# Advance Data

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# An Overview of Home Health and Hospice Care Patients: 1996 National Home and Hospice Care Survey

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### Abstract

*Objective*—This report presents numbers and percents of home health and hospice care agencies, their current patients, and their discharges. Agency characteristics include type of ownership, region, certification, location, and affiliation. Patient and discharge characteristics include age, sex, race, marital status, admission diagnoses, and procedures.

*Methods*—The data used for this report are from the National Center for Health Statistics' 1996 National Home and Hospice Care Survey. This is a sample survey through which data are collected on the use of home health and hospice care agencies in the United States.

*Results*—During 1996, there were an estimated 2.5 million current patients and 8.2 million discharges from 13,500 home health and hospice care agencies in the United States. The agencies tended to be proprietary, certified by Medicare and Medicaid as a home health agency, and located in a metropolitan statistical area. Almost half were part of a chain or group of agencies. The home health and hospice care patients and discharges tended to be 65 years of age and over, female, white, and married or widowed. The most common diagnoses for home health care patients were diseases of the circulatory system, and the most common diagnoses for hospice care patients were malignant neoplasms. About a third of the home health care patients and about a fifth of the hospice care patients had a surgical or diagnostic procedure related to their admission for care. The most common procedures for home health care patients were malignant neoplasms on the musculoskeletal system, and for hospice care patients they were miscellaneous diagnostic and therapeutic procedures.

Keywords: National Home and Hospice Care Survey • long-term care • current patients • discharges • diagnoses • surgical and diagnostic procedures

### Introduction

This report presents statistics on an estimated 2.5 million current patients and 8.2 million discharges from 13,500

home health and hospice care agencies in the United States and is the fourth in a series of reports on home health and hospice care agencies and the people

they serve (1-3). The data presented were collected through the 1996 National Home and Hospice Care Survey (NHHCS), a nationwide sample survey that was first conducted by the National Center for Health Statistics in 1992 (4-7). The NHHCS, a segment of the long-term care component of the National Health Care Survey (8), was developed in response to the rapid growth in the number of home health and hospice care agencies throughout the United States. This growth led to a need for information on the availability and utilization of services offered by these agencies. The NHHCS collects information about the agencies that provide hospice and home health care services, their current patients, and their discharges.

As shown in table 1, the number of agencies providing home health and hospice care services in the United States rose from 8,000 in 1992 to 13,500 in 1996. These agencies provided care to 1.3 million patients at the time of the survey in 1992, 2.0 million in 1994, and 2.5 million in 1996. There were 3.3 million discharges from these agencies in 1991–92, 5.6 million in 1993–94, and 8.2 million in 1995–96.



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Table 1. Number of home health and hospice care agencies, current patients, and discharges: United States, 1992, 1994, and 1996

Type of estimate	1992	1994	1996
Agencies	8,000	10,900	13,500
Current patients	1,284,200	1,950,400	2,486,800
Discharges	3,273,300	5,600,200	8,168,900

Home health agencies and hospices are usually defined in terms of the type of care they provide. Home health care is provided to individuals and families in their place of residence to promote, maintain, or restore health or to maximize the level of independence while minimizing the effects of disability and illness, including terminal illness. Hospice care is defined as a program of palliative and supportive care services that provides physical, psychological, social, and spiritual care for dying persons, their families, and other loved ones. Hospice services, which are available in both the home and inpatient settings, may be provided by home health care agencies as well as by hospices.

Although this report provides some information about the agencies that provide home health and hospice care services, the focus of the report is the patients receiving the care. Patient estimates for current patients and for discharges are presented by agency and by demographic and diagnostic characteristics.

### Methods

The 1,200 agencies included in the 1996 survey were selected from a universe of 16,700 agencies classified as agencies providing home health and hospice care. The universe was obtained from the 1991 National Health Provider Inventory (NHPI), updated to 1996 using the Agency Reporting System (9–11).

Data collection for the 1996 NHHCS was conducted between July and December 1996. Data were collected on a sample of current patients and of discharges from a representative sample of home health and hospice care agencies. Patient data were obtained from the medical records of the sampled patients and discharges. An overview of the data collection methods and estimation procedures for the 1996 NHHCS is in the Technical Notes.

Statistics presented in this report are estimated numbers and percents of home health and hospice care agencies, current patients, and discharges by selected characteristics. Current patients are patients who were on the rolls of the agency as of midnight on the day immediately before the date of the survey. Discharges refer to patients who had been removed from the rolls of the agency (including those whose care ended because of death) during a designated month (from October 1995–September 1996) that was randomly selected for each agency.

Agency characteristics examined include ownership, Medicare and Medicaid certification, affiliation, and location. Ownership refers to the type of organization that controlled and operated the agency at the time of the survey. Affiliation refers to the agency's affiliation with a hospital, a group of agencies (such as a chain), a nursing home, or a health maintenance organization. Not all agencies are affiliated, and some may have other types of affiliation that are not included. Two types of location are reported: geographic region and metropolitan statistical area. Because of the dynamic nature of this area of the health care industry, an agency may provide home health care services, hospice care services, or both. Moreover, an agency may change its focus as the demand for different types of care changes. For this reason, data are not presented by type of agency, but by the type of care the patients were provided.

Patient information included in this report consists of selected demographic characteristics (sex, age, race, and marital status), diagnoses at admission, and surgical or diagnostic procedures related to the patient's admission to the agency. Diagnoses and procedures are coded according to the *International* 

### Classification of Diseases, 9th Revision, Clinical Modification (12).

The tests of significance used to test all comparisons mentioned in this report are based on the Bonferroni multiple comparisons using the *z*-test with an overall 0.05 level of significance. Not all differences were tested, so lack of comment in the text does not mean that the difference was not statistically significant. Estimates in this report have been rounded to the nearest hundred. Therefore, detailed figures may not add to totals. Percents were calculated using unrounded figures and may not agree with computations made from the rounded data.

### Results

### **Agency Characteristics**

In 1996, there were an estimated 13,500 home health and hospice care agencies providing services to patients in the United States (table 2). Thirtyfour percent were owned by voluntary nonprofit organizations, 54 percent were proprietary or privately owned agencies, and 11 percent were owned by government and other agencies. Eighty-eight percent of the agencies were certified under Medicare (83 percent as a home health agency and 21 percent as a hospice), and 86 percent were certified under Medicaid (81 percent as a home health agency and 19 percent as a hospice). Eight percent of the agencies were not certified by either Medicare or Medicaid. Almost half—48 percent—of the agencies were part of a group or chain of agencies and 27 percent were operated by a hospital.

Forty percent of the agencies were located in the South region, 27 percent were in the Midwest, 18 percent were in the West, and 15 percent were in the Northeast. Two-thirds of the agencies were located in a metropolitan statistical area.

Table 3 provides information on current patients served by these agencies by the type of service provided (home health care or hospice care). At the time of the survey, there were a total of 2.5 million patients being served: 2.4 million (98 percent) were receiving home health care services and 59,400

# Table 2. Number and percent distribution of home health and hospice care agencies by selected agency characteristics: United States, 1996

Agency characteristic	Number	Percent distribution
All agencies	13,500	100.0
Ownership		
Proprietary	7,400	54.3
Voluntary nonprofit	4,600	34.3
Government and other	1,500	11.4
Certification		
Certified by Medicare <sup>1</sup>	11,900	88.2
As a home health agency	11,300	83.4
As a hospice	2,900	21.3
Certified by Medicaid <sup>1</sup>	11,600	86.0
As a home health agency	11,000	81.4
As a hospice	2,600	18.9
Not certified	1,100	8.1
Affiliation		
Affiliated <sup>1,2</sup>	8,500	62.9
Part of group or chain	6,400	47.5
Operated by a hospital	3,700	27.3
Not affiliated	5,000	37.1
Geographic region		
Northeast	2,000	15.0
Midwest	3,700	27.0
South	5,400	40.1
West	2,400	18.0
Location of agency		
In a metropolitan statistical area	9,100	67.5
Not in a metropolitan statistical area	4,400	32.5

<sup>1</sup>Numbers may add to more than totals since an agency may be listed in more than one category.

<sup>2</sup>Includes a small number of agencies that are operated by a nursing home or a health maintenance organization.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

(2 percent) were receiving hospice care services.

The ownership of agencies serving home health care patients differed significantly from those serving hospice care patients. Almost half of the home health care patients received care from voluntary nonprofit agencies and 42 percent were served by privately owned or proprietary agencies. On the other hand, the majority—85 percent —of hospice care patients were served by voluntary nonprofit agencies and 11 percent were served by proprietary agencies.

The majority of both home health and hospice care patients received services from agencies that were certified by Medicare and/or Medicaid. Forty-two percent were served by an agency that was part of a group or chain of agencies, and about a third were served by a hospital-affiliated agency. Although a larger percent of home health care patients than of hospice care patients were served by a chain or a hospital-affiliated agency, the differences are not significant.

Of all the current patients, 33 percent were served by agencies in the South, 27 percent by agencies in the Midwest, 26 percent by agencies in the Northeast, and 14 percent by agencies in the West. Agencies that were located in an MSA served 80 percent of the patients.

The number and percent of discharges from home health and hospice care agencies are shown in table 4. As with current patients, the majority (60 percent) of the home health care discharges were from voluntary nonprofit agencies and 32 percent were from privately owned or proprietary agencies. The distribution of discharges from hospice care was also similar to that of current patients—85 percent were discharged from voluntary nonprofit agencies and 13 percent by proprietary agencies. The majority of the discharges were from an agency that was certified under Medicare and/or Medicaid. Hospital-affiliated agencies had 47 percent of the discharges and agencies that were part of a group or chain of agencies had 39 percent of the discharges.

Of all the discharges, 30 percent were from agencies in the Northeast region, 25 percent were from agencies in the South, 24 percent were from agencies in the West, and 21 percent were from agencies in the Midwest. Eighty-eight percent of the discharges were from agencies located in an MSA.

#### **Demographic Characteristics**

Table 5 shows the number and percent of current home and hospice care patients by selected demographic characteristics. Two-thirds of the home health care patients and over half of the hospice care patients were female. Seventy-two percent of the patients receiving home health care services were elderly (65 years of age or older), 65 percent were white, 29 percent were married, and 35 percent were widowed. Of the hospice care patients, 78 percent were elderly, 84 percent were white, 44 percent were married, and 32 percent were widowed.

Table 6 presents the demographic information for home health and hospice care discharges. Sixty-four percent of the home health care discharges and 50 percent of the hospice care discharges were female. Two-thirds of the patients discharged from home health care services were elderly, 63 percent were white, 37 percent were married, and 25 percent were widowed. Of the hospice care discharges, 68 percent were elderly, 79 percent were white, 48 percent were married, and 29 percent were widowed.

Figure 1 shows that the reason for discharge from home health and from hospice care are very different. Almost 80 percent of the home health care patients were discharged because the services were no longer needed. Twenty-nine percent were discharged because they had recovered or their condition was stabilized, and 28 percent were discharged because their care was

# Table 3. Number and percent distribution of home health and hospice care current patients by selected agency characteristics, according to type of care received: United States, 1996

		Type of care			Type of care	
Agency characteristic	All patients	Home health	Hospice	All patients	Home health	Hospice
		Number			Percent distribution	
Total	2,486,800	2,427,500	59,400	100.0	100.0	100.0
Ownership						
Proprietary	1,017,500	1,010,900	6,500	40.9	41.6	11.0
Voluntary nonprofit	1,240,100	1,190,000	50,200	49.9	49.0	84.6
Government and other	229,200	226,600	*2,600	9.2	9.3	*4.4
Certification						
Certified by Medicare <sup>1</sup>	2,299,800	2,242,300	57,500	92.5	92.4	96.8
As a home health agency	2,259,300	2,229,700	29,600	90.9	91.9	49.8
As a hospice	652,100	596,000	56,100	26.2	24.6	94.4
Certified by Medicaid <sup>1</sup>	2,326,700	2,271,000	55,700	93.6	93.6	93.8
As a home health agency	2,293,700	2,264,800	28,800	92.2	93.3	48.6
As a hospice	579,200	526,600	52,600	23.3	21.7	88.5
Not certified	*104,300	*102,900	1,400	*4.2	*4.2	2.3
Affiliation						
Affiliated <sup>1,2</sup>	1,570,200	1,540,300	29,900	63.1	63.5	50.4
Part of group or chain	1,053,000	1,032,000	21,000	42.3	42.5	35.4
Operated by a hospital	844,900	828,600	16,300	34.0	34.1	27.4
Not affiliated	916,700	887,200	29,500	36.9	36.5	49.6
Geographic region						
Northeast	651,700	642,700	8,900	26.2	26.5	15.0
Midwest	668,100	646,900	21,300	26.9	26.6	35.9
South	811,300	792,300	19,000	32.6	32.6	32.0
Nest	355,700	345,600	10,100	14.3	14.2	17.1
Location of agency						
n a metropolitan statistical area	1,999,600	1,951,400	48,100	80.4	80.4	81.1
Not in a metropolitan statistical area	487,300	476,000	11,200	19.6	19.6	18.9

\* Figure does not meet standard of reliability or precision.

