ENTER NUMBER OF CURRENT PATIENTS.

\_\_\_\_\_

REFUSED  
DON'T KNOW

AQ13

In what year was this agency established to provide hospice care?

ENTER A 4-DIGIT YEAR. \_\_\_\_\_

PRESS F1 FOR HELP SCREEN.

REFUSED  
DON'T KNOW

AQ14

In what year was this agency established to provide (home health/home care)  
services?

ENTER A 4-DIGIT YEAR. \_\_\_\_\_

PRESS F1 FOR HELP SCREEN.

REFUSED  
DON'T KNOW

AQ15

Which one of these categories on this card best describes the ownership of this agency?

PRESS F1 FOR HELP SCREEN.

- 1 FOR PROFIT
  - 2 PRIVATE NONPROFIT
  - 3 CITY/COUNTY/STATE GOVERNMENT
  - 4 DEPARTMENT OF VETERANS AFFAIRS
  - 5 OTHER FEDERAL AGENCY
  - 91 OTHER (SPECIFY)
- REFUSED  
DON'T KNOW

AQ15A

SPECIFY OWNERSHIP (91)

WRITE OTHER TYPE OF OWNERSHIP. \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ16A

What are {AGENCY}'s patient referral sources for (home health/home/hospice) care?

SELECT ALL THAT APPLY.

- 1 HOSPITAL
  - 2 NURSING HOME
  - 3 ASSISTED LIVING FACILITY
  - 4 PHYSICIAN'S OFFICE
  - 5 OUTPATIENT MEDICAL/SURGICAL CENTER
  - 6 REHABILITATION FACILITY
  - 7 PATIENT/FAMILY/FRIEND
  - 8 OTHER HOME HEALTH/HOSPICE AGENCY
  - 9 INSURANCE PROVIDER/PAYER SOURCE
  - 10 COMMUNITY ORGANIZATION
  - 91 OTHER (SPECIFY)
- REFUSED  
DON'T KNOW

AQ16B

What other referral source was used for care that?

Enter other referral source(s).

\_\_\_\_\_

AQ16C

Which one of the referral sources you mentioned refers the greatest number of (home health/home care/hospice) patients to this agency?

\*\*\*What would you say is the main source of this agency's (home health/home care/hospice) patient referrals?

SELECT ONLY ONE.

ENTER NUMBER OF MAIN REFERRAL SOURCE (AQ16A). \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ17

Is this agency currently certified by MEDICARE as a Home Health Agency?  
PRESS F1 FOR HELP SCREEN.

- 1 YES
- 2 NO
- 3 PENDING  
REFUSED  
DON'T KNOW

AQ18

Is this agency currently certified by MEDICARE as a Hospice?  
PRESS F1 FOR HELP SCREEN.

- 1 YES
- 2 NO
- 3 PENDING  
REFUSED  
DON'T KNOW

AQ19

What is the MEDICARE provider number for {AGENCY}?

ENTER MEDICARE PROVIDER NUMBER. \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ19A

MEDICARE provider number verification

I have entered {AQ19/MEDICARE PROVIDER NUMBER}. Is this correct?

- 1 YES
- 2 NO

AQ20

Is this agency currently certified by MEDICAID as a Home Health Agency?

PRESS F1 FOR HELP SCREEN.

- 1 YES
- 2 NO
- 3 PENDING  
REFUSED  
DON'T KNOW

AQ21

Is this agency currently certified by MEDICAID as a Hospice?

PRESS F1 FOR HELP SCREEN.

- 1 YES
- 2 NO
- 3 PENDING  
REFUSED  
DON'T KNOW

AQ23a1

How much does MEDICAID pay this agency for \_\_\_\_\_?

- 1 RESPONDENT PROVIDES A SINGLE RATE
- 2 RESPONDENT PROVIDES A RANGE
- 3 SERVICE NOT OFFERED  
  
REFUSED  
DON'T KNOW

AQ23a2

How much does MEDICAID pay this agency for \_\_\_\_\_?

ENTER SINGLE RATE IN WHOLE DOLLARS. \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ23a2a

How much does MEDICAID pay this agency for \_\_\_\_\_?

- 1 VISIT
- 2 HOUR
- 3 HALF HOUR
- 4 15 MINUTES
- 91 OTHER (SPECIFY)

AQ23a2b

MEDICAID SINGLE RATE UNIT - OTHER SPECIFY

What is the MEDICAID single rate unit for other specify (AQ23a2a-91)?

SPECIFY UNIT. \_\_\_\_\_

AQ23a3

MEDICAID LOWEST RATE

How much does MEDICAID (lowest rate ) pay this agency for \_\_\_\_\_?

ENTER LOWEST RATE IN WHOLE DOLLARS. \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ23a4

MEDICAID HIGHEST RATE

How much does MEDICAID (highest rate) pay this agency for \_\_\_\_\_?

ENTER HIGHEST RATE IN WHOLE DOLLARS. \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ23a4a

MEDICAID HIGH AND LOW RATE UNIT

How much does MEDICAID pay this agency for \_\_\_\_\_?

- 1 VISIT
- 2 HOUR
- 3 HALF HOUR
- 4 15 MINUTES
- 91 OTHER (SPECIFY)

AQ23a4b

MEDICAID HIGH AND LOW RATE UNIT - OTHER SPECIFY

What is the MEDICAID high and low rate unit for other specify (AQ23a4a - 91)?

SPECIFY UNIT. \_\_\_\_\_

AQ23Aa1

PRIVATE HOME HEALTH CARE RATE TYPE

How much does this agency charge SELF OR PRIVATE PAY home health patients for \_\_\_\_\_?

- 1 RESPONDENT PROVIDES A SINGLE RATE
- 2 RESPONDENT PROVIDES A RANGE
- 3 SERVICE NOT OFFERED
  
- REFUSED
- DON'T KNOW

AQ23Aa2

PRIVATE HOME HEALTH CARE SINGE RATE

How much does this agency charge SELF OR PRIVATE PAY home health patients for \_\_\_\_\_?

ENTER SINGLE RATE IN WHOLE DOLLARS. \_\_\_\_\_

AQ23Aa2a

PRIVATE PAY SINGLE RATE UNIT

How much does this agency charge SELF OR PRIVATE PAY home health patients for \_\_\_\_\_ ?

- 1 VISIT
- 2 HOUR
- 3 HALF HOUR
- 4 15 MINUTES
  
- 91 OTHER (SPECIFY)

AQ23Aa2b

PRIVATE SINGLE RATE UNIT OTHER SPECIFY

ENTER OTHER SPECIFY (AQ23Aa2a - 91).

SPECIFY UNIT. \_\_\_\_\_

AQ23Aa3

PRIVATE HOME HEALTH CARE LOWEST RATE

How much does this agency charge SELF OR PRIVATE PAY home health patients for \_\_\_\_\_ ?

ENTER LOWEST RATE IN WHOLE DOLLARS. \_\_\_\_\_

AQ23Aa4

PRIVATE HOME HEALTH CARE HIGHEST RATE

How much does this agency charge SELF OR PRIVATE PAY home health patients for \_\_\_\_\_ ?

ENTER HIGHEST RATE IN WHOLE DOLLARS. \_\_\_\_\_

AQ23Aa4a

PRIVATE PAY HIGH AND LOW RATE UNIT – OTHER SPECIFY

How much does this agency charge self or private pay home health patients for \_\_\_\_\_ ?

- 1 VISIT
- 2 HOUR
- 3 HALF HOUR
- 4 15 MINUTES
  
- 91 OTHER (SPECIFY)

AQ23Aa4b

PRIVATE HIGH AND LOW RATE UNIT OTHER SPECIFY

ENTER OTHER SPECIFY (AQ23Aa4a – 91).

SPECIFY UNIT. \_\_\_\_\_

AQ25A1

HOSPICE SERVICES MIX MODE

About how many of this agency's HOSPICE patients are currently receiving \_\_\_\_\_ ?

- 1 RESPONDENT PROVIDES NUMBER OF PATIENTS
  
- 2 RESPONDENT PROVIDES % OF PATIENTS
  
- REFUSED
- DON'T KNOW

AQ25A2

HOSPICE SERVICE MIX NUMBER

About how many of this agency's HOSPICE patients are currently receiving \_\_\_\_\_ ?

ENTER NUMBER OF PATIENTS. \_\_\_\_\_

- REFUSED
- DON'T KNOW

AQ25A3

HOSPICE SERVICE MIX PERCENTAGE

About how many of this agency's hospice patients are currently receiving \_\_\_\_\_ ?

ENTER PERCENTAGE OF PATIENTS. \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ25B

Does this agency consider itself a Free Standing hospice agency, a Hospital Based agency, a Home Health Based agency or a Nursing Home Based agency?

This would be the same as this agency's MEDICARE filing status for Agency.

SELECT ONE.

PRESS F1 FOR HELP SCREEN.

- 1 FREE STANDING AGENCY
- 2 HOSPITAL BASED AGENCY
- 3 HOME HEALTH BASED AGENCY
- 4 NURSING HOME BASED AGENCY

REFUSED  
DON'T KNOW

AQ25C

Does this hospice operate any dedicated hospice facilities or units?

\*\*\*This is a facility or unit that has one or more beds that are owned or leased by the hospice and staffed by hospice, and whose major policies and procedures are set by the hospice.

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

AQ25D

How many INPATIENT HOSPICE BEDS does this agency have in these dedicated facilities or units?

ENTER NUMBER OF BEDS. \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ28

SHOW CARD AQ28.

Is this agency owned or is it in operation with any of the following places or organizations?

SELECT ONLY ONE.

PRESS F1 FOR HELP SCREEN.

- 1            OUTPATIENT MEDICAL/SURGICAL CENTER
  - 2            MANAGED CARE ORGANIZATION
  - 3            HOSPITAL
  - 4            SKILLED NURSING FACILITY
  - 5            HEALTH CARE SYSTEM
  - 6            NO, TOTALLY INDEPENDENT AGENCY
  - 91          OTHER (SPECIFY)
- REFUSED  
DON'T KNOW

AQ28A

AGENCY AFFILIATION - OTHER SPECIFY (AQ28 - 91)

SPECIFY PLACE/ORGANIZATION. \_\_\_\_\_

REFUSED  
DON'T KNOW

AQ29

SHOW CARD AQ29.

Does AGENCY have a FORMAL CONTRACT with any of these outside agencies or organizations where you provide services to their patients?

\*\*\* This refers to FORMAL CONTRACTS with other places besides the one this agency is owned or in operation with that you just mentioned.

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1            ASSISTED LIVING FACILITY/ BOARD AND CARE HOME / LIFE CARE/  
CONTINUING CARE RETIREMENT COMMUNITY
  - 2            HOSPITAL
  - 3            SKILLED NURSING FACILITY
  - 4            HOSPICE
  - 5            MANAGED CARE/PRIVATE INSURANCE PROVIDER
  - 6            NO FORMAL CONTRACT WITH OUTSIDE AGENCIES/ORGANIZATIONS
  - 91          OTHER (SPECIFY)
- REFUSED  
DON'T KNOW

AQ29A

FORMAL CONTRACT OTHER SPECIFY (AQ29 - 91)

SPECIFY TYPE OF AGENCY OR ORGANIZATION.

\_\_\_\_\_

AQ30

SHOW CARD AQ30.

Please look at this card and tell me if your agency is ACCREDITED by any of these organizations.

SELECT ALL THAT APPLY.

- 1 ACCREDITATION COMMISSION FOR HEALTH CARE (ACHC)
- 2 COMMUNITY HEALTH ACCREDITATION PROGRAM (CHAP)
- 3 JOINT COMMISSION FOR ACCREDITATION OF HEALTHCARE ORGANIZATIONS (JCAHO)
- 4 OTHER ACCREDITATION (SPECIFY)
- 5 NOT ACCREDITED

REFUSED  
DON'T KNOW

AQ30A

AGENCY ACCREDITATION OTHER SPECIFY (AQ30 - 4)

SPECIFY TYPE OF ACCREDITATION.

\_\_\_\_\_

AQ31

Does this agency provide staff training to understand CULTURAL DIFFERENCES AND BELIEFS that may affect delivery of services?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

AQ32

CULTURAL TRAINING

For which staff is training mandatory?

SELECT ALL THAT APPLY.

- 1 ADMINISTRATIVE/CLERICAL/MANAGEMENT STAFF - ALL
- 2 ADMINISTRATIVE/CLERICAL/MANAGEMENT STAFF - SOME
- 3 DIRECT SERVICE PROVIDERS - ALL
- 4 DIRECT SERVICE PROVIDERS - SOME
- 5 VOLUNTEERS - ALL
- 6 VOLUNTEERS - SOME
- 7 NO MANDATORY TRAINING FOR ANY STAFF
- 91 OTHER STAFF (SPECIFY)

REFUSED  
DON'T KNOW

AQ32A

CULTURAL TRAINING - OTHER SPECIFY (AQ32 - 91)

SPECIFY TYPE OF STAFF, AND SPECIFY IF ALL OR SOME.

\_\_\_\_\_

AQ33

SHOW CARD AQ33.

Are any of these COMMUNICATION PRACTICES used with this agency's patients?

SELECT ALL THAT APPLY.