<sup>1</sup>Numbers may add to more than totals since an agency may be listed in more than one category.

<sup>2</sup>Includes a small number of patients that were served by agencies that are operated by a nursing home or health maintenance organization.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

being provided from another source (family or friends, transferred to another agency, or admitted to hospital inpatient services or a nursing home). Patients may also be enrolled in home health agencies in order to learn how to care for themselves. These patients have not recovered from their condition, but have learned how to cope with it so they can live independently. Twenty-one percent of the discharges no longer required services primarily for this reason. For hospice care patients, the reason for discharge for the majority (82 percent) was death, while 10 percent were discharged because their care was being provided by another source.

#### **Diagnoses and Procedures**

Information on the diagnoses of home health and hospice care patients

was collected through the 1996 NHHCS. Up to six admission diagnoses were recorded for each patient. The number and percent of primary and all-listed diagnoses at admission are shown in table 7 for current patients, and similar information for discharges are shown in table 8. Home health care current patients had an average of 3.0 diagnoses per patient; for home health care discharges, there was an average of 2.7 diagnoses at admission. The average number of diagnoses at admission for hospice care patients was 2.5 for current patients and 2.2 for discharges.

The most common primary diagnosis for home health care current patients was a disease of the circulatory system—most often some form of heart disease. Other frequent primary diagnoses were diseases of the musculoskeletal system and connective tissue; diabetes mellitus; symptoms, signs, and ill-defined conditions; diseases of the respiratory system; and injury and poisoning. When looking at all-listed diagnoses, these same conditions also occurred most often. In addition, essential hypertension and diseases of the nervous system and sense organs were frequently listed secondary diagnoses.

As with current patients, the most common primary diagnosis for home health care discharges was a disease of the circulatory system—again, most often heart disease. Other frequent primary diagnoses were injury and poisoning (especially fractures, at 6 percent); malignant neoplasms;

# Table 4. Number and percent distribution of home health and hospice care discharges by selected agency characteristics, according to type of care received: United States, 1995–96

		Type of care			Type of care	
Agency characteristic	All discharges	Home health	Hospice	All discharges	Home health	Hospice
	Number				Percent distribution	
Total	8,168,900	7,775,700	393,200	100.0	100.0	100.0
Ownership						
Proprietary	2,541,000	2,488,600	52,400	31.1	32.0	13.3
Voluntary nonprofit	5,022,900	4,688,000	334,900	61.5	60.3	85.2
Government and other	605,100	599,200	*5,900	7.4	7.7	*1.5
Certification						
Certified by Medicare <sup>1</sup>	7,781,500	7,406,600	374,900	95.3	95.3	95.3
As a home health agency	7,573,200	7,370,500	202,700	92.7	94.8	51.6
As a hospice	2,477,700	2,119,100	358,600	30.3	27.3	91.2
Certified by Medicaid <sup>1</sup>	7,817,600	7,446,800	370,800	95.7	95.8	94.3
As a home health agency	7,642,400	7,430,100	212,300	93.6	95.6	54.0
As a hospice	2,265,300	1,932,000	333,300	27.7	24.8	84.8
Not certified	*181,100	*173,300	*7,800	*2.2	*2.2	*2.0
Affiliation						
Affiliated <sup>1,2</sup>	5,453,900	5,236,600	217,300	66.8	67.3	55.3
Part of a group or chain	3,145,500	3,012,700	132,700	38.5	38.7	33.8
Operated by a hospital	3,832,000	3,708,300	123,700	46.9	47.7	31.5
Not affiliated	2,715,000	2,539,100	175,900	33.2	32.7	44.7
Geographic region						
Northeast	2,422,700	2,351,100	71,700	29.7	30.2	18.2
Midwest	1,723,300	1,624,300	99,000	21.1	20.9	25.2
South	2,033,700	1,882,500	151,200	24.9	24.2	38.5
West	1,989,200	1,917,800	71,400	24.4	24.7	18.1
Location of agency						
In a metropolitan statistical area	7,216,800	6,885,600	331,300	88.3	88.6	84.2
Not in a metropolitan statistical area	952,100	890,100	62,000	11.7	11.4	15.8

\* Figure does not meet standard of reliability or precision.

<sup>1</sup>Numbers may add to more than totals since an agency may be listed in more than one category.

<sup>2</sup>Includes a small number of discharges that were discharged from agencies that are operated by a nursing home or health maintenance organization.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

diseases of the musculoskeletal system and connective tissue (especially arthropathies and related conditions, 4 percent); and diseases of the respiratory system (most often chronic obstructive pulmonary disease and allied conditions, 4 percent). When looking at all-listed diagnoses for home health care discharges, the most common diagnoses were diseases of the circulatory system, especially heart disease and essential hypertension. Other frequently listed secondary diagnoses were endocrine, nutritional, and metabolic diseases and immunity disorders, especially diabetes mellitus; and symptoms, signs, and ill-defined conditions.

The most common primary diagnosis for hospice care current patients was a malignant neoplasm (58 percent). Other frequent primary diagnoses included diseases of the circulatory system, diseases of the nervous system and sense organs, and diseases of the respiratory system. When looking at all-listed diagnoses, these same conditions also occurred frequently. In addition, endocrine, nutritional, and metabolic diseases and immunity disorders were frequently listed.

The most frequent primary admission diagnoses for hospice care discharges were malignant neoplasms (70 percent), diseases of the circulatory system (10 percent), and diseases of the respiratory system (5 percent). These were also the most common all-listed diagnoses.

In 1996, the NHHCS began collecting information on surgical or diagnostic procedures that were related to the patient's admission for care. Up to two procedures were recorded. Thirty-one percent, or 744,300 of the 2.4 million current home health care patients, had a surgical or diagnostic procedure related to their admission (table 9). These patients had 833,800 procedures, or an average of 1.1 procedures per patient. The most frequently performed procedures were operations on the musculoskeletal system, operations on the cardiovascular system, and miscellaneous diagnostic and therapeutic procedures.

Twenty-three percent, or 13,600 of the 59,400 hospice care current patients, had a procedure related to their

# Table 5. Number and percent distribution of home health and hospice care current patients by age, sex, race, and marital status, according to type of care received: United States, 1996

	Type of care				Type of care	
Patient characteristic	All patients	Home health	Hospice	All patients	Home health	Hospice
		Number			Percent distribution	
Total	2,486,800	2,427,500	59,400	100.0	100.0	100.0
Age at admission						
Under 45 years	351,700	347,400	4,300	14.1	14.3	7.3
45–54 years	132,900	130,200	2,700	5.3	5.4	4.5
55–64 years	193,800	187,600	6,100	7.8	7.7	10.3
65 years and over	1,799,500	1,753,400	46,100	72.4	72.2	77.7
65–69 years	218,600	213,600	5,000	8.8	8.8	8.4
70–74 years	323,900	314,300	9,600	13.0	12.9	16.2
75–79 years	426,000	416,200	9,800	17.1	17.1	16.6
80–84 years	413,400	404,300	9,100	16.6	16.7	15.2
85 years and over	417,600	404,900	12,700	16.8	16.7	21.3
Unknown	*	*	*	*	*	*
Sex						
Male	825,300	798,700	26,600	33.2	32.9	44.9
Female	1,661,200	1,628,500	32,700	66.8	67.1	55.1
Jnknown	*	*	*	*	*	*
Race						
White	1,629,000	1,579,300	49,700	65.5	65.1	83.7
Black and other	342,300	336,600	5,700	13.8	13.9	9.6
Black	297,400	292,400	4,900	12.0	12.0	8.3
Jnknown	515,600	511,500	4,000	20.7	21.1	6.7
Current marital status						
Married	729,000	703,000	25,900	29.3	29.0	43.7
Nidowed	876,700	857,600	19,100	35.3	35.3	32.2
Divorced or separated	105,700	100,100	5,500	4.2	4.1	9.3
Single or never married	460,200	455,100	5,000	18.5	18.7	8.5
Unknown	315,400	311,600	*3,800	12.7	12.8	*6.3

\* Figure does not meet standard of reliability or precision.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

admission for care (table 9). These patients had 18,200 procedures, or an average of 1.3 procedures per patient. The most frequently performed procedures were miscellaneous diagnostic and therapeutic procedures and operations on the digestive system.

Information on discharges with a procedure related to admission is shown in table 10. Thirty-seven percent (2.9 million) of the 7.8 million discharges from home health care had a procedure. These discharges had 3,362,100 procedures, or an average of 1.2 procedures per discharge. The most common procedures were operations on the musculoskeletal system, operations on the cardiovascular system, and operations on the digestive system.

Hospice care discharges were similar to current hospice care patients

regarding surgical and diagnostic procedures. That is, 21 percent (84,300) of the 393,200 discharges had an average of 1.3 procedures per discharge, for a total of 113,500 procedures. As with current hospice care patients, the most frequently reported procedures were miscellaneous diagnostic and therapeutic procedures and operations on the digestive system.

#### Summary and Discussion

The effort to control health care costs is one reason for the massive growth in the home health care industry. Home health care has reduced the number of hospital days in both terminally ill and nonterminally ill patients (13). Moreover, the increasing availability and use of home health care has mirrored the decreasing nursing home occupancy rate (14) and the decreasing average length of stay in nursing homes (15). Because the average cost of a home care visit is considerably less than a day in a hospital or in a skilled long-term care facility (16), the growth in the home health care industry can be seen as a way to reduce health care costs. The steady increase in the elderly Medicare population of approximately 1.9 percent annually over the past decade is another major factor in the growth of the home health care industry (17). The use of the Medicare home health care benefit has increased dramatically since 1990; in 1995 Medicare home health care expenditures were almost 9 percent of total Medicare expenditures (18). The preference of the majority of the everincreasing elderly population to recover

		Type of care			Type of	care
Discharge characteristic	All discharges	Home health	Hospice	All - discharges	Home health	Hospice
		Number			Percent distribution	
- Total	8,168,900	7,775,700	393,200	100.0	100.0	100.0
Age at admission						
Jnder 45 years	1,549,800	1,518,100	31,700	19.0	19.5	8.1
45–54 years	493,700	462,600	31,200	6.0	5.9	7.9
5–64 years	710,500	652,400	58,200	8.7	8.4	14.8
5 years and over	5,402,700	5,137,500	265,200	66.1	66.1	67.5
65–69 years	874,500	840,400	34,100	10.7	10.8	8.7
70–74 years	1,085,900	1,024,600	61,300	13.3	13.2	15.6
75–79 years	1,024,400	967,400	57,000	12.5	12.4	14.5
80–84 years	1,152,600	1,104,300	48,300	14.1	14.2	12.3
85 years and over	1,265,400	1,200,900	64,500	15.5	15.4	16.4
Inknown	*	*	*	*	*	*
Sex						
1ale	3,038,000	2,840,300	197,700	37.2	36.5	50.3
emale	5,131,000	4,935,400	195,500	62.8	63.5	49.7
Race						
Vhite	5,190,800	4,880,500	310,300	63.5	62.8	78.9
lack and other	825,400	776,900	48,500	10.1	10.0	12.3
Black	620,200	576,300	43,900	7.6	7.4	11.2
Inknown	2,152,800	2,118,300	34,500	26.4	27.2	8.8
Marital status at discharge						
1arried	3,064,700	2,874,400	190,300	37.5	37.0	48.4
/idowed	2,029,800	1,914,100	115,600	24.8	24.6	29.4
vivorced or separated.	411,400	385,900	25,500	5.0	5.0	6.5
Single or never married	1,470,400	1,433,900	36,500	18.0	18.4	9.3
Jnknown	1,192,600	1,167,300	25,300	14.6	15.0	6.4

\* Figure does not meet standard of reliability or precision.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

from illness at home rather than in a hospital or nursing home is probably the major reason for this record growth.

Data from the NHHCS indicate that between 1992 and 1996, there was a 70 percent increase in the number of agencies providing home health and hospice care services in the United States. During this time, the number of current patients being served by these agencies increased 90 percent and the number of discharges more than doubled.

In 1996, an estimated 13,500 home health and hospice care agencies were providing services to 2.5 million patients in the United States and had 8.2 million discharges from care during the year. About a third of the agencies were owned by voluntary nonprofit organizations. These agencies served half of the patients and had 62 percent of the discharges. Almost 9 out of 10 of the agencies were certified under Medicare. However, about 30 percent of the patients and discharges were under 65 years old, indicating that these agencies provide services to a substantial number of the nonelderly as well as the elderly population.

The typical patient was an elderly white woman who was either married or widowed and was receiving home health care. Four out of 5 of the home health care patients were discharged from care because they no longer needed services. This included those who had recovered or whose condition had stabilized. Four out of 5 of the hospice care patients, on the other hand, were discharged because of death.

Comorbidity was common among both home health and hospice care patients—3 out of 4 of the home health care patients and discharges and 2 out of 3 of the hospice care patients and discharges had two or more diagnoses when they were admitted to the agency. Diseases of the circulatory system, diseases of the musculoskeletal system, and injury and poisoning accounted for over 40 percent of the diagnoses of home health care patients and discharges, while 60 percent of the hospice care patients and discharges had malignant neoplasms.

About a third of the current patients and discharges who received home health care had a surgical or diagnostic procedure related to their admission. Operations on the musculoskeletal system, operations on the cardiovascular system, and miscellaneous diagnostic and therapeutic procedures accounted for 2 out of 3 of the procedures performed.

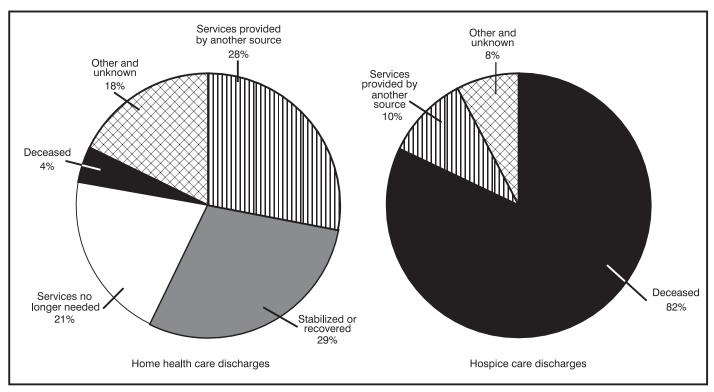


Figure 1. Percent distribution of home health and hospice care discharges by reason for discharge: United States, 1995–96

Over one-fifth of the hospice care current patients and discharges had a procedure related to their admission for care. Miscellaneous diagnostic and therapeutic procedures and operations on the digestive system accounted for 9 out of 10 of the procedures for current patients and 8 out of 10 for discharges.

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# Table 7. Number and percent distribution of home health and hospice care current patients by first-listed and all-listed diagnoses at admission, according to type of care received: United States, 1996

	Primary diagnosis			All-listed diagnoses			
		Туре с	f care		Туре с	Type of care	
Admission diagnosis and ICD-9-CM code <sup>1</sup>	All patients	Home health	Hospice	All patients	Home health	Hospice	
	patiento	nealth	Tiospiec	patients	nealth	1030100	
				nber			
Fotal	2,486,800	2,427,500	59,400	7,138,400	7,171,500	146,900	
nfectious and parasitic diseases	*19,200	*17,100	*2,100	52,800	48,300	4,500	
Human immunodeficiency virus (HIV) disease	*5,100	*	*2,000	7,200	*	*2,000	
Neoplasms	162,100	126,800	35,400	278,300	221,800	56,500	
Malignant neoplasms	149,600 30,100	115,000	34,600 9,400	259,000	203,700	55,300 11,600	
Malignant neoplasm of trachea, bronchus, and lung	13,200	*	3,400 3,700	44,000 18,600	*32,400 *14,700	3,900	
Malignant neoplasm of prostate	10,700	*	3,900	18,600	*14,400	4,300	
Endocrine, nutritional, and metabolic diseases and immunity disorders. 240–279	247,400	247,200	*	802,500	795,100	7,300	
Diabetes mellitus	203,700	203,600	*	548,300	545,200	3,200	
Diseases of the blood and blood-forming organs	58,800	58,500	*	189,800	188,000	*1,900	
Aental disorders	84,000	82,500	*	304,200	298,800	5,400	
Diseases of the nervous system and sense organs	144,100	139,300	4,800	462,400	453,700	8,800	
Diseases of the circulatory system	623,000	615,700	7,300	2,099,500	2,071,000	28,600	
Essential hypertension	107,500	107,500	*	604,100	599,800	4,200	
Heart disease	267,700	262,800	4,900	884,400	868,400	16,000	
Diseases of the respiratory system	190,500	186,200	4,400	463,500	453,700	9,800	
Diseases of the digestive system	70,000	68,400	*1,500	263,100	258,600	4,500	
Diseases of the genitourinary system	57,000	56,600	*	190,400	188,100	*2,400	
Diseases of the skin and subcutaneous tissue	85,900	85,900	*	170,000	169,400		
Diseases of the musculoskeletal system and connective tissue 710–739	211,800	211,800	*	649,800	645,500	4,300	
Symptoms, signs, and ill-defined conditions	196,100	194,800	*1,300	690,700	684,800	5,900	
njury and poisoning	166,800	166,800	*	292,800	291,800	,	
Supplementary classification	88,500	88,400	*	286,000	280,700	5,300	
All other diagnoses	62,900 *	62,800 *	*	122,500	122,300	r I	
			Descent	· · ·			
Fotal	100.0	100.0	100.0	listribution 100.0	100.0	100.0	
nfectious and parasitic diseases	*0.8	*0.7	*3.5	0.7	0.7	3.1	
Human immunodeficiency virus (HIV) disease	*0.2		*3.3	0.1		*1.4	
Neoplasms	6.5	5.2	59.6	3.9	3.1	38.4	
Malignant neoplasms	6.0	4.7	58.3	3.6	2.8	37.6	
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3 Malignant neoplasm of breast 174–175,198.81	1.2 0.5	*	15.8 6.2	0.6 0.3	*0.5 *0.2	7.9 2.7	
Malignant neoplasm of prostate	0.5	*	6.6	0.3	*0.2	2.9	
Indocrine, nutritional, and metabolic diseases and immunity disorders. 240–279	9.9	10.2	*	11.2	11.1	5.0	
Diabetes mellitus	8.2	8.4	*	7.7	7.6	2.2	
Diseases of the blood and blood-forming organs	2.4	2.4	*	2.7	2.6	*1.3	
Mental disorders         290–319	3.4	3.4	*	4.3	4.2	3.7	
Diseases of the nervous system and sense organs	5.8	5.7	8.1	6.5	6.3	6.0	
Diseases of the circulatory system	25.1	25.4	12.3	29.4	28.9	19.4	
Essential hypertension	4.3	4.4	*	8.5	8.4	2.9	
Heart disease	10.8	10.8	8.3	12.4	12.1	10.9	
biseases of the respiratory system	7.7	7.7	7.3	6.5	6.3	6.	
Diseases of the digestive system	2.8	2.8	*2.5	3.7	3.6	3.	
Diseases of the genitourinary system	2.3	2.3	*	2.7	2.6	*1.6	
Diseases of the skin and subcutaneous tissue	3.5	3.5	*	2.4	2.4		
Diseases of the musculoskeletal system and connective tissue 710–739	8.5	8.7	*	9.1	9.0	2.9	
Symptoms, signs, and ill-defined conditions	7.9	8.0	*2.2	9.7	9.5	4.0	
njury and poisoning	6.7	6.9	*	4.1	4.1	,	
Supplementary classification	3.6	3.6	*	4.0	3.9	3.6	
All other diagnoses	2.5	2.6	*	1.7	1.7	*	
Jnknown or no diagnosis.	*	*	_				

 $^{\star}$  Figure does not meet standard of reliability or precision.

- Quantity zero.

... Category not applicable.

<sup>1</sup>Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD–9–CM) (12).

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

# Table 8. Number and percent distribution of home health and hospice care discharges by first-listed and all-listed diagnoses at admission, according to type of care received: United States, 1995–96

	Primary diagnosis			All-	listed diagnose	)S	
		Туре о	f care		Type of	care	
Admission diagnosis and ICD-9-CM code <sup>1</sup>	All discharges	Home health	Hospice	All discharges	Home health	Hospice	
			Nu	mber			
Total	8,168,900	7,775,700	393,200	21,953,900	21,089,100	864,80	
nfectious and parasitic diseases	166,400	*151,200	*15,200	385,700	362,500	*23,20	
Human immunodeficiency virus (HIV) disease	*36,700	*	*11,500	*57,200	*	*13,80	
Neoplasms.         140–239	948,200	670,700	277,500	1,661,300	1,228,800	432,50	
Malignant neoplasms	923,000	649,000	274,000	1,560,600	1,131,700	428,90	
Malignant neoplasm of trachea, bronchus, and lung	127,800	*41,700	86,000	213,800	110,000	103,80	
Malignant neoplasm of breast	*175,600	*	17,300	*233,300	*204,600	18,70	
Malignant neoplasm of prostate	34,600	*	12,900	*82,700	*67,700	15,00	
Endocrine, nutritional, and metabolic diseases and immunity disorders 240–279	456,200	454,000	*	1,912,300	1,884,600	27,60	
Diabetes mellitus	333,400	332,200	*	1,256,600	1,241,700	14,80	
Diseases of the blood and blood-forming organs	*130,500	*129,700	*	488,500	482,800	*5,70	
Mental disorders	138,800	133,800	*	728,400	707,000	21,40	
Diseases of the nervous system and sense organs	271,700	259,200	*12,500	870,800	836,300	34,50	
Diseases of the circulatory system	1,776,900	1,739,300	37,600	5,779,300	5,631,000	148,30	
Essential hypertension	260,700	260,400	*	1,717,400	1,691,600	25.80	
Heart disease	999,100	972,100	26,900	2,884,400	2,810,300	74,10	
Diseases of the respiratory system	639,200	618,700	20,500	1,369,200	1,315,500	53,60	
Diseases of the digestive system	314,100	310,800	*	973,700	958,200	15,50	
Diseases of the genitourinary system	181,300	172,000	*9,300	711,100	692,600	18,50	
Diseases of the skin and subcutaneous tissue	190,100	189,400	*	421,800	417,200		
Diseases of the musculoskeletal system and connective tissue	629,200	628,300	*	1,617,600	1,600,700	*16,80	
Symptoms, signs, and ill-defined conditions	578,000	575,500	*	1,853,900	1,814,800	39,00	
njury and poisoning	974,400	974,300	*	1,343,800	1,338,200		
Supplementary classification	565,500	565,200	*	1,420,200	1,407,200	13,10	
All other diagnoses	174,900	171,200	*	416,500	411,700		
Jnknown or no diagnosis.	*	*	*				
			Percent	distribution			
Fotal	100.0	100.0	100.0	100.0	100.0	100.	
nfectious and parasitic diseases	2.0	*1.9	*3.9	1.8	1.7	*2.	
Human immunodeficiency virus (HIV) disease	*0.4	*	*2.9	*0.3	*	*1.0	
Neoplasms	11.6	8.6	70.6	7.6	5.8	50.	
Malignant neoplasms	11.3	8.3	69.7	7.1	5.4	49.	
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3	1.6	*0.5	21.9	1.0	0.5	12.	
Malignant neoplasm of breast	*2.1	*	4.4	*1.0	*1.0	2.	
Malignant neoplasm of prostate	0.4	*	3.3	*0.4	*0.3	1.	
Endocrine, nutritional, and metabolic diseases and immunity disorders 240–279	5.6	5.8	*	8.7	8.9	3.	
Diabetes mellitus	4.1	4.3	*	5.7	5.9	1.	
Diseases of the blood and blood-forming organs	*1.6	*1.7	*	2.2	2.3	*0.	
Vental disorders	1.7	1.7	*	3.3	3.4	2.	
Diseases of the nervous system and sense organs	3.3	3.3	*3.2	4.0	4.0	4.	
Diseases of the circulatory system	21.8	22.4	9.6	26.3	26.7	17.	
Essential hypertension	3.2	3.3	*	7.8	8.0	3.	
Heart disease	12.2	12.5	6.8	13.1	13.3	8.	
Diseases of the respiratory system	7.8	8.0	5.2	6.2	6.2	6.	
Diseases of the digestive system	3.8	4.0	*	4.4	4.5	1.	
Diseases of the genitourinary system	2.2	2.2	*2.4	3.2	3.3	2.	
Diseases of the skin and subcutaneous tissue	2.3	2.4	*	1.9	2.0	2.	
Diseases of the musculoskeletal system and connective tissue 710–739	7.7	8.1	*	7.4	7.6	*1.	
Symptoms, signs, and ill-defined conditions	7.1	7.4	*	8.4	8.6	4.	
njury and poisoning	11.9	12.5	*	6.1	6.3	·	
Supplementary classification	6.9	7.3	*	6.5	6.7	1.	
All other diagnoses	2.1	2.2	*	1.9	2.0		

\* Figure does not meet standard of reliability or precision.