- 1 PROVIDE INTERPRETER SERVICES
- 2 PATIENT-RELATED MATERIALS TRANSLATED INTO LANGUAGES OF COMMONLY REPRESENTED GROUPS IN SERVICE AREA
- 3 PROVIDE MULTI-LINGUAL STAFF
- 4 NONE OF THE ABOVE
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

AQ33A

COMMUNICATION PRACTICES - OTHER SPECIFY (AQ33 - 91)

SPECIFY TYPE COMMUNICATION PRACTICE.

\_\_\_\_\_

AQ34

SHOW CARD AQ34

Which of these SERVICES does this agency offer?

Include services offered by this agency as a result of contractual arrangements.

PRESS F1 FOR HELP SCREEN.

SELECT ALL THAT APPLY.

- 1 COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)
- 2 DIETARY AND NUTRITIONAL SERVICES
- 3 ENTEROSTOMAL THERAPY
- 4 IV THERAPY
- 5 PHYSICIAN SERVICES
- 6 PODIATRY SERVICES
- 7 SKILLED NURSING/NURSING SERVICES
- 8 WOUND CARE
- 9 NONE OF THESE SERVICES

REFUSED  
DON'T KNOW

AQ35

SHOW CARD AQ35.

Which of these COMPLEMENTARY AND ALTERNATIVE MEDICINE therapies does this agency use?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 ACUPUNCTURE
- 2 AROMATHERAPY
- 3 ART THERAPY
- 4 GUIDED IMAGERY/RELAXATION
- 5 MASSAGE
- 6 MUSIC THERAPY
- 7 PET THERAPY
- 8 SUPPORTIVE GROUP THERAPY
- 9 THERAPEUTIC TOUCH
- 10 TENS (TRANSCUTANEOUS ELECTRICAL NERVE STIMULATION)
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

AQ35A

ALTERNATIVE MEDICINE THERAPIES USED - OTHER SPECIFY (AQ35 - 91)

SPECIFY OTHER COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) THERAPY.

\_\_\_\_\_

AQ36

SHOW CARD AQ36.

Does AGENCY offer any of the SERVICES on this card?  
Include services offered by this agency as a result of contractual arrangements.

PRESS F1 FOR HELP SCREEN.

SELECT ALL THAT APPLY.

- 1 DURABLE MEDICAL EQUIPMENT
- 2 PHARMACY SERVICES
- 3 OCCUPATIONAL THERAPY
- 4 PHYSICAL THERAPY
- 5 RESPIRATORY THERAPY
- 6 SPEECH THERAPY/AUDIOLOGY
- 7 NONE OF THESE SERVICES
- 91 OTHER THERAPY (SPECIFY)

REFUSED  
DON'T KNOW

AQ36A

OTHER SERVICES PROVIDED OTHER SPECIFY (AQ36 - 91)  
SPECIFY OTHER THERAPY.

\_\_\_\_\_

AQ37

SHOW CARD AQ37.

Does AGENCY offer any of the OTHER SERVICES on this card?  
Include services offered by this agency as a result of contractual arrangements.

PRESS F1 FOR HELP SCREEN.

SELECT ALL THAT APPLY.

- 1 COMPANION SERVICES
- 2 CONTINUOUS HOME CARE
- 3 HOMEMAKER SERVICES
- 4 MEALS ON WHEELS SERVICES
- 5 ASSISTANCE WITH ACTIVITIES OF DAILY LIVING (ADLs)
- 6 TRANSPORTATION SERVICES
- 7 VOLUNTEER SERVICES
- 8 PASTORAL SERVICES/SPIRITUAL COUNSELING
- 9 MENTAL HEALTH SERVICES
- 10 REFERRAL SERVICES
- 11 RESPITE CARE
- 12 (MEDICAL) SOCIAL SERVICES
- 13 ETHICAL ISSUES COUNSELING
- 14 GRIEF/BEREAVEMENT COUNSELING
- 15 NONE OF THESE SERVICES

REFUSED  
DON'T KNOW

AQ38

SPECIAL PATIENT SERVICES

Does AGENCY provide services to any of the types of patients listed on this card?

SELECT ALL THAT APPLY.

- 1 DEVELOPMENTALLY DISABLED
- 2 MATERNAL AND NEONATAL CARE PATIENTS
- 3 PATIENTS WITH HIV/AIDS
- 4 PATIENTS WITH ALZHEIMER'S DISEASE/DEMENTIA
- 5 PATIENTS RECEIVING PERITONEAL OR HEMODIALYSIS
- 6 PEDIATRIC PATIENTS
- 7 NONE OF THE ABOVE

REFUSED  
DON'T KNOW

AQ39

NO ADMIT - LACK OF STAFF

In the past month, was this agency unable to admit patients because of lack of staff?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

AQ40

NO ADMIT - LACK OF CAPABILITIES

In the past month, was this agency unable to admit patients because of lack of capabilities?

[For example, patients with special or complex medical needs, ventilator patients, patients with IVs-peripheral lines, IVs-central lines.]

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

AQ41

ADVANCE DIRECTIVES POLICY

SHOW CARD AQ41.

Does this agency follow any of these procedures regarding Advance Directives?

PROBE: Any others?

SELECT ALL THAT APPLY.

- 1 ON ADMISSION, ASSESS WHETHER PATIENT HAS ANY ADVANCE DIRECTIVES
- 2 ON ADMISSION, PROVIDE WRITTEN INFORMATION ABOUT ADVANCE DIRECTIVES TO PATIENT
- 3 ON ADMISSION, PROVIDE ADVANCE DIRECTIVE FORM(S) TO PATIENT
- 4 EDUCATE PATIENT/FAMILY ABOUT ADVANCE DIRECTIVES
- 5 EDUCATE AGENCY STAFF ABOUT ADVANCE DIRECTIVES
- 6 ONLY IF REQUESTED, PROVIDE INFORMATION, FORMS, EDUCATION
- 7 NO PROCEDURES FOLLOWED
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

AQ41A

ADVANCE DIRECTIVES POLICY - OTHER SPECIFY (AQ41 - 91)

SPECIFY OTHER POLICY.

\_\_\_\_\_

AQ42

ADVANCE DIRECTIVE STORAGE

Where does this agency maintain a copy of its patients' Advance Directives?

SELECT ALL THAT APPLY.

- 1 NO DESIGNATED PLACE
  - 2 WITH PATIENT'S RECORDS AT AGENCY
  - 3 WITH PATIENT'S RECORDS AT PATIENT'S RESIDENCE
  - 4 IN SPECIAL ADVANCE DIRECTIVES FILE AT AGENCY LOCATION
  - 91 OTHER (SPECIFY)
- REFUSED

AQ42A

ADVANCE DIRECTIVE STORAGE OTHER SPECIFY (AQ42 -91)

DESCRIBE STORAGE OF ADVANCE DIRECTIVE(S).

\_\_\_\_\_

AQ43

ADVANCE DIRECTIVE IMPLEMENTATION  
SHOW CARD AQ43.

What specific actions does this agency take to make sure that patients' Advance Directives are implemented?

SELECT ALL THAT APPLY.

- 1 NOTIFY ATTENDING PHYSICIAN
  - 2 INFORM AGENCY STAFF PROVIDING CARE TO PATIENT
  - 3 INFORM FAMILY MEMBER/NEXT OF KIN
  - 4 NO SPECIFIC ACTIONS TAKEN
  - 91 OTHER (SPECIFY)
- REFUSED  
DON'T KNOW

AQ43A

ADVANCE DIRECTIVE IMPLEMENTATION OTHER SPECIFY (AQ43 -91)

DESCRIBE IMPLEMENTATION OF ADVANCE DIRECTIVES.

\_\_\_\_\_

AQ44

ADVANCE DIRECTIVES RESTRICTIONS

Does this agency have any restrictions on implementing any kinds of Advance Directives?

For example, not providing palliative sedation, CPR, or artificial life support services?

- 1 YES
  - 2 NO
- REFUSED  
DON'T KNOW

AQ45

ADVANCE DIRECTIVES RESTRICTIONS

What restrictions does this agency have?

DESCRIBE ADVANCE DIRECTIVES RESTRICTIONS.

\_\_\_\_\_

AQ46

OPEN ACCESS POLICY FOR HOSPICE PATIENTS

Does this agency have an Open Access policy for hospice patients?

This is when an agency admits patients that are starting or in the middle of a course of Radiation or Chemotherapy.

PRESS F1 FOR HELP SCREEN.

- 1 YES
- 2 NO
  
- REFUSED
- DON'T KNOW

AQ46A

OPEN ACCESS POLICY OTHER

About how many of this agency's current hospice patients were admitted under Open Access?

IF AGENCY HAS NO CURRENT HOSPICE PATIENTS, ENTER 9996.

ENTER NUMBER OF OPEN ACCESS ADMISSIONS. \_\_\_\_\_

- REFUSED
- DON'T KNOW

AQ48

ENCOURAGE FLU VACCINATION

SHOW CARD AQ48.

Does AGENCY do any of the following to encourage employees' influenza vaccinations?

SELECT ALL THAT APPLY.

- 1 VACCINATIONS OFFERED ON SITE
- 2 VACCINATIONS OFFERED FOR FREE
- 3 VACCINATIONS OFFERED AT REDUCED COST
- 4 EMPLOYEE INCENTIVES PROVIDED FOR VACCINATION
- 5 PROOF OF VACCINATION (OR CONTRAINDICATION) REQUIRED FOR WORK/EMPLOYMENT
- 6 NONE OF THE ABOVE
- 91 OTHER (SPECIFY)
  
- REFUSED
- DON'T KNOW

AQ48A

ENCOURAGE FLU VACCINATION OTHER SPECIFY (AQ48 - 91)

DESCRIBE OTHER WAYS TO ENCOURAGE VACCINATIONS.

---

AQ49

STAFF PERCENTAGE VACCINATED FOR FLU

SHOW CARD AQ49.

About what percentage of employees received a Flu shot last Flu season?

- |   |           |
|---|-----------|
| 1 | 0%        |
| 2 | 1 TO 20%  |
| 3 | 21 TO 40% |
| 4 | 41 TO 60% |
| 5 | 61 TO 80% |
| 6 | 81 TO 99% |
| 7 | 100%      |

REFUSED  
DON'T KNOW

## Appendix XII. CAPI: Patient Health (PH) Questionnaire

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### PHPRE Help Screens

Form Approved OMB No. 0920-0298 Exp. Date 07/31/2009

**NOTICE** – Public reporting burden of this collection of information is estimated to average 25 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road, MS E-11, Atlanta, GA 30333, ATTN: PRA (0920-0298).

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**PH14A** - Served as a member of the Army, Navy, Air Force, Marine Corps, Coast Guard, or as a commissioned officer of the Public Health Service, Environmental Science Services Administration or National Oceanic and Atmospheric Administration, or its predecessor, the Coast and Geodetic Survey.

**PH24** – A living will is a written document that allows a person to state in advance his/her wishes regarding the use or removal of life-sustaining or death-delaying procedures in the event of illness or injury.

Do not resuscitate is a written order from a doctor that resuscitation should not be attempted if a person suffers cardiac or respiratory arrest. Such an order may be instituted on the basis of an advance directive from a person or from someone entitled to make decisions on his/her behalf, such as a health care proxy.

Comfort measures only refer to pain medications, nursing care and treatments for the purpose of providing comfort and relieving pain only, not for curative purposes.

A durable power of attorney is a written legal document by which an individual designates another person to act on his or her behalf. The power is durable in the sense that the authority endures in the event the individual becomes disabled or incapacitated.

A health care proxy is a legal document in which an individual designates another person to make health care decisions if he or she is rendered incapable of making his/her wishes known. The health care proxy has, in essence, the same rights to request or refuse treatment that the individual would have if capable of making and communicating decisions.

Organ donation is the removal of specific tissues of the human body from a person who has recently died, or from a living donor, for the purpose of transplanting them into other persons.

PH25 - Refers to the place or location {SP} was staying in when he/she was referred to home health or hospice care.

PH25A - A skilled nursing facility provides short-term skilled nursing care on an inpatient basis, following hospitalization. These facilities provide the most intensive care available outside of a hospital.

A rehabilitation facility is a facility that provides an organized program of medical and clinical treatment designed to maximize residual physical, perceptual, and cognitive abilities following disablement.

Assisted living is a supportive housing facility designed for those who need extra help in their day-to-day lives but who do not require the 24-hour skilled nursing care found in traditional nursing homes.

PH30 – A Primary Caregiver is a person who helps the majority of time in caring for someone who is ill, disabled, or aged. Some caregivers are friends or relatives who volunteer their help. Some people provide caregiving services for a cost.

PH36 a-o – Co-morbid conditions are other diseases or illnesses the patient has.

PH41 – Healing status of pressure ulcers:

- Fully granulating:
  - wound bed filled with granulation tissue to the level of the surrounding skin or new epithelium
  - no dead space
  - no avascular tissue (eschar and/or slough)
  - no signs or symptoms of infection
  - wound edges are open
- Early/partial granulation:
  - ≥ 25% of the wound bed is covered with granulation tissue
  - there is minimal avascular tissue (eschar and/or slough) (i.e., <25% of the wound bed is covered with avascular tissue)
  - may have dead space
  - no signs or symptoms of infection
  - wound edges are open
- Not healing
  - Wound with ≥ 25% avascular tissue (eschar and/or slough) or
  - Signs/symptoms of infection or
  - Clean but non-granulating wound bed or
  - Closed/hyperkeratotic wound edges or
  - Persistent failure to improve despite appropriate comprehensive wound management

PH42 A – A person does not need assistance if they are able to get clothes and shoes out of closets and drawers, put them on and remove them (with or without dressing aids) without assistance.

PH42 F – This refers only to the process of eating, chewing, and swallowing the food to be eaten, not preparing the food. If the patient had a feeding tube, code “yes.”

PH44 G – A person does not need assistance if they are able to prepare and take all prescribed oral medications with the proper dosages and at the correct times.

PH50 – Do not include medical devices that were used only during a visit to a doctor’s office or other medical care setting.

PH64 – Standing order for pain medication refers to a pain medication that is administered at regular intervals, 24/7. Examples include timed doses around the clock and a synchroed pump. PRN order for pain medication refers to taking pain medication periodically, only when the patient feels that he/she needs it.

PH66 - Telemedicine is the use of electronic communication and information technologies to provide or support clinical care at a distance.

*Services received from the hospice agency, even if performed through a contractor on behalf of the agency, are considered the same as the hospice agency providing the services itself.*

PH67 – Homemaker services include assistance in personal care, maintenance of a safe and healthy environment and services to enable the individual to carry out the plan of care.

Continuous home care is where the hospice provides a minimum of eight hours during a 24-hour day, which begins and ends at midnight. This care need not be continuous, i.e., four hours could be provided in the morning and another four hours in the evening, but care must reflect the needs of an individual in crisis (the period is which an individual requires continuous care for as much as 24 hours to achieve palliation or management of acute medical symptoms). The care must be predominantly nursing care provided by either a registered nurse (RN) or licensed practical nurse (LPN). In other words, at least half of the hours of care are provided by the RN or LPN. Homemaker or home health aide services may be provided to supplement the nursing care.

Complementary and Alternative Medicine (CAM) is a diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. CAM includes acupuncture, aromatherapy, art therapy, guided imagery/relaxation, hypnosis, massage, music therapy, pet therapy, reflexology, reiki, supportive group therapy, therapeutic touch, and TENS (transcutaneous electrical nerve stimulation).

**PH68 – Referral Services** provide information about services available from public and private providers. They may also order or arrange services but they do not provide the services directly.

**Interpreter Services** – refer to bilingual staff and/or health education materials that enable agency staff to provide health care to patients whose native language is not English.

**PH70 - Safety training** – refers to when the hospice agency comes into a patient's home to evaluate real or potential threats to the health and safety of the patient and to make recommendations (e.g., remove throw rugs that can trip a patient who uses a walker) to reduce or eliminate those threats.

**PH71 a-k** – A **visit** is an episode of personal contact with the patient by staff of the HHA, or others under arrangements with the HHA, for the purpose of providing a covered home health service. One visit may be counted each time an HHA employee, or someone providing home health services under arrangements with the HHA, enters the patient's home and provides a covered service to a patient who meets the criteria. If the HHA furnishes services in an outpatient facility under arrangements with the facility, one visit may be counted for each type of services provided.

**PH71 a-k** If two individuals are needed to provide a service, two visits may be counted. If two individuals are present, but only one is needed to provide the care, only one visit may be counted.

Example: (a) if an occupational therapist and an occupational therapist assistant visit the patient together to provide therapy and the therapist is there to supervise the assistant, one visit is counted; (b) if a nurse visits the patient in the morning to dress a wound and later must return to replace a catheter, two visits are counted; and (c) if the therapist visits the patient for treatment in the morning and the patient is later visited by the assistant for additional treatment, two are counted.

**PH71 f – Skilled Nursing Visits** refer to nursing care provided by or under the supervision of a registered nurse (RN).

**PH73 – Emergent Care** refers to any urgent, unplanned medical care.

**PH74 – Cardiac problems** refers to problems related to the heart.

**Hypoglycemia** refers to a deficiency of sugar in the blood caused by too much insulin or too little glucose.

**Hyperglycemia** refers to a higher than normal blood glucose level.

**GI bleeding** is gastrointestinal bleeding from a source within the gastrointestinal tract such as an ulcer.

PH78 - IV Therapy: Includes hydration, pain pump.

Respiratory Therapy: Includes oxygen (intermittent or continuous), ventilator (continually or at night), and continuous positive airway pressure received in one's home. Therefore, a respiratory therapist does not need to be there in order for the respondent to indicate that the patient received respiratory therapy.

Palliative Sedation: Palliative sedation is the use of sedative medications to relieve extreme suffering by making the patient unaware and unconscious (as in a deep sleep) while the disease takes its course, eventually leading to death. The sedative medication is gradually increased until the patient is comfortable and able to relax. Palliative sedation is not intended to cause death or shorten life.

PH81 – Anorexia is diminished appetite or an aversion to food (distinct from anorexia nervosa).

**Patient Sampling HELP SCREEN****Selecting the Current Patient Sample**

1. Get the list. It must contain all the patients currently receiving care from the agency as of midnight of the night before the interview.
2. Clean the list
  - Check for duplicates on the list.
  - Correct the list if necessary.
3. Number the list. Number all eligible names on the list sequentially.
  - Check the numbers by groups of 50 or 100.
4. Select the sample. Follow the instructions on CAPI:
  - Enter the number of current patients (last number on your list) at item PS5.
  - Find the line numbers displayed in the 'Circle Number' column in the roster at PS8, and circle the corresponding line numbers on the list of current patients.

**Discharge Sampling HELP SCREEN****Selecting the Hospice Discharges Sample**

1. Get the list. It must contain all the hospice discharges for 3 months from the beginning month through the ending month 2007 as specified at PS2.
2. Clean the list
  - Correct the list if necessary.
3. Number the list. Number all eligible names on the list sequentially.
  - Check the numbers by groups of 50 or 100.
4. Select the sample. Follow the instructions on CAPI:
  - Enter the number of discharges (last number on your list) at item PS6.
  - Find the line numbers displayed in the 'Circle Number' column in the roster at PS12, and circle the corresponding line numbers on the list of discharges.
  - Enter the name corresponding to the line number into the roster, and the discharge date (month and day), if provided.

PH1A ZIP CODE  
What {is/was} {sampled patient}'s zip code?  
ENTER ZIP CODE. \_\_\_\_\_  
IF HOME ADDRESS NOT AVAILABLE, ENTER 99.  
REFUSED  
DON'T KNOW

PH1 Patient OASIS Form Completion  
Is there an OASIS form completed on this patient?  
1 YES  
2 NO  
REFUSED  
DON'T KNOW

PH2A Assessment Month OASIS Form  
What is the assessment date of the most recent OASIS form completed for {sampled patient} ?  
ENTER MONTH (1-12). \_\_\_\_\_  
REFUSED  
DON'T KNOW

PH2B Assessment Day OASIS Form  
What is the assessment date of the most recent OASIS form completed for {sampled patient} ?  
ENTER DAY. \_\_\_\_\_  
REFUSED  
DON'T KNOW

PH2C Assessment Year OASIS Form  
What is the assessment date of the most recent OASIS form completed for {sampled person} ?  
ENTER A 4-DIGIT YEAR. \_\_\_\_\_  
REFUSED  
DON'T KNOW

PH4A Admission Month

What was the date of {sampled patient}'s most recent admission with this agency?

That is, the date (he/she) was admitted for the current episode of care.

On what date was the {sampled patient} admitted to this agency for the episode of care that ended on {Discharge date}?

ENTER MONTH (1-12). \_\_\_\_\_

IF PATIENT RECEIVED ASSESSMENT ONLY, ENTER 99.

REFUSED  
DON'T KNOW

PH4B Recent Admission Day

What was the date of {sampled patient}'s most recent admission with this agency?

That is, the date (he/she) was admitted for the current episode of care).

On what date was the {sampled patient} admitted to this agency for the episode of care that ended on {Discharge date}?

ENTER DAY (1-31). \_\_\_\_\_

PH4 Recent Admission Year

What was the date of {sampled patient}'s most recent admission with this agency?

That is, the date (he/she) was admitted for the current episode of care.

On what date was the {sampled patient} admitted to this agency for the episode of care that ended on {Discharge date} ?

ENTER A 4-DIGIT YEAR. \_\_\_\_\_

PH4D Readmission

Was this a re-admission for {sampled patient} to this agency for {home health/hospice} Care?

1 YES  
2 NO  
REFUSED  
DON'T KNOW

PH5A Discharge Month

On what date was the {sampled patient} discharged from this agency?

ENTER MONTH (1-12). \_\_\_\_\_

REFUSED  
DON'T KNOW

PH5B DischargeDay

On what date was the {patient} discharged from this agency?

ENTER DAY (1-31). \_\_\_\_\_

REFUSED  
DON'T KNOW

PH5C Discharge Year

On what date was {patient} discharged from this agency?

ENTER A 4-DIGIT YEAR. \_\_\_\_\_

PH6 Deceased At Discharge

At discharge, was {patient} deceased?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH7 Reason For Discharge

Why was {patient} discharged from this agency?

- 1 CONDITION STABILIZED OR IMPROVED
- 2 OBTAIN MORE AGGRESSIVE TREATMENT FOR CONDITION
- 3 MOVED TO GEOGRAPHIC LOCATION NOT SERVICED BY THIS AGENCY
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

PH7A Specify Discharge Reason

SPECIFY REASON FOR DISCHARGE. (PH7 - 91)

\_\_\_\_\_

PH8 Destination After Discharge

Where did {sampled patient} go after (he/she) was discharged from this agency?

1 PRIVATE HOME OR APARTMENT  
 2 RESIDENTIAL CARE PLACE  
 3 SKILLED NURSING FACILITY  
 4 HOSPITAL  
 5 ANOTHER HOSPICE FACILITY  
 91 OTHER PLACE (SPECIFY)  
 REFUSED  
 DON'T KNOW

PH8A Facility Type Description

DESCRIBE FACILITY TYPE. (PH8 - 91)

\_\_\_\_\_

PH9 Gender

Is/Was {sampled patient} male or female?

1 MALE  
 2 FEMALE  
 REFUSED  
 DON'T KNOW

PH10A Birth Month

What {is/was} {sampled patient}'s date of birth?

ENTER MONTH (1-12). \_\_\_\_\_

REFUSED  
 DON'T KNOW

PH10B Day of Birth

What {is/was} {sampled patient}'s date of birth?

ENTER DAY (1-31). \_\_\_\_\_

REFUSED  
DON'T KNOW

PH10C Birth Year

What {is/was} {sampled patient}'s date of birth?

ENTER A 4-DIGIT YEAR. \_\_\_\_\_

REFUSED  
DON'T KNOW

PH11 Discharge Age

Approximately how old {is/was} {sampled patient} at the time of discharge?

Enter Age. \_\_\_\_\_

REFUSED  
DON'T KNOW

PH12 Hispanic or Latino Origin

{Is/Was} (he/she) of Hispanic or Latino origin?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

## PH13 Race

SHOW CARD PH13.

Please look at this card and tell me what {sampled patient}'s race {is/was}?

SELECT ALL THAT APPLY.

- 1 AMERICAN INDIAN OR ALASKA NATIVE
- 2 ASIAN
- 3 BLACK OR AFRICAN AMERICAN
- 4 NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER
- 5 WHITE
- 91 OTHER RACE (SPECIFY)

REFUSED  
DON'T KNOW

## PH13A Specify Race

SPECIFY RACE. (PH13 - 91)

\_\_\_\_\_

## PH14 Marital Status

{Is/Was} {sampled patient} married, widowed, divorced, separated, never married, or living with a partner in a marriage-like relationship?

IF NEEDED: (at time of discharge.)

- 1 MARRIED
- 2 WIDOWED
- 3 DIVORCED
- 4 SEPARATED
- 5 NEVER MARRIED
- 6 LIVING WITH A PARTNER

REFUSED  
DON'T KNOW

## PH14A Veteran Status

{Is/Was} {sampled patient} a veteran of U.S. military service?

PRESS F1 FOR HELP SCREEN.

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH15 Medicare Enrolled

SHOW CARD PH15

{Is/Was} {sampled patient} enrolled in Medicare?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH16 Medicare ID Number

What {is/was} (his/her) Medicare ID Number?

\_\_\_\_\_

REFUSED  
DON'T KNOW

PH17 Verify Medicare Number

I have entered {PH16/MEDICARE NUMBER}. Is this correct?

- 1 YES
- 2 NO

PH18 Medicaid Enrolled

Is/Was {sampled patient} enrolled in Medicaid?

- 1 YES
- 2 NO
- 3 MEDICAID PENDING

REFUSED  
DON'T KNOW

PH19 Medicaid ID Number

What {is/was} (his/her) {'PREFERRED' NAME FOR MEDICAID} {or 'ALLOWED FOR' NAME FOR MEDICAID} ID number?

IF NO MEDICAID NUMBER, ENTER 99. \_\_\_\_\_

REFUSED  
DON'T KNOW

PH20    Verify Medicaid Number

I have entered {MEDICAID NUMBER}. Is this correct?

1        YES  
2        NO

PH21    Alpha Or Numeric SSN

Does {sampled patient}'s Social Security number begin with a letter or a number?