... Category not applicable.

<sup>1</sup>Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD–9–CM) (12).

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

Table 9. Number and percent of current patients that had a surgical or diagnostic procedure related to admission for home health and hospice care by type of procedure and type of care received: United States, 1996

		Туре	of care
Procedure and ICD-9-CM code <sup>1</sup>	Total	Home health	Hospice
		Number	
Patients with a procedure	757,900	744,300	13,600
		Percent	
Operations on the respiratory system	2.0	*1.8	10.1
Operations on the cardiovascular system	22.1	22.4	*
Operations on the heart and pericardium	10.1	10.2	*
Operations on the digestive system	15.2	15.1	19.9
Operations on the intestines	4.9	4.8	*7.3
Operations on the musculoskeletal system	26.1	26.6	*
Reduction of fracture	7.2	7.3	*
Repair or replacement of hip	4.4	*4.4	*
Repair or replacement of knee	*6.1	*6.2	-
Operations on the integumentary system	6.7	6.6	*10.7
Miscellaneous diagnostic and therapeutic procedures	21.5	20.6	72.2
Diagnostic radiology and related techniques and radioisotope scan and function study 87-88,92.0-92.1	6.8	6.2	*38.9
Microscopic examination (laboratory tests)	6.2	6.2	*8.5
Therapeutic radiology and chemotherapy 92.2,99.25	*1.7	*	13.9
All other procedures	18.9	19.0	13.7

\* Figure does not meet standard of reliability or precision.

- Quantity zero.

<sup>1</sup>Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) (12).

NOTES: Figures may add to more than totals because a patient may have had more than one procedure. Percents are based on the unrounded numbers.

# Table 10. Number and percent of discharges that had a surgical or diagnostic procedure related to admission for home health and hospice care by type of procedure and type of care received: United States, 1995–96

		Туре о	f care
Procedure and ICD-9-CM code <sup>1</sup>	Total	Home health	Hospice
		Number	
Discharges with a procedure	2,978,100	2,893,800	84,300
		Percent	
Operations on the respiratory system	4.9	*4.6	*13.9
Operations on the cardiovascular system	18.8	19.1	*
Operations on the heart and pericardium	12.6	12.9	*
Operations on the digestive system	16.9	16.9	18.1
Operations on the intestines	*9.3	*9.4	*5.7
Operations on the musculoskeletal system	33.3	34.2	*
Reduction of fracture	8.5	8.7	*
Repair or replacement of hip	5.4	5.6	-
Repair or replacement of knee	9.7	10.0	-
Operations on the integumentary system	9.7	9.8	*
Niscellaneous diagnostic and therapeutic procedures	16.6	15.3	*61.4
Diagnostic radiology and related techniques and radioisotope scan and function study 87-88,92.0-92.1	6.5	*6.0	*22.9
Microscopic examination (laboratory tests)	*4.5	*4.0	*21.0
Therapeutic radiology and chemotherapy 92.2,99.25	*1.4	*	*4.8
All other procedures	16.5	16.3	23.3

\* Figure does not meet standard of reliability or precision.

- Quantity zero.

<sup>1</sup>Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) (12).

NOTES: Figures may add to more than totals because a discharge may have had more than one procedure. Percents are based on the unrounded numbers.

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# **Technical Notes**

Although a detailed report has been published about the development and conduct of the survey (4), a brief description of the technical aspects of the NHHCS are presented in this report because some aspects of the survey have changed since that earlier report. The sample design was changed from a three-stage to a two-stage probability design, and the data collection forms were slightly modified. Copies of the data collection forms are included in this report (figures I–III) and a more detailed description of the 1996 NHHCS will be included in a future report (19).

### Scope of the Survey

The sampling frame for the 1996 National Home and Hospice Care Survey (NHHCS) consisted of 16,700 agencies classified as agencies providing home health and hospice care. These agencies were identified through the 1991 National Health Provider Inventory (NHPI), updated to 1996 using the Agency Reporting System (9–11). The NHPI is a comprehensive census of nursing and related care homes, residential care homes, home health care agencies, and hospices. It is conducted periodically by NCHS. The sample consisted of 1,200 agencies selected from this universe.

Only agencies providing home health or hospice care services at the time of the survey were eligible to participate in the 1996 NHHCS. Of the 1,200 agencies in the sample, 1,091 were considered in scope of the survey. Of the 109 out-of-scope agencies, 89 were not providing home health or hospice care services at the time of the survey and 20 were duplicates or had merged with other sampled agencies. Of the in-scope agencies, 1,053 (97 percent) agreed to participate in the 1996 NHHCS, 34 refused to participate, and 3 could not be located.

### Sampling Design

The sample design for the 1996 NHHCS was a stratified two-stage probability design (20). The first stage consisted of selecting a stratified sample of agencies. Each agency was placed into 1 of 24 strata based on type of agency (home health agency, hospice, or mixed agency), metropolitan statistical area (MSA) status (has an MSA code versus has no code), and region (Northeast, Midwest, South, and West). MSA is defined by the U.S. Office of Management and Budget on the basis of the 1980 Census. Within these sampling strata, agencies were arrayed by four types of ownership (profit, nonprofit, government, and unknown), three types of certification status (certified by Medicare and/or Medicaid, not certified, and unknown), State, MSA code, county, zip code, and size (number of current patients).

The second stage of sample selection, sampling of six current patients and six discharges within each agency, was done using a sample selection table to obtain systematic probability samples of current patients and of discharges. The patients and discharges were selected from lists constructed for each agency at the time of the interview. Current patients were defined as those patients who were on the rolls of the agency as of midnight on the day immediately before the date of the survey. Discharges referred to those patients who were discharged from care by the home health agency or hospice during a designated month between October 1995 and September 1996. Discharges that occurred because of death were included.

### **Data Collection and Processing**

Data collection for the 1996 NHHCS began with a letter sent to all sampled agencies informing the administrator of the authorizing legislation, purpose, and content of the survey. Each agency was then contacted by an interviewer to discuss the survey and to arrange an appointment with the administrator.

Three questionnaires and two sampling lists were used to collect the data. The Agency Questionnaire was completed with the administrator or a person designated by the administrator. The interviewer then constructed the Current Patient Sampling List and the Discharged Patient Sampling List. These lists were used to select the sample patients and discharges. Sampling was accomplished by using tables showing sets of sample line numbers for each possible count of current patients and discharges in the agency. Up to six current patients and six discharges were selected.

After the samples had been selected, the Current Patient Questionnaires and the Discharged Patient Questionnaires were completed for each sampled person by interviewing the staff member most familiar with the care provided to the patient. The respondent referred to patient medical and other records as necessary. No patient was interviewed directly.

After the data had been collected, it was converted into machine-readable form by NCHS. Extensive editing was then conducted by computer to ensure that all responses were accurate, consistent, logical, and complete. The medical information recorded on the patient questionnaires was coded by NCHS staff according to the *International Classification of Diseases,* 9th Revision, Clinical Modification (12). Up to 12 diagnostic codes (a maximum of six at admission, and a maximum of six at the time of survey or discharge) and up to two procedure codes were assigned for each sample patient or discharge.

### **Estimation Procedures**

Statistics presented in this report were derived by a multistage estimation procedure (21) that produces essentially unbiased national estimates and has three principal components. The first component, inflation by the reciprocals of the probabilities of sample selection, is the basic inflation weight. This component consists of the inverse of the probability of selecting the agency and the patient or discharge within each agency. The second component, which consists of an adjustment for nonresponse, brings estimates based only on the responding cases up to the level that would have been achieved if all eligible cases had responded. The third component, ratio adjustment to fixed totals, adjusts for over- or undersampling of agencies reported in the sampling frame.

### **Reliability of Estimates**

Because the statistics presented in this report are based on a sample, they will differ somewhat from figures that would have been obtained if a complete census had been taken using the same schedules, instructions, and procedures. The standard error (SE) is primarily a measure of the variability that occurs by chance because a sample, rather than the entire universe, is surveyed. The SE also reflects part of the measurement error, but it does not measure any systematic biases in the data. The chances are about 95 in 100 that an estimate from the sample differs from the value that would be obtained from a complete census by less than twice the SE. However, SE's typically underestimate the true errors of the statistics because they reflect only errors due to sampling.

The SE's used in this report were approximated using SUDAAN software. SUDAAN computes SE's by using a first-order Taylor approximation of the deviation of estimates from their expected values. A description of the software and the approach it uses has been published (22). Although exact SE

#### Table I. Parameters used to compute standard error of numbers by type of estimate

	Parameters		
Type of estimate	A	В	
Agency	0.019261	4.425270	
Home health care			
Current patient	0.115800 0.265410	1,328.865818 4,886.944977	
Hospice care			
Current patient	0.018098 0.026362	97.086178 432.006607	

estimates were used in tests of significance in this report, SE's for aggregate estimates presented may be estimated using the general formula:

$$SE(X) = X \cdot RSE(X)$$

where X is the estimate and RSE(X) is the relative standard error of the estimate. The relative standard error (RSE(X)) may be estimated using the following general formula (23):

$$RSE(X) = \sqrt{A + \frac{B}{X}}$$

where *X* is the estimate and *A* and *B* are the appropriate coefficients from table I.

To approximate the relative standard error (RSE(p)) and the standard error (SE(p)) of a percent *p*, the appropriate value of parameter *B* from table I is used in the following equation:

$$RSE(p) = \sqrt{\frac{B \cdot (1-p)}{p \cdot y}}$$

where  $p = 100 \cdot X/Y$ , X = the numerator of the estimated percent, and Y = the denominator of the estimated percent and

$$SE(p) = p \ge RSE(p)$$

The standard error of a percent is valid only when one of the following conditions is satisfied: the relative standard error of the denominator is 5 percent or less (24) or the relative standard errors of the numerator and the denominator are both 10 percent or less (25).

### **Presentation of Estimates**

Publication of estimates for the NHHCS is based on the RSE of the

estimate and the number of sample records on which the estimate is based (referred to as the sample size). Estimates are not presented in NCHS reports unless a reasonable assumption regarding the probability distribution of the sampling error is possible.

Because of the complex sample design of the NHHCS, the following guidelines are used for presenting the estimates:

If the sample size is less than 30, the value of the estimate is not reported.

If the sample size is 30–59, or if the sample is 60 or more and the RSE is 30 percent or more, the estimate is reported but should not be assumed reliable. This is indicated by an asterisk (\*) in the tables.

If the sample size is 60 or more and the RSE is less than 30 percent, the estimate is reported and is considered reliable.