1        LETTER  
2        NUMBER

REFUSED  
DON'T KNOW

PH21A   Social Security Number

What is {sampled patient}'s Social Security number?

\_\_\_\_\_

PH22    Social Security Number

What is {sampled patient}'s Social Security number?

\_\_\_\_\_

PH23    Verify Social Security Number

I have entered {SOCIAL SECURITY NUMBER}. Is this correct?

1        YES  
2        NO

PH24 Advanced Directives Request

SHOW CARD PH24.

Which of the following Advance Directives {has {sampled patient} requested/are listed in {sampled patient}'s medical records}?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 LIVING WILL
- 2 DO NOT RESUSCITATE (DNR)
- 3 DO NOT HOSPITALIZE/DO NOT SEND TO EMERGENCY DEPARTMENT
- 4 FEEDING RESTRICTIONS
- 5 MEDICATION RESTRICTIONS
- 6 COMFORT MEASURES ONLY
- 7 DURABLE POWER OF ATTORNEY
- 8 HEALTH CARE PROXY/SURROGATE
- 9 ORGAN DONATION
- 10 NO ADVANCED DIRECTIVES PROVIDED
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

PH24A Directive Description

DESCRIBE OTHER ADVANCE DIRECTIVE(S). (PH24 - 91)

\_\_\_\_\_

PH25 Where Stayed Before HHC

Immediately before {sampled patient} began receiving {home health/hospice} care from this agency, was he/she an inpatient in a hospital, nursing home, or some other kind of health care facility?

For the most recent episode of care.

PRESS F1 FOR HELP SCREEN.

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH25A Place Stayed Before Care

What kind of place was that?

PRESS F1 FOR HELP SCREEN.

- 1 HOSPITAL/EMERGENCY ROOM
- 2 NURSING HOME/SKILLED NURSING FACILITY/SUB-ACUTE FACILITY
- 3 REHABILITATION FACILITY
- 4 ASSISTED LIVING
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

PH25B SPECIFY FACILITY TYPE

What kind of place was that {OTHER SPECIFY}? (PH25A - 91)

\_\_\_\_\_

PH26 Where Stay After HHC

Does {sampled patient} now live in a private home or apartment, in a residential care place or somewhere else?

Residential care place refers to an assisted living facility, a board and care home, a life care or a continuing care retirement community.

- 1 PRIVATE HOME OR APARTMENT
- 2 RESIDENTIAL CARE PLACE
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

PH26A Specify Place

Specify Place. (PH 26 - 91)

\_\_\_\_\_

PH27 Where Staying Before HHC

Where was {sampled patient} staying when (he/she) first began receiving hospice care?

NOTE: A RESIDENTIAL CARE PLACE INCLUDES AN ASSISTED LIVING FACILITY, A BOARD AND CARE HOME, A LIFE CARE OR A CONTINUING CARE RETIREMENT COMMUNITY.

- 1 THIS AGENCY'S INPATIENT/ RESIDENTIAL FACILITY
- 2 PRIVATE HOME OR APARTMENT
- 3 RESIDENTIAL CARE PLACE
- 4 SKILLED NURSING FACILITY (NURSING HOME)
- 5 HOSPITAL
- 91 OTHER PLACE (SPECIFY)

REFUSED  
DON'T KNOW

PH27A Specify Facility Type

SPECIFY FACILITY TYPE.

\_\_\_\_\_

PH28 Where Last Day Hospice Care

Where was {sampled patient} staying on the last day (he/she) received hospice care ?

NOTE: A RESIDENTIAL CARE PLACE INCLUDES AN ASSISTED LIVING FACILITY, A BOARD AND CARE HOME, A LIFE CARE OR A CONTINUING CARE RETIREMENT COMMUNITY.

- 1 THIS AGENCY'S INPATIENT/ RESIDENTIAL FACILITY
- 2 PRIVATE HOME OR APARTMENT
- 3 RESIDENTIAL CARE PLACE
- 4 SKILLED NURSING FACILITY (NURSING HOME)
- 5 HOSPITAL
- 91 OTHER PLACE (SPECIFY)

REFUSED  
DON'T KNOW

PH28A Facility Type

SPECIFY FACILITY TYPE. (PH28 - 91)

\_\_\_\_\_

## PH29 Living Companion During HHC

Who does {sampled patient} currently live with? Or Who was (he/she) living with while receiving hospice care?

SELECT ALL THAT APPLY.

- 1 ALONE
- 2 SPOUSE/SIGNIFICANT OTHER
- 3 PARENT
- 4 CHILD (INCLUDING DAUGHTER/SON-IN-LAW)
- 5 OTHER FAMILY MEMBER
- 6 NON-FAMILY MEMBER(S)

REFUSED  
DON'T KNOW

## PH30 Any Outside Primary Care

Does {sampled patient} now/or Did {sampled patient} have a primary caregiver outside of this agency?

PRESS F1 FOR HELP SCREEN.

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

## PH32 Caregiver Relationship to Sampled Patient

Who {is/was} {PATIENT}'s primary caregiver?

- 1 SPOUSE/SIGNIFICANT OTHER
- 2 PARENT
- 3 CHILD (INCLUDING DAUGHTER/SON-IN-LAW)
- 4 OTHER FAMILY MEMBER
- 5 NOT RELATED

REFUSED  
DON'T KNOW

PH34 Primary Diagnosis

According to {sample patient}'s medical records, what was the primary diagnosis or condition at the time (he/she) was admitted to this agency (that is, on or around ADMISSION DATE)? \_\_\_\_\_

REFUSED  
DON'T KNOW

PH34A SPECIFY Primary Diagnosis

Specify Primary Diagnosis.

\_\_\_\_\_

PH35 Current Primary Diagnosis

What is {sampled patients}'s current primary diagnosis or condition/What was the primary diagnosis or condition at discharge?

\_\_\_\_\_

REFUSED  
DON'T KNOW

PH35A Specify Primary Diagnosis

Specify Primary Diagnosis.

\_\_\_\_\_

PH36a\_o Diagnoses At Discharge

What {are/were} all the other conditions {sampled patient} {currently has/had at discharge}?

Anything else?

PRESS F1 FOR HELP SCREEN.

PH36A1\_15 Specify Secondary Diagnoses

\_\_\_\_\_

## PH37 Surgical/Diagnostic Procedures at Admission

Did {sampled patient} have any surgical, diagnostic or therapeutic procedures or treatments that were related to (his/her) admission to this agency (for the current episode of care)?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

## PH38 Procedure/Operation Description

What kind of operation or procedure did {sampled patient} have?

Any others?

Enter all procedures. \_\_\_\_\_

## PH38A1\_5 Other Specify Procedure / Operation

Enter other specified procedures. \_\_\_\_\_

## PH39 Pressure Ulcers Prior to Discharge

Does (sampled patient) now/or on the last day (patient) received hospice care, did (he/she) have pressure ulcers?

\*\*A pressure ulcer is any lesion caused by pressure, resulting in damage to underlying tissue.

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH40 Highest Stage of Pressure Ulcer  
SHOW CARD PH40

Please look at this card and tell me the highest stage of any pressure ulcer the patient has now or had.

- 1 STAGE I
- 2 STAGE II
- 3 STAGE III
- 4 STAGE IV
- 5 UNSTAGED (NOT ASSESSED)

REFUSED  
DON'T KNOW

PH41 Status At Highest Pressure Ulcer Stage

SHOW CARD PH41

What {is/was} the last recorded healing status of this pressure ulcer?

PRESS F1 FOR HELP SCREEN.

- 1 FULLY GRANULATING
- 2 EARLY/PARTIAL GRANULATION
- 3 NOT HEALING
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

PH41A Specify Pressure Ulcer Status (PH41 - 91)

Other Specify status of pressure ulcer

\_\_\_\_\_

PH42 Pressure Ulcers Prior to Discharge

Is/Was patient comatose or in a vegetative state {at the time (he/she) was admitted to this agency for hospice care}?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH42A      Need Help Dressing

Does/At admission, did patient need any help from another person with the following activity?

Dressing

PRESS F1 FOR HELP SCREEN.

1      YES  
2      NO

REFUSED  
DON'T KNOW

PH42A1    Agency Help Dressing

Do/Did any agency staff help the patient with dressing?

1      YES  
2      NO

REFUSED  
DON'T KNOW

PH42B      Need Help Bathing

Does/At admission, did patient need any help from another person with the following activity ?

Bathing

1      YES  
2      NO

REFUSED  
DON'T KNOW

PH42B1    Agency Help Bathing

Do/Did any agency staff help patient with bathing?

1      YES  
2      NO

REFUSED  
DON'T KNOW

PH42C Need Help Using Toilet

Does/At admission, did patient need any help from another person with the following activity?

Using Toilet

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH42C1 Agency Help Toilet

Do/Did any agency staff help patient with using the toilet?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH42D Help Getting In or Out of Bed or Chairs

At admission, did patient need any help from another person with the following activity?

Getting in or out of bed or chairs

- 1 YES
- 2 NO
- 3 DOESN'T DO

REFUSED  
DON'T KNOW

PH42D1 Agency Help Getting In or Out of Bed

Do/Did any agency staff help the patient with getting in or out of bed or chairs?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH42E Help in Walking Or Climbing Stairs

Does/At admission, did patient need any help from another person with the following activity?

Walking or Climbing Stairs

1 YES  
2 NO  
3 DOESN'T DO

REFUSED  
DON'T KNOW

PH42E1 Agency Help with Walking Or Climbing Stairs

Do/Did any agency staff help the patient with walking or climbing stairs?

1 YES  
2 NO

REFUSED  
DON'T KNOW

PH42F Help Eating Or Feeding

At admission, did patient need any help from another person with the following activity?

Eating or feeding (himself/herself)

PRESS F1 FOR HELP SCREEN.

\_\_\_\_\_

REFUSED  
DON'T KNOW

PH42F1 Agency Help Eating

Do/Did any agency staff help the patient with eating or feeding himself/herself?

1 YES  
2 NO

REFUSED  
DON'T KNOW

PH44G Preparing or Taking Medication Help

Does patient currently/did patient receive any help from this agency's staff with the following activity?

PRESS F1 FOR HELP SCREEN.

- 1 YES
  - 2 NO
  - 3 DOESN'T DO
- REFUSED  
DON'T KNOW

PH47 Mental Status In Hospice Care

SHOW CARD PH47

Please look at this card and tell me which category best describes patient's current level of cognitive functioning or current mental status at the time (he/she) was admitted to this agency for hospice care.

- 0 NO COGNITIVE IMPAIRMENT
  - 1 REQUIRE{S/D} ONLY OCCASIONAL REMINDERS (IN NEW SITUATIONS)
  - 2 REQUIRE{S/D} SOME ASSISTANCE/DIRECTION IN CERTAIN SITUATIONS (IS EASILY DISTRACTED)
  - 3 REQUIRES A GREAT DEAL OF ASSISTANCE/DIRECTION IN ROUTINE SITUATIONS
  - 4 SEVERE COGNITIVE IMPAIRMENT (CONSTANTLY DISORIENTED, COMATOSE, DELIRIUM)
- REFUSED  
DON'T KNOW

PH48 Aids Or Devices Used

SHOW CARD PH48

Which of these aids or special devices on this card does the patient use?

PROBE: Any others?

SELECT ALL THAT APPLY.

- 1 WALKER/CANE/CRUTCH
- 2 WHEELCHAIR
- 3 MOTORIZED CART/SCOOTER
- 4 ORTHOTICS (INCLUDING BRACES)
- 5 PROSTHETICS (LIMBS)
- 6 NONE OF THESE

REFUSED  
DON'T KNOW

PH49 Activity Assistive Devices

SHOW CARD PH49

Which of these aids or special devices on this card does the patient use?

PROBE: Any others?

SELECT ALL THAT APPLY.

- 1 BEDSIDE COMMUNE
- 2 ELEVATED/RAISED TOILET SEAT
- 3 HOSPITAL BED
- 4 SPECIALIZED MATTRESS (EGG CRATE, FOAM, AIR, GEL, ETC.)
- 5 SPECIALIZED CHAIRS (GERI CHAIR, LIFT CHAIRS)
- 6 GRAB BARS
- 7 TRANSFER EQUIPMENT (LIFTS, GAIT BELTS)
- 8 SHOWER CHAIR/BATH BENCH
- 9 OVER BED TABLE
- 10 EATING DEVICES (BUILT UP UTENSILS, PLATE GUARD, NON-SPILL CUP)
- 11 NONE OF THESE

REFUSED  
DON'T KNOW

PH50 Hospice Medical Devices Used

SHOW CARD {PH50a/PH50b}

Which of the medical devices on this card does the patient use/did patient use while in hospice care?