Bestimung of the service accession of the content of the cont				······	OMB No. 0920-0298: Approval Expires 03/31/97
1a. Agency telephone number         b. Alternate telephone number         c. Alternate telephone number         c. Alternate telephone number         2a. Administrator name         b. Respondent name         Section B - RECORD OF CONTACTS         Day       Date         (b)       (c)         (c)       (c) </th <th colspan="4">(3:29:96) U.S. DEPARTMENT OF COMMERCE BUREAU OF THE CENSUS ACTING AS COLLECTING AGENT FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES U.S. PUBLIC HEALTH SERVICE CENTERS FOR DISEASE CONTROL AND PREVENTION NATIONAL CENTER FOR HEALTH STATISTICS AGENCY QUESTIONNAIRE 1996 NATIONAL HOME AND</th> <th>Is estimated to average 20 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. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to DHHS Reports Clearance Officer; Paperwork Reduction Project (0920-0298) Room 531-H; Hubert H. Humphrey Bldg.; 200 Independence Ave., SW; Washington, DC 20201. Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308(d) of the</th>	(3:29:96) U.S. DEPARTMENT OF COMMERCE BUREAU OF THE CENSUS ACTING AS COLLECTING AGENT FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES U.S. PUBLIC HEALTH SERVICE CENTERS FOR DISEASE CONTROL AND PREVENTION NATIONAL CENTER FOR HEALTH STATISTICS AGENCY QUESTIONNAIRE 1996 NATIONAL HOME AND				Is estimated to average 20 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. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to DHHS Reports Clearance Officer; Paperwork Reduction Project (0920-0298) Room 531-H; Hubert H. Humphrey Bldg.; 200 Independence Ave., SW; Washington, DC 20201. Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308(d) of the
1a. Agency telephone number         b. Alternate telephone number         c. Alternate telephone number         c. Alternate telephone number         2a. Administrator name         b. Respondent name         Section B - RECORD OF CONTACTS         Day       Date         (b)       (c)         (c)       (c) </th <th></th> <th></th> <th></th> <th></th> <th></th>					
c. Alternate telephone number   2a. Administrator name   b. Respondent name     Section 8 - RECORD OF CONTACTS   Day Data   (a) (b)   (c) (c)   (a) (c)   (b) (c)   (c) (c)   (c					-
b. Respondent name         Section B - RECORD OF CONTACTS         Day       Date       Time       Notes         (a)       (b)       (c)       (d)         (a)       0       a.m.       (d)         (a)       a.m.       p.m.       (d)         (b)       Section C - RECORD OF INTERVIEW       Mark (X) appropriate box.       (d)         (c)       Depte interview       (d)       (d)         (c)       Depte interview       (d)       (d)         (c)       Depte interview       (d)       (d)         (c)       Depteration (control No.)       (d)       (d)         (c)       Depteration (control No.)       (d)       (d)         (c)       Importable (control No.)       (d)       (d)         (c)       Depteration (control No.)       (d)       (d)					
Section B - RECORD OF CONTACTS         Day       Date       Time       Notes         (a)       (b)       a.m.       (d)         a.m.       p.m.       a.m.         b.m.       a.m.       p.m.         a.m.       p.m.       a.m.         p.m.       a.m.       p.m.         a.m.       p.m.       a.m.         b.m.       a.m.       p.m.         a.m.       p.m.       a.m.         b.m.       b.m.       b.m.         b.m.<	2a. Admini	istrator name			
Day         Date         Time         Notes           (a)         a.m.         p.m.         (d)           a.m.         p.m.         a.m.           a.m.         p.m.         (d)           a.m.         (d)         (d)           a.m.         (d)         (d)           a.m.         (d)         (d)           a.m.         (d)         (d) <th>b. Respor</th> <th>ndent name</th> <th></th> <th></th> <th></th>	b. Respor	ndent name			
(a)         (b)         (c)         (d)           a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            p.m.         a.m.         p.m.           a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.            a.m.         p.m.		Section B -	RECORD OF CO	NTACTS	
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a.m.       p.m.       a.m.       p.m. <th></th> <th></th> <th>a.m.</th> <th></th> <th></th>			a.m.		
a.m.     p.m.       b. STATUS OF INTERVIEW - Mark (X) appropriate box.     01       Complete interview     02       Partial interview     03       Refusal     04       Otable to locate     05       Socion C - RECORD GE INTERVIEW			a.m.		
a.m.     p.m.       b.ot a Hospice/Home Health Agency       b.ot a Hospice/Home Health Agency       c.add     p.m.       c.b. ot yet in operation       c.b. ot yet in operation       c.b. ot yet in operation       c.b. of duplicate (Control No. of duplicate)       iiiiiiiiiiiiiiiiiiiiiiiiiiiiiiiiiiii			a.m.		
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a.m.     p.m.       a.m.     p.m.       a.m.     p.m.       a.m.     p.m.       section C - RECORD OF INTERVIEW       Section C - RECORD OF INTERVIEW       I. STATUS OF INTERVIEW - Mark (X) appropriate box.       oi Complete interview       o2 Partial interview       o3 Refusal       o4 Unable to locate       o5 Not a Hospice/Home Health Agency       o6 Temporarily closed       o7 Not yet in operation       08 No longer operating       09 Merged with (Control No.)       10 Duplicate (Control No. of duplicate)       11 Other noninterview - Specify       12 Date of interview       Month       I Day			a.m.		
a.m.     p.m.       a.m.     p.m.       a.m.     p.m.       section C - RECORD OF INTERVIEW       Section C - RECORD OF INTERVIEW       I. STATUS OF INTERVIEW - Mark (X) appropriate box.       o1 □ Complete interview       o2 □ Partial interview       o3 □ Refusal       o4 □ Unable to locate       o5 □ Not a Hospice/Home Health Agency       o6 □ Temporarily closed       o7 □ Not yet in operation       o8 □ No longer operating       o9 □ Merged with (Control No.) □       11 □ Other noninterview - Specify □       22. Date of interview       Month □ □ Day □ Year			a.m.		4
a.m. p.m.       Section C - RECORD OF INTERVIEW       I. STATUS OF INTERVIEW - Mark (X) appropriate box.       o1 Complete interview       02 Partial interview       03 Refusal       04 Unable to locate       05 Not a Hospice/Home Health Agency       06 Temporarily closed       07 Not yet in operation       08 No longer operating       09 Merged with (Control No.)       10 Duplicate (Control No. of duplicate)       11 Other noninterview - Specify       2. Date of interview				· · · · · · · · · · · · · · · · · · ·	
section C - RECORD OF INTERVIEW       I. STATUS OF INTERVIEW - Mark (X) appropriate box.       01 Complete interview       02 Partial interview       03 Refusal       04 Unable to locate       05 Not a Hospice/Home Health Agency       06 Temporarily closed       07 Not yet in operation       08 No longer operating       09 Merged with (Control No.)       10 Duplicate (Control No. of duplicate)       11 Other noninterview - Specify       12 Date of interview					
I. STATUS OF INTERVIEW - Mark (X) appropriate box.   01 Complete interview   02 Partial interview   03 Refusal   04 Unable to locate   05 Not a Hospice/Home Health Agency   06 Temporarily closed   07 Not yet in operation   08 No longer operating   09 Merged with (Control No.)   10 Duplicate (Control No. of duplicate)   11 Other noninterview - Specify   22 Date of interview   Month		ection C P			
2. Date of interview Month   Day   Year	1. STATU: 01 Cc 02 Pa 03 Re 04 Ur 05 Nc 06 Te 07 Nc 08 Nc 08 Nc 09 Mc 10 Dc	S OF INTERVI mplete interview rtial interview fusal nable to locate t a Hospice/H mporarily clo ty et in opera b longer opera orgad with (Contri	EW – Mark (X) ap iew iew iome Health Ager sed sed tition tition ontrol No.) rol No. of duplicat	propriate box. Icy	
	2. Date of	interview	Day	Year	
	3. Field Re			FR Code	

	Section D – ARRANGING THE ADM	INIS	TRA	FOR APPOIN	ITMENT		
I. IN	TRODUCTION	3.	NAI	ME VERIFICA	TION		
ti cS sPh rAS	ood morning (afternoon). My name is I'm from ne Bureau of the Census. We are currently onducting the National Home and Hospice Care urvey for the National Center for Health Statistics /hich is part of the Centers for Disease Control and revention. We are studying home health agencies, ospices and their patients. You should have sceived a letter from Mr. John Anderson, the acting Director of the National Center for Health tatistics, which describes this project. Have you		rec of y	ords. Is (Nar your agency 'es – Go to Ite	ne of agency on		
	aceived this letter? ] Yes – Skip to Item 3 , NAME VERIFICATION. ] No – Continue with Item 2, SURVEY EXPLANATION.	4.	ls (/			he correct addr	ress?
. s	URVEY EXPLANATION	1		o – Enter cor	rect agency ado	lress below. 룾	
	administrator wants a copy of the letter, explain that you ill bring a copy when you visit the agency.			mber Str	eet	P.O. Box, F	loute, etc.
	m sorry that you did not receive the letter. Let me riefly outline its contents.						
	he National Home and Hospice Care Survey is		Sta	te		ZIP	Code
S	uthorized under Section 306 of the Public Health ervice Act to collect information about home and	L					ı
hospice care agencies, their services, and patients. The survey is endorsed by the National Association for Home Care and the National Hospice Organization. The statistics compiled from the data are used to support research for effective treatment of long-term health problems and to study utilization of hospice and home care agencies and the efficient use of the Nation's health care resources.	5.	l we you	r convenien	arrange a mori ce to conduct	ning appointme the survey. Wh e to visit your a	at would	
		Day	/	Date	Time	a.m. p.m.	
ti c	Il information which would permit identification of re individual patient or agency will be held in strict onfidence, will be used ONLY by persons involved t he survey and only for the purposes of the		Day	/	Date	Time	a.m. p.m.
Thisto R W Poctiti	thers for any purpose. he survey includes a small sample of hospices and ome health agencies. Although your participation is voluntary and there are no penalties for refusing answer any questions, it is essential that we btain data from all sample agencies. <i>EAD IF NECESSARY:</i> We are asking participants for a list of current atients and a list of discharges during a designated ne-month period. We will draw a sample of 6 urrent patients and a sample of 6 discharges from te 12 sampled patients. <i>Continue with Item 3, NAME VERIFICATION.</i> Section E – QUESTIONS	7. S AB	dire Tha (Tin DIRI	ctions in nun nk you very ne) on (Date). ECTIONS TO	nber 7 below.) much for you Good-bye. AGENCY (If nee	g point? (Record r time. I will see	
	Before I begin the interview, I'd like to take a mome					nyev I believe v	<u></u>
	(received/did not receive) the letter from the Nationa	al Ce	nter	for Health S	tatistics.		- 14
	If administrator did not receive the letter, hand him/her a	• •			,	0	
	As it says in the letter, the purpose of the National H about hospices and home health agencies such as y and will be used only by persons involved in the sur	ours	. The	informatio	1 you provide i	is strictly confid	
	AND FLASHCARD 1	   		PROPRIETAR partnership,		lividual or private	),
s	hat is the type of ownership of this agency as hown on this card?	1 6 8	02 🗌	NONPROFIT	•	ch-related, nonpro ownership	ofit
N	lark (X) only ONE box.	   				MENT – Includes S pital district or au	
		i I	_	Forces, Veter	ans Administral	ncludes USPHS, / tion	Armed
		1	05 🗀	Other – Spec	ity 🖌		
	uthority of a hospital?		01 🗌 02 🗌				



Figure I. Agency Questionnaire—Con.

-	Section E - QUESTIONS ABO	
Ic.	Does this agency operate under the general authority of a nursing home?	01 □ Yes 02 □ No
d.	Is (Name of agency) a member of a group of agencies operating under one corporate authority or corporate ownership?	01 □ Yes 02 □ No
2.	Does this agency operate under the authority of a Health Maintenance Organization (HMO)?	01 □ Yes 02 □ No
3a.	Is this agency certified under Medicare as a Home Health Agency?	01 ☐ Yes 02 ☐ No 03 ☐ Certification pending
b.	Is this agency certified under Medicare as a Hospice?	01 ☐ Yes 02 ☐ No 03 ☐ Certification pending
4a.	Is this agency certified under Medicaid as a Home Health Agency?	01 ☐ Yes 02 ☐ No 03 ☐ Certification pending
b.	Is this agency certified under Medicaid as a Hospice?	01 ☐ Yes 02 ☐ No 03 ☐ Certification pending
5a.	Does this agency provide bereavement care to families of the patients that you serve?	01 □ Yes 02 □ No
b.	Does this agency provide pastoral care?	01 □ Yes 02 □ No
	HAND FLASHCARD 2	I 00 🗌 None
6.	Does this agency provide any of the following services?	01 ☐ Continuous home care 02 ☐ Counseling
	Mark (X) all that apply.	<ul> <li>03 Dental treatment services</li> <li>04 Dietary and nutritional services</li> </ul>
7a.	Probe: Any other services?	05       Durable medical equipment and supplies         06       Enterostomal therapy         07       High tech care (e.g., IV therapy)         08       Homemaker/Companion services         09       Meals on Wheels         10       Medications         11       Occupational therapy/Vocational therapy         12       Oral hygiene/Prevention services         13       Personal care         14       Physical therapy         15       Physician services         16       Referral services         17       Respite care (inpatient)         18       Skilled nursing services         19       Social Services         20       Speech therapy/Audiology         21       Spiritual care         22       Transportation         23       Volunteers         24       Other services – Specify 🗸         01       Yes – GO to item 7b
<b>L</b>	·	01 Tes = 00 thank THE RESPONDENT, END THE 102 No – THANK THE RESPONDENT, END THE INTERVIEW, AND MARK CODE 11 IN SECTION C ON THE COVER PAGE,
	What is the number of your current active patients?	99999 Don't know
3a.	What is the number of home health care patients currently being served by this agency?	Number of home health patients ∞∞∞ □ None ∞∞∞ □ Don't know
b.	What is the number of hospice care patients currently being served by this agency?	Number of hospice patients 0000 □ None 99999 □ Don't know

DEAD		UT THE AGENCY - Continued
READ		all current home health and hospice patients, and a s for the month of (Insert discharge sample month and year).
9a. From wi	hom shall I obtain the list of current	Name
patients	37	
		Title
coopera these pa	ed these patients' medical records and the tion of a staff member best acquainted with atients in order to obtain the information on stionnaire.	
question	administrator a copy of the current patient naire. Allow him/her to examine it briefly. the questionnaire and continue reading.	01 □ Yes – GO to item 10a 02 □ No – Determine which staff member would have this 1 02 □ No – Determine which staff member would have this
in any w	t be contacting or interviewing the patients /ay. I will depend on your staff to consult the records.	Name
member	person named in item 9a) know which staff I should interview for those patients I for the sample?	l Title
0a. From wi	nom shall I obtain the list of discharges?	□ Same as 9a
		Name
		Title
		1
the disc informa	ed the help of a staff person familiar with harge records to aid me in completing the tion requested in this questionnaire.	01 □ Yes – GO to item 11 below 02 □ No – Determine which staff member would have this
question	administrator a copy of the discharged patient naire. Allow him/her to examine it briefly. the questionnaire and continue reading.	knowledge and enter the name and title below. $\vec{r}$
b. Would (	person named in item 10a) know which staff	I Name I
member fall into	I should interview for those discharges that the sample?	l
		1
1. Thank y	ou for your time. I will be checking with you b	efore I leave to say good-bye.
At this t	ime, could you introduce me to (Names of pers	on(s) listed in items 9a, 9b, 10a, and 10b).
lotes		
	,	

	OMB No. 0920-0	0298: Approval Expires 03/31/97
FORM HHCS-3 (3-29-96) U.S. DEPARTMENT OF COMMERCE BUREAU OF THE CENSUS ACTING AS COLLECTING AGENT FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES U.S. PUBLIC HEALTH SERVICE CENTERS FOR DISEASE CONTROL AND PREVENTION NATIONAL CENTER FOR HEALTH STATISTICS CURRENT PATIENT QUESTIONNAIRE 1996 NATIONAL HOME AND HOSPICE CARE SURVEY	NOTICE – Public reporting burden for th is estimated to average 10 minutes per r for reviewing instructions, searching exis and maintaining the data needed, and co collection of information. Send commen estimate or any other aspect of this colle including suggestions for reducing this to Clearance Officer; Paperwork Reduction 531-H; Hubert H. Humphrey Bidg.; 200 In Washington, DC 20201. Information cont would permit identification of any indivi- been collected with a guarantee that it w confidence, will be used for purposes sta not be disclosed or released to others wi individual or establishment in accordance Public Health Service Act (42 USC 242m)	esponse, including the time sting data sources, gathering ompleting and reviewing the ts regarding this burden setion of information, burden to DHHS Reports Project (0920-0298) Room independence Ave., SW; tained on this form which dual or establishment has vill be held in strict ated for this study, and will ithout the consent of the ew with Section 308(d) of the
Section A – ADMINISTR	ATIVE INFORMATION	
1. Field representative name	2. FR code	<b>3.</b> Date of interview Month/Day/Year
		/ /
Section B – PATIENT IN	FORMATION	
1. Patient name or other identifier First M.I. Last	2.	Patient line number
Section C – STATU	JS OF INTERVIEW	
<ul> <li>O1 Complete</li> <li>O2 Partial</li> <li>O3 Patient included in sampling list in error</li> <li>O4 Incorrect sample line number selected</li> <li>O5 Refused</li> <li>O6 Assessment only</li> <li>O7 Unable to locate record</li> <li>O8 Less than 6 patients selected</li> <li>O9 Other noninterview - Specify</li></ul>		
NOTES		

Figure II. Current Patient Questionnaire

Read to each new respondent.

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

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

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

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

• • • • • • • • • • • • • • • • • • •	1.	What is's sex?	
2. What is's date of birth?       Age (at admission)         Month       Day       Year       OR       OR         HAND FLASHCARD 1.       01       White       02       Black       03       American Indian, Eskimo, Alaut       04       04       04       04       06		Wildt 15 5 Sex?	01 🗖 Male
Hand FLASHCARD 1.         3a. Which of these best describes's race?         Mark (X) only one box.         Mark (X) only one box.         b. Is of Hispanic origin?         ot			02 🗆 Female
Hand FLASHCARD 1.       Image for dumstory         Image for dumstory       Image for dumstory         Image for dumst			
HAND FLASHCARD 1.       OR       OR       OR       Months         3a. Which of these best describes's race?       ot    White       Black	2.	What is's date of birth?	Age (at admission)
HAND FLASHCARD 1.       OR       OR       Veers       Months         3a. Which of these best describes's race?       or       White       Black       <			
HAND FLASHCARD 1.       or White         3a. Which of these best describes's race?       or Black         Mark (X) only one box.       a American Indian, Eskimo, Aleut         • Cher - Specify       or Don't know         b. Is of Hispanic origin?       or Private         • What is's current marital status?       or Married         Mark (X) only one box.       or Married         • What is's current marital status?       or Married         Mark (X) only one box.       or Don't know         HAND FLASHCARD 2.       or Private residence         • Mark (X) only one box.       or Private residence         • HAND FLASHCARD 2.       or Private residence         • Back (X) only one box.       or Private residence         • Back (X) only one box.       or Private residence         • Back (X) only one box.       or Private residence         • Back (X) only one box.       or Private residence         • Back (X) only one box.       or Private residence         • Back (X) only one box.       or Private residence         • Back (X) only one box.       or Private residence         • Back (X) only one box.       or Private residence         • Don't know       or Private residence         • Don't know       or Private residence			
3a. Which of these best describes's race?       oi □ With         Mark (X) only one box.       a American Indian, Eskimo, Aleut         0 □ Ofter - Specify		······································	Years Months
3a. Which of these best describes 's race?       02 Black         Mark (X) only one box.       02 American Indian, Eskimo, Aleut         04 Asian, Pacific Islander       05 Other - Specify         05 Don't know       01 Yes         02 Don't know       02 Don't know         04 Mark (X) only one box.       01 Yes         02 Don't know       02 Mo         03 Don't know       01 Yes         04 Don't know       02 Mo         05 Don't know       01 Married         06 Don't know       02 Midowed         07 Don't know       01 Separated         08 Separated       05 Never married         09 Don't know       01 Separated         09 Don't know       01 Private residence         09 Don't know       02 Rented room, boading house         09 Dott prive of heath facility (including mental health facility) - SKIP to item 6 Introduction		HAND FLASHCARD 1.	
Mark (X) only one box.       0       American Indian, Eskimo, Aleut         4       Asian, Pacific Islander       0         05       Other - Specify       0         06       Don't know       0         10       Yes       0         20       No       03         01       Yes       02         02       No       03         03       Don't know         4.       What is's current marital status?       01         Mark (X) only one box.       01       Married         02       Widowed       03         03       Divorced       04       Separated         04       Separated       05       Single         07       Don't know       01       Private residence         02       Renterd room, boarding house       03       Retirement home         04       Board and care assisted living or residential care facility       04       Board and care assisted living or residential care facility         05       Other type of health facility (including mental health facility) - SKIP to item 6 Introduction       06       Other - Specify z         0       Imarity members, both family and nonfamily members, or alone?       01       With honfamily members and nonf	3a.	Which of these best describes's race?	
Mark (x) only one box.       04 Asian, Pacific Islander         05 Other - Specify       06 Don't know         01 Yes       20 No         02 No       03 Don't know         03 Don't know       01 Married         04 Asian, Pacific Islander       01 Yes         05 Don't know       01 Yes         04 Married       01 Married         05 Don't know       01 Married         06 Don't know       01 Married         07 Don't know       01 Separated         08 Single       07 Don't know         HAND FLASHCARD 2.       01 Private residence         02 Rented room, boarding house       03 Retirement home         04 Board and care assisted living or residential care facility       05 Other type of health facility (including mental health facility 0 - SK/P to item 6 Introduction         06 Other - Specify Z       01 With family members, nonfamily members, or alone?         01 With tonfamily members       01 With family members         02 With honfamily members       02 With home         03 Diversed       03 Diversed         04 Alone       04 Alone			
05       Other - Specify         06       Don't know         01       Yes         02       No         03       Don't know         4.       What is 's current marital status?         01       Mark (X) only one box.         01       Married         02       Widowed         03       Divorced         04       Separated         05       Never married         06       Single         07       Don't know		Mark (X) only one box.	
<ul> <li>b. Is of Hispanic origin?</li> <li>ot ☐ Yes</li> <li>oz ☐ No</li> <li>o3 ☐ Don't know</li> <li>4. What is 's current marital status?</li> <li>Mark (X) only one box.</li> <li>i ☐ Married</li> <li>i ☐ Warried</li> <li>i ☐ Widowed</li> <li>i ☐ Divorced</li> <li>i ☐ Separated</li> <li>i ☐ Never married</li> <li>i ☐ Single</li> <li>i ☐ Private residence</li> <li>i ☐ Private residence</li> <li>i ☐ Retirement home</li> <li>i ☐ Board and care assisted living or residential care facility</li> <li>i ☐ Other type of health facility (including mental health facility) - SKIP to item 6 Introduction</li> <li>i ☐ Other - Specify r</li> <li>i ☐ With family members, or alone?</li> <li>i ☐ With family members</li> <li>i ☐ None</li> </ul>			
<ul> <li>a. What is 's current marital status?</li> <li>A. What is 's current marital status?</li> <li>Mark (X) only one box.</li> <li>a. Divorced</li> <li>b. S living with family members, nonfamily members, both family and nonfamily members, or alone?</li> <li>b. Is living with family and nonfamily members, or alone?</li> <li>a. With both family members, nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> </ul>			06 🗌 Don't know
<ul> <li>a. What is 's current marital status?</li> <li>A. What is 's current marital status?</li> <li>Mark (X) only one box.</li> <li>a. Divorced</li> <li>b. S living with family members, nonfamily members, both family and nonfamily members, or alone?</li> <li>b. Is living with family and nonfamily members, or alone?</li> <li>a. With both family members, nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> </ul>	h	le of Hienenio origin?	
a:       □ Don't know         4.       What is 's current marital status?       oi □ Married         Mark (X) only one box.       □ □ Vidowed         a:       □ Divorced         b:	<b>D</b> .		01 🗋 Yes
<ul> <li>4. What is,'s current marital status?</li> <li>Mark (X) only one box.</li> <li>01 ☐ Married</li> <li>02 ☐ Widowed</li> <li>03 ☐ Divorced</li> <li>04 ☐ Separated</li> <li>05 ☐ Never married</li> <li>06 ☐ Single</li> <li>07 ☐ Don't know</li> </ul> HAND FLASHCARD 2. 5a. Where is currently living? <ul> <li>Mark (X) only one box.</li> <li>01 ☐ Private residence</li> <li>02 ☐ Rented room, boarding house</li> <li>03 ☐ Retirement home</li> <li>04 ☐ Board and care assisted living or residential care facility</li> <li>06 ☐ Other type of health facility (including mental health facility) = SKIP to item 6 Introduction</li> <li>06 ☐ Other - Specify Z</li> <li>with family members, nonfamily members, or alone?</li> <li>01 ☐ With family members and nonfamily members</li> <li>04 ☐ Alone</li> </ul>			02 🗆 No
Mark (X) only one box.       01 Married         02 Widowed       03 Divorced         04 Separated       05 Never married         06 Single       07 Don't know         HAND FLASHCARD 2.         5a. Where is currently living?       01 Private residence         02 Retter com, boarding house       03 Retirement home         04 Board and care assisted living or residential care facility       05 Other type of health facility (including mental health facility) - SKIP to item 6 Introduction         06 Other - Specify residence       01 With family members, nonfamily members, or alone?			03 🗌 Don't know
Mark (X) only one box.       01 Married         02 Widowed       03 Divorced         03 Divorced       04 Separated         05 Never married       06 Single         07 Don't know       01 Private residence         08 Retirement home       02 Rented room, boarding house         09 Mark (X) only one box.       01 Private residence         09 Board and care assisted living or residential care facility       05 Other type of health facility (including mental health facility) - SKIP to item 6 Introduction         06 Other - Specify residence       01 With family members, nonfamily members, or alone?	4.	What is's current marital status?	
b. Is living with family members, nonfamily members, both family and nonfamily members, or alone?       01       Private residence         02       Rented room, boarding house       03       Rented room, boarding house         03       Board and care assisted living or residential care facility       05         04       Board and care assisted living or residential care facility         05       Other type of health facility (including mental health facility) - <i>SKIP to item 6 Introduction</i> 06       Other - <i>Specify</i> 07       Other and care assisted living members, and nonfamily members, or alone?			
<ul> <li>b. Is living with family members, nonfamily members, both family and nonfamily members, or alone?</li> <li>b. Is living with family and nonfamily members, or alone?</li> </ul>		Mark (X) only one box.	
<ul> <li>b. Is living with family members, nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> </ul>			
06       Single         07       Don't know         HAND FLASHCARD 2.       01         5a. Where is currently living?       02         Mark (X) only one box.       01         Board and care assisted living or residential care facility         05       Other type of health facility (including mental health facility) – SKIP to item 6 Introduction         06       Other - Specify r         members, both family members, nonfamily members, or alone?       01         With family members       01         With both family members       01			
07 □ Don't know         HAND FLASHCARD 2.         5a. Where is currently living?         Mark (X) only one box.         Mark (X) only one box.         01 □ Private residence         02 □ Rented room, boarding house         03 □ Retirement home         04 □ Board and care assisted living or residential care facility         05 □ Other type of health facility (including mental health facility) - SKIP to item 6 Introduction         06 □ Other - Specify r         01 □ With family members, nonfamily members, or alone?         01 □ With family members         02 □ With nonfamily members         03 □ With both family members         04 □ Alone			
<ul> <li>5a. Where is currently living?</li> <li>Mark (X) only one box.</li> <li>b. Is living with family members, nonfamily members, both family and nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> <li>c. C. C.</li></ul>			07 🗋 Don't know
<ul> <li>5a. Where is currently living?</li> <li>Mark (X) only one box.</li> <li>b. Is living with family members, nonfamily members, both family and nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, or alone?</li> <li>01 □ Private residence</li> <li>02 □ Rented room, boarding house</li> <li>03 □ Retirement home</li> <li>04 □ Board and care assisted living or residential care facility</li> <li>05 □ Other type of health facility (including mental health facility) - SKIP to item 6 Introduction</li> <li>06 □ Other - Specify ∠</li> <li>01 □ With family members, nonfamily members, or alone?</li> <li>01 □ With family members and nonfamily members</li> <li>02 □ With nonfamily members and nonfamily members</li> <li>04 □ Alone</li> </ul>		HAND ELASHCARD 2	
Mark (X) only one box.       03 Retirement home         04 Board and care assisted living or residential care facility         05 Other type of health facility (including mental health facility) – SKIP to item 6 Introduction         06 Other – Specify         07 Other system         08 Other – Specify         09 Other – Specify         01 With family members, or alone?         01 Other – Specify         02 Other – Specify         03 Other – Specify         04 Other – Specify         05 Other – Specify         06 Other – Specify         07 Other – Specify         08 Other – Specify         09 Other – Specify         01 Other – Specify         02 Other – Specify         03 Other – Specify         04 Other – Specify         05 Other – Specify         06 Other – Specify         07 Other – Specify         08 Other – Specify         09 Other – Specify         01 Other – Specify         02 Other – Specify         03 Other – Specify         04 Other – Specify <t< th=""><th></th><th></th><th>01 🗆 Private residence</th></t<>			01 🗆 Private residence
<ul> <li>b. Is living with family members, nonfamily members, both family and nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, both family and nonfamily members, of alone?</li> </ul>	5a.	Where is currently living?	
<ul> <li>b. Is living with family members, nonfamily members, both family and nonfamily members, or alone?</li> <li>b. Is living with family members, nonfamily members, both family and nonfamily members, or alone?</li> </ul>		Mark (X) only one box.	
facility) – SKIP to item 6 Introduction         06 □ Other – Specify r         07 □ With family members, nonfamily members, both family and nonfamily members, or alone?         01 □ With family members         02 □ With nonfamily members         03 □ With both family members and nonfamily members         04 □ Alone			
06 □ Other - Specify ∠         b. lsliving with family members, nonfamily members, both family and nonfamily members, or alone?         01 □ With family members         02 □ With nonfamily members         03 □ With both family members and nonfamily members         04 □ Alone			facility) – SKIP to item 6 Introduction
or alone? 02			06 🗌 Other – Specify 📈
or alone? 02			
or alone? 02			
or alone? 02	b.	Is living with family members, nonfamily members, both family and nonfamily members	01 🗌 With family members
03 🗌 With both family members and nonfamily members 04 🗌 Alone		or alone?	02 🗆 With nonfamily members
04 🗆 Alone			03 🗌 With both family members and nonfamily members
05 🗌 Don't know			04 🗌 Alone
			05 └─ Don't know