PROBE: Any others?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 IV INFUSION PUMP (LARGE VOLUME)
- 2 PATIENT CONTROLLED ANALGESIA PUMP
- 3 AMBULATORY INFUSION PUMP (OTHER THAN INSULIN)
- 4 PERITONEAL/HEMODIALYSIS
- 5 OXYGEN (OXYGEN CONCENTRATOR, LIQUID, TANK OR OTHER DELIVERY SYSTEM)
- 6 METERED DOSE INHALER
- 7 APNEA MONITOR
- 8 CONTINUOUS POSITIVE PRESSURE AIRWAY (CPAP)
- 9 BLOOD GLUCOSE MONITOR
- 10 ENTEROSTOMAL DEVICE (URINE OR STOOL BAG)
- 11 ENTERAL (NASOGASTRIC OR OTHER) TUBE FEEDING EQUIPMENT
- 12 PARENTERAL IV (TPN)
- 13 PRESSURE RELIEVING DEVICES (SPECIAL BED, MATTRESS, OR OVERLAY)
- 14 NONE OF THESE

REFUSED  
DON'T KNOW

PH51 Agency Staff Support

Does/Did this agency's staff provide support with instruction, maintenance or monitoring of any of those medical devices for patient?

- 1 YES
  - 2 NO
- REFUSED  
DON'T KNOW

## PH52 Medical Devices

Which ones?

PROBE: Any others?

SELECT ALL THAT APPLY.

- 1 IV INFUSION PUMP (LARGE VOLUME)
- 2 PATIENT CONTROLLED ANALGESIA PUMP
- 3 AMBULATORY INFUSION PUMP (OTHER THAN INSULIN)
- 4 PERITONEAL/HEMODIALYSIS
- 5 OXYGEN (OXYGEN CONCENTRATOR, LIQUID, TANK OR OTHER DELIVERY SYSTEM)
- 6 METERED DOSE INHALER
- 7 APNEA MONITOR
- 8 CONTINUOUS POSITIVE PRESSURE AIRWAY (CPAP)
- 9 BLOOD GLUCOSE MONITOR
- 10 ENTEROSTOMAL DEVICE (URINE OR STOOL BAG)
- 11 ENTERAL (NASOGASTRIC OR OTHER) TUBE FEEDING EQUIPMENT
- 12 PARENTERAL IV (TPN)
- 13 PRESSURE RELIEVING DEVICES (SPECIAL BED, MATTRESS, OR OVERLAY)

REFUSED

DON'T KNOW

## PH53 Urinary Catheter Use

During hospice care did patient have a urinary catheter?

- 1 YES
- 2 NO

REFUSED

DON'T KNOW

## PH54 Bladder Control Difficulty

Does / Did patient have difficulty controlling (his/her) bladder?

- 1 YES
- 2 NO
- 3 NOT APPLICABLE

REFUSED

DON'T KNOW

PH55 Ostomy Usage

Does/Did patient have a colostomy or ileostomy for bowel elimination?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH56 Bowel Control Problem

Does/Did patient have difficulty controlling (his/her) bowels?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH57A Month First Pain Assessed

On what date was patient first assessed for pain (for the episode of care beginning on (admission date))?

ENTER MONTH. \_\_\_\_\_

IF PATIENT NOT ASSESSED FOR PAIN SINCE ADMISSION, ENTER 99.

IF PATIENT ASSESSED FOR PAIN ON SAME DAY AS ADMISSION, ENTER 97.

PH57B Day First Pain Assessed

On what date was patient first assessed for pain (for the episode of care beginning on (admission date)).

ENTER DAY. \_\_\_\_\_

PH57B Year First Pain Assessed

On what date was patient first assessed for pain (for the episode of care beginning on (admission date)).

ENTER 4-DIGIT YEAR. \_\_\_\_\_

PH58 Pain Assessment Tool Used

SHOW CARD PH58

What type of pain assessment tool was used to assess patient's pain?

IF MORE THAN ONE PAIN ASSESSMENT TOOL REPORTED, ASK:

Which of those pain assessment tools gave the most accurate assessment for patient's pain level?

- 1 0-10 SCALE
- 2 0-5 SCALE
- 3 WORD SCALE (MILD, MODERATE, SEVERE)
- 4 FACE SCALE (0-5)
- 5 FACE SCALE (0-10)
- 6 FLACC
- 7 OBSERVATION OF PATIENT'S BEHAVIOR
- 8 PATIENT'S/FAMILY'S DESCRIPTION OF PAIN
- 91 OTHER ASSESSMENT TOOLS (SPECIFY)

REFUSED  
DON'T KNOW

PH58A Specify Pain Assessment Tool

Specify pain assessment tool.

\_\_\_\_\_

PH59A Pain Level Recorded 1

What was the level of patient's pain recorded at that assessment  
(Date of assessment)?

- 0 PAIN LEVEL 0
- 1 PAIN LEVEL 1
- 2 PAIN LEVEL 2
- 3 PAIN LEVEL 3
- 4 PAIN LEVEL 4
- 5 PAIN LEVEL 5
- 6 PAIN LEVEL 6
- 7 PAIN LEVEL 7
- 8 PAIN LEVEL 8
- 9 PAIN LEVEL 9
- 10 PAIN LEVEL 10

REFUSED  
DON'T KNOW

PH59B Pain Level Recorded 2

What was the level of patient's pain recorded at that assessment on date of assessment?

- 0 PAIN LEVEL 0
- 1 PAIN LEVEL 1
- 2 PAIN LEVEL 2
- 3 PAIN LEVEL 3
- 4 PAIN LEVEL 4
- 5 PAIN LEVEL 5

REFUSED  
DON'T KNOW

PH59C Pain Level Recorded 3

What was the level of patient's pain recorded at that assessment on date of assessment?

- 1 PAIN LEVEL MILD
- 2 PAIN LEVEL MODERATE
- 3 PAIN LEVEL SEVERE
- 4 NO PAIN

REFUSED  
DON'T KNOW

PH59D What Level Pain Recorded

What was the level of patient's pain recorded at that assessment on date of assessment?

IF PAIN CANNOT BE DESCRIBED, STATED OR REPORTED, ENTER 999.

\_\_\_\_\_

REFUSED  
DON'T KNOW

PH60A Month Last Pain Assessed

When was the last time the patient was assessed for pain for the episode of care that ended on (discharge date)?

ENTER MONTH. \_\_\_\_\_

REFUSED  
DON'T KNOW

PH60B Day Last Pain Assessed

When was the last time the patient was assessed for pain for the episode of care that ended on (discharge date).

ENTER DAY. \_\_\_\_\_

REFUSED  
DON'T KNOW

PH60C Year Last Pain Assessed

When was the last time the patient was assessed for pain for the episode of care that ended on (discharge date)?

ENTER A 4-DIGIT YEAR. \_\_\_\_\_

REFUSED  
DON'T KNOW

PH61 Pain Assessment Tool Used 1

SHOW CARD PH61

What type of pain assessment tool was used to assess patient's pain {that time}?

IF MORE THAN ONE PAIN ASSESSMENT TOOL REPORTED, ASK:  
Which of those pain assessment tools gave the most accurate  
assessment for the patient's pain level?

- 1 0-10 SCALE
- 2 0-5 SCALE
- 3 WORD SCALE (MILD, MODERATE, SEVERE)
- 4 FACE SCALE (0-5)
- 5 FACE SCALE (0-10)
- 6 FLACC
- 7 OBSERVATION OF PATIENT'S BEHAVIOR
- 8 PATIENT'S/FAMILY'S DESCRIPTION OF PAIN
- 91 OTHER ASSESSMENT TOOLS (SPECIFY)

REFUSED  
DON'T KNOW

PH61A Specify Pain Assessment Tool X

Specify pain assessment tool.

\_\_\_\_\_

PH61B Pain Level Recorded 3X

What was the level of the patient's pain recorded at that assessment (date of assessment)?

- 0 PAIN LEVEL 0
- 1 PAIN LEVEL 1
- 2 PAIN LEVEL 2
- 3 PAIN LEVEL 3
- 4 PAIN LEVEL 4
- 5 PAIN LEVEL 5
- 6 PAIN LEVEL 6
- 7 PAIN LEVEL 7
- 8 PAIN LEVEL 8
- 9 PAIN LEVEL 9
- 10 PAIN LEVEL 10

REFUSED  
DON'T KNOW

PH61C Pain Level Recorded 4

What was the level of the patient's pain recorded at that assessment (date of assessment)?

- 0 PAIN LEVEL 0
- 1 PAIN LEVEL 1
- 2 PAIN LEVEL 2
- 3 PAIN LEVEL 3
- 4 PAIN LEVEL 4
- 5 PAIN LEVEL 5

REFUSED  
DON'T KNOW

PH61D Pain Level Recorded 5

What was the level of the patient's pain recorded at that assessment (on date of assessment).

- 1 PAIN LEVEL MILD
- 2 PAIN LEVEL MODERATE
- 3 PAIN LEVEL SEVERE
- 4 NO PAIN

REFUSED  
DON'T KNOW

PH62 Pain Level Assessment Date

What was the level of the patient's pain recorded at that assessment (on date of Assessment).

RECORD DESCRIPTION OF PAIN LEVEL.

IF PAIN LEVEL CANNOT BE DESCRIBED, STATED OR REPORTED, ENTER 999.

\_\_\_\_\_

REFUSED  
DON'T KNOW

PH64 Pain Management Strategy

SHOW CARD PH64

According to the patient's medical record, what strategies on this card are/were used to manage (his/her) pain.

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 STANDING ORDER FOR PAIN MEDICATION
- 2 PRN ORDER FOR PAIN MEDICATION
- 3 NON-PHARMACOLOGICAL METHODS (DISTRACTION, HEAT/COLD  
MASSAGE/POSITIONING, MUSIC THERAPY)
- 4 NO STRATEGIES SPECIFIED
- 91 OTHER (SPECIFY)

REFUSED  
DON'T KNOW

PH64A Specify Pain Management Strategy.

---

## PH66 Medical Services Received

SHOW CARD {PH66A/PH66B}

What services did/does the patient receive from this agency during the last 60 days in which the patient was receiving care from the agency since admission during his/her hospice care?

Include services received from the agency as a result of contractual arrangements.

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP.

- 1 SKILLED NURSING SERVICES
- 2 PHYSICIAN SERVICES
- 3 PHARMACY SERVICES
- 4 PODIATRY SERVICES
- 5 WOUND CARE
- 6 DIETARY AND NUTRITIONAL SERVICES
- 7 TELEMEDICINE
- 8 NONE OF THESE

REFUSED

DON'T KNOW

## PH67 Other Services Received

SHOW CARD PH67

What other services did/does the patient receive from this agency during the last 60 days in which the patient was receiving care from the agency since admission during his/her hospice care?

Include services received from the agency as a result of contractual arrangements.

PROBE: Any others on this card?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP

- 1 HOMEMAKER SERVICES
- 2 ASSISTANCE WITH ADLs
- 3 VOLUNTEER SERVICES
- 4 CONTINUOUS HOME CARE
- 5 MEALS ON WHEELS
- 6 TRANSPORTATION
- 7 OCCUPATIONAL THERAPY
- 8 PHYSICAL THERAPY
- 9 RESPIRATORY THERAPY
- 10 SPEECH THERAPY/AUDIOLOGY
- 11 COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)
- 12 NONE OF THESE

REFUSED

DON'T KNOW

PH68 Counseling and/or Psychosocial Services

SHOW CARD PH68

Which of these services were provided from this agency during the last 60 days of care since admission?

Include services received from {AGENCY} as a result of contractual arrangements.

PROBE: Any others on this card?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 PASTORAL SPIRITUAL SERVICES
- 2 DIETARY COUNSELING
- 3 ETHICAL ISSUES COUNSELING
- 4 REFERRAL SERVICES
- 5 (MEDICAL) SOCIAL SERVICES
- 6 MENTAL HEALTH SERVICES
- 7 RESPITE SERVICES
- 8 INTERPRETER SERVICES
- 9 NONE OF THESE

REFUSED

DON'T KNOW

PH70 Service Type Provided

SHOW CARD PH70

Did this agency offer or provide the patient's family members or friends any of the services listed on this card? Which ones?

Include services received from the agency as a result of contractual arrangements.

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 BEREAVEMENT
- 2 CAREGIVER HEALTH/WELLNESS
- 3 SPIRITUAL
- 4 DIETARY
- 5 DEALING WITH DIFFICULT BEHAVIORS
- 6 MEDICATION MANAGEMENT/ADMINISTRATION
- 7 EQUIPMENT USE
- 8 PATIENT ADLS (BATHING, DRESSING, TOILETING, FEEDING, ETC.)
- 9 SAFETY TRAINING
- 10 SUSPECTED ABUSE/NEGLECT/EXPLOITATION
- 11 REFERRAL/RESOURCE INFORMATION
- 12 RESPITE CARE
- 13 NO SERVICES OFFERED OR PROVIDED
- 91 OTHER (SPECIFY)

REFUSED

DON'T KNOW

PH70A Specify Service Type

Specify type of service.

\_\_\_\_\_

PH71A Staff Visits Received

How many visits did (he/she) receive from agency's staff for nursing services?

Nursing services include nursing care and nursing services provided by or under the supervision of a RN.

Number of (nursing service) visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71B Number of Staff Visits

How many visits did the patient receive from this agency's staff during his/her hospice care?

Number of (physician services) visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71D Medical Social Services Visits

How many visits were there for medical social services?

PRESS F1 FOR HELP SCREEN.

Number of (medical social services) visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71E Volunteer Services Visits

How many visits were there for volunteer services?

Number of (volunteer services) visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71F Skilled Nursing Visits

How many visits did the patient receive for skilled nursing service from the agency's staff in the past 60 days (prior to interview) since admission?

Nursing services include: nursing care and nursing services provided by or under the supervision of an RN.

PRESS F1 FOR HELP SCREEN.

Number of skilled nursing service visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71G Physical Therapy Visits

How many visits did the patient receive for physical therapy from the agency's staff in the past 60 days (prior to interview) since admission?

PRESS F1 FOR HELP SCREEN.

Number of physical therapy visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71H Occupational Therapy Visits

How many visits did the patient receive for occupational therapy from the agency's staff in the past 60 days (prior to interview) since admission?

PRESS F1 FOR HELP SCREEN.

Number of occupational therapy visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71I Speech Therapy Visits

How many visits did the patient receive for occupational therapy from the agency's staff in the past 60 days (prior to interview) since admission?

PRESS F1 FOR HELP SCREEN.

Number of speech therapy visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71J Medical Social Services Visits

How many visits did the patient receive for occupational therapy from the agency's staff in the past 60 days (prior to interview) since admission?

PRESS F1 FOR HELP SCREEN.

Number of medical social service visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH71K Home Health Aide and Homemaker Visits

How many visits did the patient receive for occupational therapy from the agency's staff in the past 60 days (prior to interview) since admission?

PRESS F1 FOR HELP SCREEN.

Number of home health aide and homemaker visits \_\_\_\_\_

REFUSED  
DON'T KNOW

PH73 Emergency Care Services

SHOW CARD PH73

Did or has the patient used any of these services for emergent care during the last 60 days (prior to interview) since admission ?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 HOSPITAL EMERGENCY ROOM (INCLUDES 23-HOUR HOLDING)
- 2 DOCTOR'S OFFICE EMERGENCY VISIT/HOUSE CALL
- 3 OUTPATIENT DEPARTMENT/CLINIC (INCLUDES URGICENTER SITES)
- 4 NO EMERENT CARE

REFUSED  
DON'T KNOW

PH74 Emergency Care Reason

For what reason did (he/she) obtain emergent care?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 MEDICATION PROBLEM/COMPLICATION (IMPROPER MEDICATION ADMINISTRATION, MEDICATION SIDE EFFECTS, TOXICITY, ANAPHYLAXIS)
  - 2 NAUSEA, DEHYDRATION, MALNUTRITION, CONSTIPATION, IMPACTION
  - 3 INJURY DUE TO A FALL
  - 4 OTHER TYPE OF INJURY
  - 5 RESPIRATORY PROBLEMS (E.G., SHORTNESS OF BREATH, RESPIRATORY INFECTION, TRACHEOBRONCHIAL OBSTRUCTION)
  - 6 WOUND INFECTION, DETERIORATING WOUND STATUS, NEW LESION/ULCER
  - 7 CARDIAC PROBLEMS (E.G., FLUID OVERLOAD, EXACERBATION OF CHF, CHEST PAIN)
  - 8 HYPOGLYCEMIA/HYPERGLYCEMIA, DIABETES OUT OF CONTROL
  - 9 GI BLEEDING/OBSTRUCTION
  - 10 URINARY TRACT INFECTION (UTI)
  - 11 UNCONTROLLED PAIN
  - 91 OTHER (SPECIFY)
- REFUSED  
DON'T KNOW

PH74A Specify Reason for Emergent Care

SPECIFY REASON FOR EMERGENT CARE.

\_\_\_\_\_

PH75 Overnight Hospital Stay

Since being admitted to this agency has the patient had a hospital admission that required an overnight stay where (he/she) she was not formally discharged from the agency?

- 1 YES
- 2 NO

REFUSED  
DON'T KNOW

PH76a_y	PRN Medications
What are the names of all the medications and drugs the patient currently takes or was taking seven days prior to and on the day of his/her discharge/death while in hospice?	
Please include any standing, routine, or PRN medications.	
Enter all drugs. _____	

PH76A1_25	Specify Medication
_____	

PH77	Symptoms Prior to Discharge SHOW CARD PH77
When this agency last provided care to the patient did (he/she) have any of these symptoms? Before (his/her) death.	
SELECT ALL THAT APPLY.	
1	DIFFICULTY BREATHING (DYSPNEA)
2	END STAGE RESTLESSNESS
3	DEPRESSION
4	PAIN
5	CONSTIPATION
6	ANOREXIA
7	NONE OF THESE
	REFUSED
	DON'T KNOW

PH78

Care Or Treatments Received

SHOW CARD PH78

Which formal care or treatments did the patient receive while in hospice care?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 IV THERAPY
- 2 TRANSFUSION
- 3 TUBE FEEDING (NASOGASTRIC/OTHER ENTERAL FEEDINGS)
- 4 HYPODERMCLYSIS
- 5 TOTAL PARENTERAL NUTRITION (TPN)
- 6 RESPIRATORY THERAPY
- 7 RADIATION THERAPY
- 8 CHEMOTHERAPY
- 9 PALLIATIVE SEDATION
- 10 NONE OF THESE

REFUSED  
DON'T KNOW

PH79

Level of Hospice Care

SHOW CARD PH79

Which level of hospice care on this card was the patient receiving at the time of his/her discharge?

- 1 ROUTINE HOME CARE FOR PATIENTS  
RECEIVING HOSPICE SERVICES IN THEIR HOMES
- 2 CONTINUOUS HOME CARE PROVIDED 8 TO 24 HOURS PER DAY  
PRIMARILY BY SKILLED HOSPICE PERSONNEL
- 3 GENERAL INPATIENT CARE PROVIDED BY SKILLED HOSPICE STAFF
- 4 INPATIENT RESPITE CARE TO RELIEVE THE PRIMARY CAREGIVER

REFUSED  
DON'T KNOW

## PH80 Life Expectancy

According to the patient's medical record, does (his/her) current prognoses indicate a life expectancy of greater than 6 months, or 6 months or less?

Is (he/she) only receiving palliative, end of life, or terminal care instead of active or curative treatment?

- 0 YES, LIFE EXPECTANCY GREATER THAN 6 MONTHS
  - 1 YES, LIFE EXPECTANCY 6 MONTHS OR LESS
  - 2 NO, LIFE EXPECTANCY NOT INDICATED BUT RECEIVING PALLIATIVE/END OF LIFE CARE ONLY
  - 3 NO, LIFE EXPECTANCY NOT INDICATED AND NOT RECEIVING PALLIATIVE/END OF LIFE CARE
- REFUSED  
DON'T KNOW

## PH81 Symptoms Last Visit

SHOW CARD PH81

During this agency's last visit to provide care to the patient, did (he/she) have any of these symptoms?

SELECT ALL THAT APPLY.

PRESS F1 FOR HELP SCREEN.

- 1 DIFFICULTY BREATHING (DYSPNEA)
- 2 END STAGE RESTLESSNESS
- 3 DEPRESSION
- 4 PAIN
- 5 CONSTIPATION
- 6 ANOREXIA
- 7 NONE OF THESE

PH82 Care or Treatment At Last Visit

SHOW CARD PH82

During this agency's last visit, which formal care or treatments was {PATIENT} receiving?

Include formal care/treatments the patient obtained from ANY provider, not just what the agency provided.

SELECT ALL THAT APPLY.

- 1 IV THERAPY
- 2 TRANSFUSION
- 3 TUBE FEEDING (NASOGASTRIC/OTHER ENTERAL FEEDINGS)
- 4 HYPODERMCLYSIS
- 5 TOTAL PARENTERAL NUTRITION (TPN)
- 6 RESPIRATORY THERAPY
- 7 RADIATION THERAPY
- 8 CHEMOTHERAPY
- 9 PALLIATIVE SEDATION
- 10 NONE OF THESE

REFUSED  
DON'T KNOW

## Appendix XIII. CAPI: Charges and Payments (PA) Questionnaire

---

PA1	Primary Source of Payment
What {is/was} the primary source of payment for (sampled patient's) home health/hospice care?	
IF PAYMENT NOT RECEIVED YET: What is the expected primary source of payment?	
1	MEDICARE
2	MEDICAID
3	TRICARE (FORMERLY CHAMPUS)
4	DEPARTMENT OF VETERANS AFFAIRS
5	CHAMPVA
6	WORKER'S COMPENSATION
7	OTHER GOVERNMENT
8	PRIVATE INSURANCE
9	LONG-TERM CARE INSURANCE
10	SELF-PAY (PATIENT/FAMILY)
11	NO CHARGE FOR CARE
12	PAYMENT SOURCE NOT DETERMINED
91	OTHER (SPECIFY)
	REFUSED
	DON'T KNOW

PA1A	Medicare Fee Type
Is the Medicare fee for service (traditional Medicare), managed care, or some other type of Medicare?	
1	FEE FOR SERVICE/TRADITIONAL MEDICARE
2	MANAGED CARE
91	OTHER MEDICARE
	REFUSED
	DON'T KNOW

PA1B	Specify Medicare Type (PA1A - 91)
SPECIFY TYPE OF MEDICARE.	
_____	

PA1C Medicaid Fee Type

Is the Medicaid fee for service (traditional Medicaid), managed care, or some other type of Medicaid?

- 1 FEE FOR SERVICE/TRADITIONAL MEDICAID
  - 2 MANAGED CARE
  - 91 OTHER MEDICAID
- REFUSED  
DON'T KNOW

PA1D Specify Medicaid Type (PA1C - 91)

SPECIFY TYPE OF MEDICAID.

\_\_\_\_\_

PA1E Specify Govt Source Payment

SPECIFY OTHER TYPE OF GOVERNMENT SOURCE FOR PAYMENT.

\_\_\_\_\_

PA1F Private Insurance Fee Type

Is the private insurance fee for service, managed care, or some other type of private insurance?

- 1 FEE FOR SERVICE
  - 2 MANAGED CARE
  - 91 OTHER PRIVATE INSURANCE
- REFUSED  
DON'T KNOW

PA1G Specify Private Insurance (PA1F - 91)

SPECIFY TYPE PRIVATE INSURANCE.

\_\_\_\_\_

PA1H Specify Other Source Payment

SPECIFY OTHER SOURCE OF PAYMENT.

\_\_\_\_\_

PA2 Why Other Source Payment

Is this because sampled patient (does/did not) have health insurance, or the agency's services (he/she) received are not covered by insurance or some other reason?

1 PATIENT DID NOT HAVE HEALTH INSURANCE  
 2 SERVICES NOT COVERED BY INSURANCE  
 91 OTHER (SPECIFY)

PA2A Specify Self Pay Reason (PA2 - 91)

SPECIFY REASON FOR SELF-PAY.

---

PA3 Other Payment Sources

Besides {PA1 OR PA1F RESPONSE}, what {are/were} all other sources of payment for (sampled patient's home health care) /(sampled patient's hospice care)?

SELECT ALL THAT APPLY.

1 MEDICARE  
 2 MEDICAID  
 3 TRICARE (FORMERLY CHAMPUS)  
 4 DEPARTMENT OF VETERANS AFFAIRS  
 5 CHAMPVA  
 6 WORKERS COMPENSATION  
 7 OTHER GOVERNMENT  
 8 PRIVATE INSURANCE  
 9 LONG-TERM CARE INSURANCE  
 10 SELF-PAY (PATIENT/FAMILY)  
 11 NO OTHER PAYMENT SOURCES  
 91 OTHER (SPECIFY)

REFUSED  
 DON'T KNOW

PA3A Medicare Fee Type X

Is the Medicare fee for service (traditional Medicare), managed care, or some other type of Medicare?

- 1 FEE FOR SERVICE/TRADITIONAL MEDICARE
  - 2 MANAGED CARE
  - 91 OTHER MEDICARE
- REFUSED  
DON'T KNOW

PA3B Specify Type Medicare

SPECIFY TYPE OF MEDICARE.

\_\_\_\_\_

PA3C Medicaid Type Fee

Is the Medicaid fee for service (traditional Medicaid), managed care, or some other type of Medicaid?

- 1 FEE FOR SERVICE/TRADITIONAL MEDICAID
  - 2 MANAGED CARE
  - 91 OTHER MEDICAID
- REFUSED  
DON'T KNOW

PA3D Specify Type Medicaid

SPECIFY TYPE OF MEDICAID.

\_\_\_\_\_

PA3E Specify Other Govt Source Pay

SPECIFY OTHER TYPE OF GOVERNMENT SOURCE FOR PAYMENT.

\_\_\_\_\_

PA3F Private Insurance Fee Type X

Is the private insurance fee for service, managed care, or some other type of private insurance?

1 FEE FOR SERVICE  
 2 MANAGED CARE  
 91 OTHER PRIVATE INSURANCE

REFUSED  
 DON'T KNOW

PA3G Private Insurance

SPECIFY TYPE PRIVATE INSURANCE.

\_\_\_\_\_

PA3H Other Source Payment Specify

SPECIFY OTHER SOURCE OF PAYMENT.

\_\_\_\_\_

PA4 Other Source Payment Reason

{Is/Was} the other source of payment "patient or family" because sampled patient does not have health insurance, because the {agency's services/hospice services} received {are/were} not covered by insurance, or for some other reason?

1 PATIENT DID NOT HAVE HEALTH INSURANCE  
 2 SERVICES NOT COVERED BY INSURANCE  
 91 OTHER (SPECIFY)

REFUSED  
 DON'T KNOW

PA4A Self Pay Reason (PA4 - 91)

SPECIFY REASON FOR SELF-PAY.