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Figure II. Current Patient Questionnaire—Con.

r				
	Read the introductory paragraph for the Social Security Number only once for each respondent.			
	number will be useful in conducting fu	o have's Social Security Number. Provision of this number is ng the number will have no effect in any way on's benefits. This ture followup studies. It will be used to match against the vital ational Center for Health Statistics. This information is collected under blic Health Service Act.		
6.	What is's Social Security Number?	Social Security Number 01 Refused 02 Don't know		
7.	HAND FLASHCARD 3. <b>Who referred to this agency?</b> Mark (X) all that apply. PROBE: <b>Any other sources?</b>	<ul> <li>01 Self/Family</li> <li>02 Nursing home</li> <li>03 Hospital</li> <li>04 Physician</li> <li>05 Health department</li> <li>06 Social service agency</li> <li>07 Home health agency</li> <li>08 Hospice</li> <li>09 Religious organization</li> <li>10 Other - Specify</li></ul>		
8.	What was the date of's most recent admission with your agency, that is, the date on which was admitted for the current episode of care?	Month       Day       Year       00       Only an assessment was done for this patient (patient was not provided services by this agency)		
9a	According to's medical record, what were the primary and other diagnoses at the time of that (admission/assessment)?	00 🗆 No diagnosis		
	PROBE: Any other diagnoses?	Primary: 1 Others: 2 3 4 5 6		
	Refer to Q8. If <b>ONLY</b> an assessment was done for this patient, END THE INTERVIEW AND COMPLETE SECTION C ON THE COVER. THEN GO TO the next current patient questionnaire.	00 □ No diagnosis 01 □ Same as 9a		
	If the patient was admitted to the agency and provided services by the agency, CONTINUE this interview.	Primary: 1 Others: 2		
b.	According to's medical records, what are's CURRENT primary and other diagnoses?	3		
	PROBE: Any other diagnoses?	5		
		6		

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Figure II. Current Patient Questionnaire—Con.

9c.	According to's medical record, did have any diagnostic or surgical procedures that were related to's admission to this agency?	00 □ No procedures 01 □ Yes 1
		2
10.	What type of care is currently receiving from your agency? Is it home health care or hospice care?	01 🗌 Home health care 02 🗌 Hospice care
11a.	Does have a primary caregiver (outside of this agency)?	01 ☐ Yes 02 ☐ No 03 ☐ Don't know } <i>SKIP to item 12</i>
b.	Does usually live with (his/her) primary caregiver?	   01 □ Yes   02 □ No   03 □ Don't know
	HAND FLASHCARD 5.	! 01 □ Spouse
C.	What is the relationship of the primary caregiver to?	02 □ Parent 03 □ Child 04 □ Daughter-in-law/Son-in-law
	Mark (X) only one box.	04       Daughter-in-raw/son-in-raw         05       Other relative - Specify
	HAND FLASHCARD 6.	│ │ 00 □ No aids used
12.	Which of these aids does currently use?	01 🗌 Bedside commode
	Mark (X) all that apply.	02  Brace (any type) 03  Cane
	PROBE: Any other aids?	<ul> <li>04 Crutches</li> <li>05 Dentures (full or partial)</li> <li>06 Eyeglasses (including contact lenses)</li> <li>07 Hearing aid</li> <li>08 Hospital bed</li> <li>09 Orthotics</li> <li>10 Shower chair</li> <li>11 Walker</li> <li>12 Wheel chair - Manually operated</li> <li>13 Wheel chair - Motorized</li> <li>14 Other - Specify</li></ul>
NOT	ES	

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Figure II. Current Patient Questionnaire—Con.

	For items 13a–14b, refer to item 12.	01 🗌 Yes
13a.	Does have any difficulty in seeing (when	02 No 03 Not applicable (e.g., comatose)
	wearing glasses)?	$1  04 \square \text{ Don't know} \dots \dots$
-	HAND FLASHCARD 7.	01  Partially impaired
b.	ls's sight (when wearing glasses) partially,	02 🗆 Severely impaired
	severely, or completely impaired as defined on	03 Completely lost, blind
	this card?	04 🗌 Don't know
14a.	Does have any difficulty in hearing (when wearing a hearing aid)?	01 □ Yes   02 □ No
		03 Not applicable (e.g., comatose) } SKIP to item 15a
		04 Don't know
	HAND FLASHCARD 8.	01  Partially impaired
Ь.	ls's hearing (when wearing a hearing aid)	02 🗆 Severely impaired
	partially, severely, or completely impaired, as defined on this card?	03 □ Completely lost, deaf 04 □ Don't know
15	HAND FLASHCARD 9.	
	Ask questions 15a through 15k in <b>PART I FIRST</b> . As you ask respondent time to refer to the flashcard. Mark (X) the "Yes" b	each part of the question, PAUSE to allow the pox for each item the respondent says the patient
	has in his/her home. Then, GO TO PART II, and ask the ques	tion for each item marked "Yes" in Part I.
PAR	T I Which of the following items does have in	PART II Does receive assistance from your agency
	(his/her) home?	staff in caring for or using:
a.	Oxygen, respiratory therapy equipment?	1
	(1) Ventilator/Respirator	
	(2) Liquid oxygen delivery system	
	(3) Oxygen concentrator	
	(4) Gaseous oxygen delivery system $\dots \dots \dots \dots \square$ Yes	
	(5) Nebulizer	
	(6) Humidifier	
	(7) Suction equipment	
	(8) Tracheostomy	01 □ Yes 02 □ No 03 □ Don't know
b.	Intravenous therapy equipment?	1
	(1) Peripheral catheter	I I 01 □ Yes 02 □ No 03 □ Don't know
	(2) Midline catheter	
	(3) Central venous catheter (e.g. Hickman,	
		01 🗌 Yes 02 🗌 No 03 🗔 Don't know
	(4) Infusion pumps 01 🗌 Yes	01 └─ Yes 02 └─ No 03 └─ Don't know
c.	Decubitus ulcer prevention/treatment equipment?	1
	(1) Air mattress/air fluidized bed	
	(2) Foam mattress (egg-crate mattress) 01 🗌 Yes	01 □ Yes 02 □ No 03 □ Don't know
d.	Enteral nutrition equipment?	1
	(1) Nasogastric tube	
	(2) Gastrostomy/jejunostomy tube	
	(3) Pump 01 [] Yes	
	CONTINUED ON NEXT PAGE	CONTINUED ON NEXT PAGE

Figure II. Current Patient Questionnaire—Con.