\_\_\_\_\_

PA6 Total Amount Billed

What was the total amount of the charges billed for sampled patient's care received for the last complete billing period (or since admission if (he/she) has not been here for a complete billing period)/hospice care at the AGENCY?

IF NEEDED: This covers the time period from (his/her) admission on {ADMISSION DATE} to (his/her) discharge on {DISCHARGE DATE}.

ENTER TOTAL AMOUNT OF CHARGES IN WHOLE DOLLARS.

IF NO CHARGES BILLED TO DATE, ENTER 0.

\_\_\_\_\_

REFUSED  
DON'T KNOW

PA7A Beginning Month Billed

What was the beginning date of the time period covered by this amount?

ENTER MONTH (1-12). \_\_\_\_\_

REFUSED  
DON'T KNOW

PA7B Beginning Day Billed

What was the beginning date of the time period covered by this amount?

ENTER DAY (1-31). \_\_\_\_\_

REFUSED  
DON'T KNOW

PA7C Beginning Year Billed

What was the beginning date of the time period covered by this amount?

ENTER YEAR. \_\_\_\_\_

PA8A Ending Date Billed Month

What was the ending date of the time period covered by this amount?

ENTER MONTH (1-12). \_\_\_\_\_

REFUSED  
DON'T KNOW

PA8B Ending Day Billed

What was the ending date of the time period covered by this amount?

ENTER DAY (1-31). \_\_\_\_\_

REFUSED  
DON'T KNOW

PA8C Ending Year Billed

What was the ending date of the time period covered by this amount?

ENTER YEAR. \_\_\_\_\_

REFUSED  
DON'T KNOW

PA11 Total Amount Billed For Year

What was the total amount of the charges billed for sampled patient's hospice care at AGENCY for the 12-month period before (he/she) was discharged?

That would include the time period from (DATE ONE YEAR BEFORE DISCHARGE) to (his/her) discharge on (DISCHARGE DATE).

ENTER WHOLE DOLLAR AMOUNT (0 to 999999). \_\_\_\_\_

REFUSED  
DON'T KNOW

PA14 Total Amount Paid

Of the total charges, how much did {PA1} pay?  
Include any amount {PA1} has already paid and additional payments you expect from {PA1}.

ENTER WHOLE DOLLAR AMOUNT (0 to 999999). \_\_\_\_\_

REFUSED  
DON'T KNOW

PA14A Total Amount Paid Medicare FFS or TRICAR

Based on sampled patient's current 60-day plan of care, what is the total Medicare/TRICARE PPS payment, that is the RAP plus the final payment you expect to receive for this 60-day episode?

ENTER WHOLE DOLLAR AMOUNT (0 to 999999). \_\_\_\_\_

## Appendix XIV. Agency Gaining Cooperation Debriefing Agenda and Discussion Guide

---

**National Home and Hospice Care Survey  
Gaining Cooperation Debriefing Conference Call  
A 90-minute Call Scheduled between  
Wednesday, August 8, and Saturday, August 11, 2007**

**Chair: Field Supervisor**

**Participants: About Half of the Interviewers in the Region per Call, 2 Calls per Region**

**Observers: Westat Home Office, Field Management Staff, NCHS Staff**

**Objectives:**

1. To Provide Interviewers with a General Understanding of What Has Happened in the Region Since Training
2. To Adjust Gaining Cooperation Approaches, Based on the Early Experience
3. To Improve Gaining Cooperation Skills by Leveraging Off the Experience of the More Successful Interviewers

**Notes:**

1. Supervisors need to think about which interviewers to invite for each session and ask the interviewers to prepare for the call.
2. A discussion guide for the calls will be drafted and distributed to supervisors before the end of training.
3. More detailed planning for the gaining cooperation calls will occur in a conference call with supervisors late the week of July 29.
4. Telephony monitoring will provide source material for the conference call, at the national level and (depending on accessibility) at the regional level. Home office staff will provide supervisors with the relevant numbers.
5. A Westat home office member or the field manager will document the call.

**Agenda**

1. **Roll Call and Welcome (less than 5 minutes)**
2. **Summary of Activity in the Region (10 min.)**
  - a. Supervisor reviews number of eligible cases by priority group and provides current information on number/percent in the following statuses: appointment, complete, corporate approval required, initial refusal, no action, other pending.
  - b. Comparison of region with national production.

**3. What Happens in a Visit (15 min.)**

- a. Supervisor asks several interviewers who have completed interviews to summarize their experiences.
- b. Supervisor invites interviewers to reflect on what they might have done differently in the appointment setting and confirmation calls, based on the visit experience.

**4. Getting to the Director: What Works, What Doesn't (15 min.)**

- a. Supervisor invites selected interviewers to discuss experiences in getting through to the director on the phone, using the discussion guide
- b. Supervisor reviews minimum and maximum number of calls each interviewer in the group has made to get through to the director on their cases

**5. Director Questions that Surprised You (5 min.)**

- a. Supervisor leads review of conversations with directors, using discussion guide, and invites interviewers to volunteer their most unusual questions and their most common experiences

**6. Scheduling an Appointment: Effective Tools (10 min.)**

- a. Supervisor calls on 2 of the most successful interviewers to volunteer their approach in scheduling appointments
- b. Supervisor presents list of tools and techniques (listed in discussion guide), and invites group to discuss which has been most effective and ineffective so far

**7. Evaluation of Training, Materials Effectiveness (10 min.)**

- a. Supervisor asks interviewers how prepared they felt to contact directors and set appointments after the classroom training; were there some skill areas that should have been more developed?
- b. Supervisor guides interviewers through review of a short list of gaining cooperation materials: what seemed most useful? Least useful?

**8. Review of Cooperation Goals for the Region and Next Steps (10 min.)**

- a. Supervisor discusses remaining cooperation goals for the region and plan for achieving them
- b. Supervisor lists next steps for gaining cooperation

**9. Reminder and Preview of Next Week's Call on Agency Visits (5 min.)**

## National Home and Hospice Care Survey Gaining Cooperation Debriefing Conference Call

### Discussion Guide

#### 1. Roll Call and Welcome (less than 5 minutes)

**[TAKE ATTENDANCE AND WELCOME EVERYONE TO THE CALL]**

#### 2. Summary of Activity in the Region (10 min.)

**[PREPARE FOR THIS PART BY REVIEWING THE FIRST REPORTS AND FILLING IN THE NUMBERS.]**

We thought it would be good to start this call with a review of where we are coming out of training. Nationally we had 86 interviewers coming out of training in Baltimore, \_\_\_ in our region, and \_\_\_ of you are on this call.

I receive a set of reports every Tuesday reflecting work you transmitted through Sunday night – these are what we call the “static” reports. I also get updates on-line, and I can look at the systems at any time and see the current status of things in our region.

We have \_\_\_ eligible cases altogether in our region, and \_\_\_ of them have been assigned to interviewers. About half of them are Priority 1, and the other half are priority 2.

You have \_\_\_ appointments (and \_\_\_ completes, we’ll talk more about the completes in a minute). There are \_\_\_ cases with corporate approval required (32), \_\_\_ initial refusal ( ), and \_\_\_ in some other pending status.

\_\_\_ have not been touched yet. Most of those are our priority 2s.

This is (a little better than/about the same as/a little worse than) the country as a whole. Here are the national numbers:

1530 eligible cases

\_\_\_ appointments

\_\_\_ completes

\_\_\_ corporate approval required

\_\_\_ initial refusal

\_\_\_ other pending

\_\_\_ no action

Are there any questions before we go on?

### 3. What Happens in a Visit (15 min.)

**[IF NO ONE IN THIS GROUP HAS COMPLETED ANY INTERVIEWS YET, SKIP TO SECTION 4.]**

Next, I think it would be interesting for everyone to hear about how our first completed interview(s) went.

**[CALL ON INTERVIEWERS WHO HAVE TO COMPLETED INTERVIEWS TO GIVE HIGHLIGHTS FROM THE EXPERIENCE. USE THE FOLLOWING QUESTIONS TO GUIDE THE DISCUSSION]:**

How many respondents did you have in the agency?

Was it a home health, a hospice, or a mixed agency?

How did sampling go?

Did you have any trouble completing everything in a day?

**[FOR HOSPICE AND MIXED]:** How did the zip code form work?

What was your biggest problem during the interview?

Given what happened on the visit, is there anything you wish you had done differently in the appointment setting call or the confirmation call or the reminder call?

### 4. Getting to the Director: What Works, What Doesn't (15 min.)

Another issue we spent some time preparing you for in during the Baltimore training was getting through to the director on the phone. I'd like us to spend a few minutes reviewing how that has gone in the past few days, since you got home and started working through your Priority 1 cases in earnest.

**[CALL ON OTHER INTERVIEWERS WHO HAVEN'T SPOKEN YET TO TALK ABOUT THEIR EXPERIENCES GETTING THROUGH TO THE DIRECTOR. USE THE FOLLOWING QUESTIONS AS GUIDES]:**

We know that it can take a number of calls to each agency to reach the director and gain the agency's cooperation.

Let's go around the group now. I'd like each of you to tell us how many agencies you called, how many agency directors you reached, and the outcome of each call you placed. That information will help guide the rest of our discussion.

**[CALL ON EACH INTERVIEWER TO REPORT ON THEIR EXPERIENCES CALLING THE AGENCY DIRECTORS.]**

Now I'd like to hear from those of you who were able to speak with at least one agency director. Please share your experiences speaking with the directors and what you think worked especially well that contributed to your success.

**[ASK ABOUT DIRECTOR QUESTIONS, COMMENTS, REACTIONS, OUTCOME OF CALLS. LISTEN TO RESPONSES AND GUIDE DISCUSSION. PROBE FOR APPROACHES THAT SEEMED TO BE EFFECTIVE IN GAINING DIRECTORS' COOPERATION OR INTEREST IN THE SURVEY.]**

Now I'd like to hear about calls that did not result in a conversation with an agency director. Tell us any challenges you encountered trying to reach the agency director and your experiences with gatekeepers.

**[LISTEN TO RESPONSES AND GUIDE DISCUSSION. PROMPT TRAINEES TO ELICIT STORIES ABOUT GETTING ACCESS TO AGENCY DIRECTOR.]**

Based on your experiences today and our discussion, is there anything you would do differently when placing appointment-setting calls?

**[LISTEN TO RESPONSES AND GUIDE DISCUSSION.]**

The least number of calls any of you has had to make to reach a director is 1, but most of the time you're not that lucky. What's the greatest number of calls you've made to reach a director?

## **5. Director Questions that Surprised You (5 min.)**

It helps to be prepared with answers to common questions directors ask. I know some of you write them down on post its and stick them up on the wall in front of you as you're calling. Others make out lists. Whatever helps!

Have any of your directors come up with new questions, something you didn't anticipate?

What do you think is the hardest question to answer?

## 6. Scheduling an Appointment: Effective Tools (10 min.)

Next, I'd like to spend a few minutes talking about the process of actually scheduling the appointment.

**[CALL ON 2 OF THE MOST SUCCESSFUL INTERVIEWERS TO VOLUNTEER THEIR APPROACH IN SCHEDULING APPOINTMENTS.]**

There are a lot of tools that can help in scheduling appointments. Some of them were in the agency advance package, and others were in your case folders or bulk supplies. Some of the best ones may be ones you've made yourself. Let's talk for a few minutes about what seems to be most effective so far.

First, the set an appointment script. How has that been working for you?

How about the NHHCS calendar?

There are a number of things in the advance package:

- The advance letter from Dr. Sondik;
- The FAQs;
- The NHHCS folder;
- The ERB letters;
- The confidentiality brochure;
- The endorsement letters; and
- The report from the 2000 survey on computerized records.

Have you found yourself referring to any of these to catch the director's attention? Which ones?

Do the directors volunteer anything about any of these materials? Good or bad?

The advance letter mentions the NHHCS web site and the DVD that's available there. Have any of you mentioned this in your appointment calls? Have any directors mentioned it?

What about your own list of common questions and answers, or stock phrases like "HIPAA compliant", or things you've written down on post it notes in front of your phone – have you done anything like this? Has it been helpful?

## 7. Evaluation of Training, Materials Effectiveness (10 min.)

Now, let's talk about the classroom training a little bit. The home office staff have reviewed your evaluation forms, and for the most part, most of you rated the training pretty highly. Some things were clear low points – telephony practice

Sunday night, for instance – but the agency calls and the debriefing we had Tuesday morning were rated very well.

Now that you've had a little more experience contacting directors on your own, I want you to look back on the training and tell me how well you think the training prepared you to contact directors and set appointments.

**[PAUSE FOR TRAINEES TO ANSWER. CALL FOR VOLUNTEERS IF NECESSARY.]**

Were there some skill areas that could have been more developed?

**8. Review of Cooperation Goals for the Region and Next Steps (10 min.)**

**[DISCUSS THE REMAINING COOPERATION GOALS FOR THE REGION AND PLAN FOR ACHIEVING THEM.]**

**[DISCUSS NEXT STEPS FOR GAINING COOPERATION; REVIEW PLANS FOR FINISHING UP PRIORITY 1 AND BEGINNING WORK ON PRIORITY 2.]**

**9. Reminder and Preview of Next Week's Call on Agency Visits (5 min.)**

Next week I'll be scheduling another call, this one focused more on the first visits to agencies and what we've learned from them. I will be in touch with you about a schedule for that. The call will be sometime between Friday August 17 and Monday August 20.

Do you have any questions about that, or anything else we've covered today?

## Appendix XV. Agency Visit Debriefing Agenda and Discussion Guide

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**National Home and Hospice Care Survey  
Agency Visit Conference Call  
A 90-minute Call Scheduled between  
Friday, August 17, and Monday, August 20, 2007**

**Chair: Field Supervisor**

**Participants: Interviewers in the Region**

**Observers: Westat Home Office, Field Management Staff, NCHS Staff**

**Objectives:**

1. To Share More Experiences from Data Collection Visits and Build More Confidence in Data Collection Skills
2. To Identify Early Problems in Agency Visits and Take Corrective Action
3. To Improve Interviewing Skills Early in the Data Collection Period

**Notes:**

1. Supervisors need to schedule the call with interviewers and ask them to prepare for the call.
2. Supervisors need to review the discussion guide for the calls.
3. Field observations, interviewer remarks, IRQs, and WesCARI behavior coding may provide source material for the conference call.
4. A Westat home office member or the field manager will document the call.

### **Agenda**

1. **Roll Call and Welcome (less than 5 min.)**
2. **Summary of Activity in the Region (10 min.)**
  - a. Supervisor reviews number of eligible cases by priority group and provides updated numbers/percents in the following statuses: appointment, complete, corporate approval required, initial refusal, no action, other pending
  - b. Comparison of region with national production; emphasis on number of completes

**3. What Happens in a Visit (20 min.)**

- a. Supervisor asks several interviewers who have completed interviews (perhaps different interviewers from the gaining cooperation calls the previous week) to summarize their experiences
- b. Supervisor polls interviewers on how much time their visits have taken so far.
- c. Guided discussion of longer cases, covering reasons for length, multiple respondents, degree of completion

**4. Time Management Tools During the Visit (10 min.)**

- a. Supervisor lists tools available: staff schedules, choose-person screen, conducting PA by phone, etc.
- b. Tips for Efficient Interviewing (to be included in the discussion guide)

**5. Review of Sections and Questions That Can Be Problematic (20 min.)**

- a. AQ
- b. PS
- c. AS
- d. PH
- e. PA

**6. Evaluation of Training, Materials, and CAPI Program Effectiveness (10 min.)**

- a. Supervisor asks interviewers how prepared they felt to **conduct the CAPI interview** after the classroom training; were there some skill areas that should have been more developed?
- b. Supervisor asks interviewers how prepared they felt to **complete the other data collection tasks** (sampling, collecting HHA contact info, obtaining and reviewing the SAQ, using the ROC and EROC, etc.) after the classroom training; were there some skill areas that should have been more developed?
- c. Supervisor guides interviewers through review of data collection materials: what seemed most useful? Least useful?

**7. Review of Cooperation Goals for the Region and Next Steps (10 min.)**

## National Home and Hospice Care Survey Agency Visit Debriefing Conference Call

### Discussion Guide

#### 1. Roll Call and Welcome (less than 5 minutes)

**[TAKE ATTENDANCE AND WELCOME EVERYONE TO THE CALL]**

#### 2. Summary of Activity in the Region (10 min.)

**[PREPARE FOR THIS PART BY REVIEWING THE SECOND WEEK'S REPORTS AND FILLING IN THE NUMBERS.]**

We're going to start this call like we did the last one, with a review of where we are now, after you've all had at least a full week of time to work.

I received my "static" report this Tuesday reflecting work you transmitted through Sunday. [I also got updates on-line, to see the current status of things in our region.]

We have \_\_\_ eligible cases altogether in our region, and \_\_\_ of them have been assigned to interviewers.

You have \_\_\_ appointments  
\_\_\_ completes  
\_\_\_ cases with corporate approval required (36),  
\_\_\_ initial refusal ( ), and  
\_\_\_ in some other pending status.

\_\_\_ have not been touched yet. Most of those are our priority 2s.

This is (a little better than/about the same as/a little worse than) the country as a whole. Here are the national numbers:

1530 eligible cases  
\_\_\_ appointments  
\_\_\_ completes  
\_\_\_ corporate approval required  
\_\_\_ initial refusal  
\_\_\_ other pending  
\_\_\_ no action

Are there any questions before we go on?

### 3. What Happens in a Visit (20 min.)

Next, let's talk about how everyone's first visits to agencies have gone in the past week. This call is going to focus on those first visits in some detail. We want to hear mostly from those of you who have gone out on your first visit, but I want everyone else to listen in and ask questions whenever you hear something you're curious about and want to understand better. OK?

So how many of you have gone out on an agency visit?

**[COLLECT NAMES. CALL ON INTERVIEWERS WHO HAVE TO COMPLETED INTERVIEWS TO GIVE HIGHLIGHTS FROM THE EXPERIENCE. USE THE FOLLOWING QUESTIONS TO GUIDE THE DISCUSSION]:**

How many different people did you have to talk to in the agency to complete the interview? Did anyone have just one person all day, from the AQ through sampling and all the person-level sections?

Who had the most people to talk to?

How many hospice agencies have we completed altogether so far? \_\_\_\_\_

How many home health? \_\_\_\_\_

Any mixed agencies?

Did any of you have any problems with sampling?

Did you have any trouble completing everything in a day?

I'd like to take down some numbers.

**ASK EACH INTERVIEWER WITH COMPLETES:**

What time was your appointment?

When did you show up at the agency?

When did you leave the agency?

Did you have time to take any breaks?

What was the total time you were there collecting data?

Were you able to complete everything before you left?

**IF ANYONE SAYS NO:** How many PH sections were you able to complete?

**IF ANY INTERVIEW TOOK 8 HOURS OR MORE,  
OR IF ANY INTERVIEW WAS NOT COMPLETED IN ONE DAY,  
ASK:**

How many different people did you have to collect data from?

Why do you think the interview took that long?

Can you think of anything that might have cut down on the time?

**OTHER QUESTIONS:**

How did the zip code form work in the hospice agencies?

What was your biggest problem during the interview?

Given what happened on the visit, is there anything you wish you had done differently in the appointment setting call or the confirmation call or the reminder call?

**4. Time Management Tools During the Visit (10 min.)**

There are a number of tools to help you keep track of everything, to move through the interview as quickly as possible and get everything done that you need to finish in a day. I'm thinking of things like:

- using the ORG to keep track of staff schedules
- using the choose-person screen to follow the best order for people in the agency
- offering to conduct PA by phone, and
- a checklist that was mailed to everyone earlier this week

What has been effective for you so far in these early interviews? Anything else?

Are there personal strategies you've tried that have worked for keeping things flowing and making the most efficient use of your time?

If our region had to put a list together of ways to get everything done in the agencies, to help the other regions, what would you put at the top of the list?

**5. Review of Sections and Questions That Can Be Problematic (20 min.)**

Now let's talk about each section of the CAPI instrument.

- a. **AQ.** First, the AQ. Has anyone had any problems with questions in the AQ? Which ones?

- b. **PS.** How about the patient sampling section? Has anything been problematic or confusing in it?
- c. **AS.** How about Aides Sampling?
- d. **PH.** Next, let's spend some time talking about PH. Are there any questions your respondents find it hard to answer?

How about the look-up lists for conditions and prescribed medicines?  
How have those been working for you?

- e. **PA.** And finally, PA. Anything that's been difficult there?

## 6. Evaluation of Training, Materials, and CAPI Program Effectiveness (10 min.)

Now let's think back to your training at BWI two weeks ago. I want to ask you all something. How prepared did you feel to **conduct the CAPI interview** after the classroom training?

Was there anything about CAPI that you wish you'd gotten more training on?

How about the other data collection tasks?

- Sampling?
- Collecting HHA contact info
- Obtaining and reviewing the SAQ
- Using the ROC and EROC
- Transmitting

Finally, let's review the data collection materials: what seemed most useful to you?

**[PAUSE FOR VOLUNTEERS]**

How about the case folder and agency information sheet?

The pens and ruler?

The DVDs?

The job aid booklet?

The show cards?

The help screens in CAPI?

The aides contact info form?

Anything else?

Which of these do you think was least useful?

**7. Review of Cooperation Goals for the Region and Next Steps (10 min.)**

**[DISCUSS THE REMAINING COOPERATION GOALS AND AGENCY VISIT GOALS FOR THE REGION AND PLAN FOR ACHIEVING THEM.]**

**[DISCUSS NEXT STEPS FOR GAINING COOPERATION; REVIEW PLANS FOR FINISHING CONTACT WORK ON PRIORITY 2.]**

Do you have any questions about anything we've covered today?

# Vital and Health Statistics Series Descriptions

## ACTIVE SERIES

- Series 1. **Programs and Collection Procedures**—This type of report describes the data collection programs of the National Center for Health Statistics. Series 1 includes descriptions of the methods used to collect and process the data, definitions, and other material necessary for understanding the data.
- Series 2. **Data Evaluation and Methods Research**—This type of report concerns statistical methods and includes analytical techniques, objective evaluations of reliability of collected data, and contributions to statistical theory. Also included are experimental tests of new survey methods, comparisons of U.S. methodologies with those of other countries, and as of 2009, studies of cognition and survey measurement, and final reports of major committees concerning vital and health statistics measurement and methods.
- Series 3. **Analytical and Epidemiological Studies**—This type of report presents analytical or interpretive studies based on vital and health statistics. As of 2009, Series 3 also includes studies based on surveys that are not part of continuing data systems of the National Center for Health Statistics and international vital and health statistics reports.
- Series 10. **Data From the National Health Interview Survey**—This type of report contains statistics on illness; unintentional injuries; disability; use of hospital, medical, and other health services; and a wide range of special current health topics covering many aspects of health behaviors, health status, and health care utilization. Series 10 is based on data collected in this continuing national household interview survey.
- Series 11. **Data From the National Health Examination Survey, the National Health and Nutrition Examination Surveys, and the Hispanic Health and Nutrition Examination Survey**—In this type of report, data from direct examination, testing, and measurement on representative samples of the civilian noninstitutionalized population provide the basis for (1) medically defined total prevalence of specific diseases or conditions in the United States and the distributions of the population with respect to physical, physiological, and psychological characteristics, and (2) analyses of trends and relationships among various measurements and between survey periods.
- Series 13. **Data From the National Health Care Survey**—This type of report contains statistics on health resources and the public's use of health care resources including ambulatory, hospital, and long-term care services based on data collected directly from health care providers and provider records.
- Series 20. **Data on Mortality**—This type of report contains statistics on mortality that are not included in regular, annual, or monthly reports. Special analyses by cause of death, age, other demographic variables, and geographic and trend analyses are included.
- Series 21. **Data on Natality, Marriage, and Divorce**—This type of report contains statistics on natality, marriage, and divorce that are not included in regular, annual, or monthly reports. Special analyses by health and demographic variables and geographic and trend analyses are included.
- Series 23. **Data From the National Survey of Family Growth**—These reports contain statistics on factors that affect birth rates, including contraception and infertility; factors affecting the formation and dissolution of families, including cohabitation, marriage, divorce, and remarriage; and behavior related to the risk of HIV and other sexually transmitted diseases. These statistics are based on national surveys of women and men of childbearing age.

## DISCONTINUED SERIES

- Series 4. **Documents and Committee Reports**—These are final reports of major committees concerned with vital and health statistics and documents. The last Series 4 report was published in 2002. As of 2009, this type of report is included in Series 2 or another appropriate series, depending on the report topic.
- Series 5. **International Vital and Health Statistics Reports**—This type of report compares U.S. vital and health statistics with those of other countries or presents other international data of relevance to the health statistics system of the United States. The last Series 5 report was published in 2003. As of 2009, this type of report is included in Series 3 or another series, depending on the report topic.
- Series 6. **Cognition and Survey Measurement**—This type of report uses methods of cognitive science to design, evaluate, and test survey instruments. The last Series 6 report was published in 1999. As of 2009, this type of report is included in Series 2.
- Series 12. **Data From the Institutionalized Population Surveys**—The last Series 12 report was published in 1974. Reports from these surveys are included in Series 13.
- Series 14. **Data on Health Resources: Manpower and Facilities**—The last Series 14 report was published in 1989. Reports on health resources are included in Series 13.
- Series 15. **Data From Special Surveys**—This type of report contains statistics on health and health-related topics collected in special surveys that are not part of the continuing data systems of the National Center for Health Statistics. The last Series 15 report was published in 2002. As of 2009, reports based on these surveys are included in Series 3.
- Series 16. **Compilations of Advance Data From Vital and Health Statistics**—The last Series 16 report was published in 1996. All reports are available online, and so compilations of Advance Data reports are no longer needed.
- Series 22. **Data From the National Mortality and Natality Surveys**—The last Series 22 report was published in 1973. Reports from these sample surveys, based on vital records, are published in Series 20 or 21.
- Series 24. **Compilations of Data on Natality, Mortality, Marriage, and Divorce**—The last Series 24 report was published in 1996. All reports are available online, and so compilations of reports are no longer needed.

For answers to questions about this report or for a list of reports published in these series, contact:

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