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PART I – Continued	15. PART II – Continued
Which of the following items does have in (his/her) home?	Does receive assistance from your agency staff in caring for or using:
Dialysis equipment?	1
(1) Peritoneal Dialysis – Manual (continuous) 01 🗌 Yes	I 01 □ Yes 02 □ No 03 □ Don't know
(2) Peritoneal Dialysis – Automated (intermittent/continuous cyclic)	
(4) Hemodialysis	
Blood glucose monitor?	01 🗆 Yes 02 🗆 No 03 🗆 Don't know
Drainage devices? 01 🗆 Yes	01 🗆 Yes 02 🗋 No 03 🗌 Don't know
(1) Wound/bile duct/ureteral drainage catheter $\ldots$ on $\Box$ Yes	01 🗌 Yes 02 🗌 No 03 🗌 Don't know
(2) Foley catheter	01 □ Yes 02 □ No 03 □ Don't know
(3) Intermittent bladder catheterization $\ldots$ of $\Box$ Yes	¦ 01 □ Yes 02 □ No 03 □ Don't know
(4) External urinary collection devices (e.g. condom catheter)	1
(5) Urostomy 01 🗆 Yes	01 🗆 Yes 02 🗆 No 03 🗔 Don't know
(6) Ileostomy/Colostomy	01 🗌 Yes 02 🗌 No 03 🗌 Don't know
Protective restraints (e.g. vests, belts)? $\ldots$ 01 $\Box$ Yes	01 □ Yes 02 □ No 03 □ Don't know
<b>Pediatric care?</b>	01 🗌 Yes 02 🗌 No 03 🗌 Don't know
(1) Apnea monitor	
(2) Phototherapy lights/equipment 01 🗋 Yes	01 🗋 Yes 02 🗌 No 03 🗔 Don't know
Prenatal uterine monitoring?	01 □ Yes 02 □ No 03 □ Don't know
<b>Other?</b> – <i>Specify</i> 01 🗌 Yes	01 🗌 Yes 02 🗌 No 03 🗌 Don't know
Does have any difficulty in controlling (his/her) bowels?	01 ☐ Yes 02 ☐ No 03 ☐ Not applicable (e.g. infant, has an ostomy) 04 ☐ Don't know
Does have any difficulty in controlling (his/her) bladder?	01 ☐ Yes 02 ☐ No 03 ☐ Not applicable (e.g. infant, has an indwelling catheter, has an ostomy) 04 ☐ Don't know
ES	•
	Which of the following items does have in (his/her) home?         Dialysis equipment?         (1) Peritoneal Dialysis - Manual (continuous) 01    Yes         (2) Peritoneal Dialysis - Automated (intermittent/continuous cyclic) 01    Yes         (3) Peritoneal - unspecified 01    Yes         (4) Hemodialysis 01    Yes         Blood glucose monitor? 01    Yes         Drainage devices? 01    Yes         (1) Wound/bile duct/ureteral drainage catheter 01    Yes         (2) Foley catheter 01    Yes         (3) Intermittent bladder catheterization 01    Yes         (4) External urinary collection devices (e.g. condom catheter) 01    Yes         (5) Urostomy

18.	HAND FLASHCARD 10. Does currently receive personal help from this agency in any of the following activities as defined on this card	I I Yes I	No	Don't know	Not applicable (e.g., patient is bedfast)
	Mark (X) one box for each activity.	1			
a.	Bathing or showering?	01	02 🗌	03 🗌	04 🗆
b.	Dressing?	I I 01 🗌	02 🗌	03 🗌	04 🗌
c.	Eating?		02 🗌	03 🗌	04 🗌
d.	Transferring in or out of beds or chairs?	01 🗌	02 🗌	03 🗌	04 🗌
e.	Walking?	   01 🗌 ·	02 🗌	03 🗌	04 🗌
f.	Using the toilet room?	01 🗌	02 🗌	03 🗌	04 🗌
19.	HAND FLASHCARD 11. Does receive personal help from your agency in any of the following activities –	Yes	No	Don't know	Not applicable (e.g., patient is bedfast)
a.	Mark (X) one box for each activity. Doing light housework?	     01 []	02	03 🗌	04 🗌
	Managing money?		02	03 🗌	04 🗌
c.	Shopping for groceries or clothes?	01	02 🗌	03 🗌	04 🗌
d.	Using the telephone (dialing or receiving calls)?	01	02 🗌	03 🗌	04 🗌
e.	Preparing meals?	01	02 🗌	03 🗌	04 🗌
f.	Taking medications?	01 🗌	02 🗌	03 🗆	04 🗖
20a.	HAND FLASHCARD 12. Which of these services does currently receive FROM YOUR AGENCY? Mark (X) all that apply. PROBE: Any other services?	04       Medication         05       Mental h         06       Nursing s         07       Nutrition         08       Occupati         09       Physical         10       Physical         11       Social se         12       Speech t         13       Transport         14       Voluntee	ng aker-household s ons sealth services services ist services onal therapy therapy n services ervices herapy/Audiolog tation	у	
NOTE		l			

Page 8 Figure II. Current Patient Questionnaire—Con.

P <sup>111</sup>					
HAND FLASHCARD 13.					
20b. Which of these service providers FROM YOUR					
AGENCY visited during the last 30 days?	I 01 ☐ Chaplain				
	02 Dieticians/Nutritionists				
Mark (X) all that apply.	03 🗌 Home health aides				
PROBE: Any other providers?	Ⅰ 04				
	05 Licensed practical or vocational nurses				
	06 🔲 Nursing aides and attendants				
	1 07 🖸 Occupational therapists				
	08 🗌 Physical therapists				
	09 🗌 Physicians				
	10 🗆 Registered nurses				
	11 🗌 Respiratory therapists				
	12 🗌 Social workers				
	13 Speech pathologists/audiologists				
	14 🗆 Volunteers				
	$15 \Box$ Other providers – Specify $\mathbf{z}$				
	· · · · · · · · · · · · · · · · · · ·				
	· · · · · · · · · · · · · · · · · · ·				
HAND FLASHCARD 14.	Home Health Hospic Care Care				
21 What is the DDIMARY supported source of	I Cale Cale Cale Cale Cale Cale Cale Cale				
21. What is the PRIMARY expected source of payment for 's care?		7			
	│ 02 □ Own income, family support, 02 □ 02 □ 02 □	J			
Mark (X) only one source.	retirement funds, or welfare	n r			
For the source of payment ask: Is the (source of payment) for home health care	I 03 Supplemental Security 03 03 03 03 03 03 03 03 03 03 03 00 03 00 03 00 03 00 03 00 00	]			
or hospice care?	04 🗌 Medicare 04 🗌 04 🗌	י ר			
	1   05   Medicaid   05   05   05   05   05   05   05   0				
	06 ☐ Other government medical 06 ☐ 06 ☐	_			
		J			
	07 ☐ Religious organizations, 07 ☐ 07 ☐ 07 ☐ 07 ☐	]			
	08     VA contract, pensions, or     08     08       08     08     08	]			
	<sup>1</sup> 09 □ No charge made for care 09 □ 09 □	]			
	10 Payment source not yet 10 10 10	1			
	determined	_			
	11 🗌 Other – Specify 📈 🛛 11 🗌 👘 11	]			
	12 🗋 Don't know				
NOTES	1				
1					

HAND FLASHCARD 14.	1 1	Home Health Care	Hospice Care
22. What are ALL the secondary sources of	I 01	01	01
payment for 's care? Mark (X) all that apply.	02 Own income, family support, Social Security benefits, retirement funds, or welfare	02 🗌	02 🗌
PROBE: Any other sources of payment?	1 03 Supplemental Security 1 Income (SSI)	03 🗌	оз 🗌
For the source of payment ask: <b>Is the</b> (source of payment) <b>for home health care</b>	04 🗌 Medicare	04 🗔	04 🗔
or hospice care?	05 🗌 Medicaid	05 🗌	05 🗌
	06 Other government medical assistance	06 🗌	06 🗌
	07 CReligious organizations, foundations, agencies	07 🗖	07 🗌
	08 VA contract, pensions, or other VA compensation	08 🗌	08 🗌
	1 09 🗌 No charge made for care	09 🗌	09 🗌
	10 Payment source not yet determined	10 🗌	10 🗌
	11 □ Other – <i>Specify <sub>¥</sub></i>	11 🗔	11 🗔
	12 🗌 Don't know		
23. When was the last time service was provided?	I Month Day Year		
	I Month Day Year		
	OF THIS FORM AND CONTINUE		
		· · · · ·	

	UMB NO. 0920	-0298: Approval Expires 03/31/97
FORM HHCS-5 (3-29-96) U.S. DEPARTMENT OF COMMERCE BUREAU OF THE CENSUS ACTING AS COLLECTING AGENT FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES U.S. PUBLIC HEALTH SERVICE CENTERS FOR DISEASE CONTROL AND PREVENTION NATIONAL CENTER FOR HEALTH STATISTICS DISCHARGED PATIENT QUESTIONNAIRE 1996 NATIONAL HOME AND HOSPICE CARE SURVEY	NOTICE – Public reporting burden for t is estimated to average 10 minutes per for reviewing instructions, searching ex and maintaining the data needed, and o collection of information. Send commen estimate or any other aspect of this coll including suggestions for reducing this Clearance Officer; Paperwork Reduction 531-H; Hubert H. Humphrey Bldg.; 2001 Washington, DC 20201. Information cor would permit identification of any indiv been collected with a guarantee that it i confidence, will be used for purposes s not be disclosed or released to others v individual or establishment in accordan Public Health Service Act (42 USC 242m	response, including the time isting data sources, gathering completing and reviewing the ints regarding this burden lection of information, burden to DHHS Reports Project (0920-0298) Room independence Ave., SW; itained on this form which idual or establishment has will be held in strict tated for this study, and will vithout the consent of the ice with Section 308(d) of the
Section A – ADMINISTI	RATIVE INFORMATION	
1. Field representative name	2. FR code	3. Date of interview Month/Day/Year
Section B – PATIENT IN		
1. Patient name or other identifier First I M.I. Last     1     1     1	2. Patient line number	<b>3.</b> Date of Discharge Month/Day/Year / /
Section C – STATU	JS OF INTERVIEW	
<ul> <li>01 Complete</li> <li>02 Partial</li> <li>03 Patient included in sampling list in error</li> <li>04 Incorrect sample line number selected</li> <li>05 Refused</li> <li>06 Assessment only</li> <li>07 Unable to locate record</li> <li>08 Less than 6 discharges selected</li> <li>09 Other noninterview - Specify</li></ul>		
NOTES		

Read to each new respondent.

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

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

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

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

<b>—</b>		
1.	What was's sex?	01 🗆 Male 1 02 🗔 Female
2.	What was's date of birth?	Age (at admission)
		Month Day Year OR OR OR Months
	HAND FLASHCARD 1.	
За.	Which of these best described's race?	I 01 ☐ White 02 ☐ Black
	Mark (X) only one box.	03 🗌 American Indian, Eskimo, Aleut 04 🗌 Asian, Pacific Islander 05 🗌 Other – <i>Specify</i> 06 🗌 Don't know
h	Was of Hispanic origin?	
		01 ☐ Yes 02 ☐ No 03 ☐ Don't know
4.	What was's marital status at the time of discharge?	01 🗆 Married
	Mark (X) only one box.	02 Widowed 03 Divorced 04 Separated 05 Never Married 06 Single 07 Don't know
5a.	HAND FLASHCARD 2. <b>During the episode of care that ended on</b> (date of discharge), where was living? Mark (X) only one box.	<ul> <li>01 □ Private residence</li> <li>02 □ Rented room, boarding house</li> <li>03 □ Retirement home</li> <li>04 □ Board and care assisted living or residential care facility</li> <li>05 □ Other type of health facility (including mental health facility) - SKIP to item 6 Introduction</li> <li>06 □ Other - Specify ¥</li> </ul>
b.	Was living with family members, nonfamily members, both family and nonfamily members, or alone?	01

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	As part of this survey, we would like to	ocial Security Number only once for each respondent. To have's Social Security Number. Provision of this number is ng the number will have no effect in any way on's benefits. This ture followup studies. It will be used to match against the vital ational Center for Health Statistics. This information is collected under blic Health Service Act.
6.	What was's Social Security Number?	Social Security Number 01
7.	HAND FLASHCARD 3. <b>Who referred to this agency?</b> Mark (X) all that apply. PROBE: <b>Any other sources?</b>	01 Self/Family 02 Nursing home 03 Hospital 04 Physician 05 Health department 06 Social service agency 07 Home health agency 08 Hospice 09 Religious organization 10 Other - Specify
8.	What was the date of's admission for the period of care which ended on (Date of discharge)?	Month     Day     Year     00 □     Only an assessment was done for this patient (patient was not provided services by this agency)
9a	According to's medical record, what were the primary and other diagnoses at the time of's admission that ended with this (discharge/assessment)? <i>PROBE</i> : Any other diagnoses?	00 □ No diagnosis         Primary:       1
b	Refer to Q8. If <b>ONLY</b> an assessment was done for this patient, END THE INTERVIEW AND COMPLETE SECTION C ON THE COVER. THEN GO TO the next discharged patient questionnaire. If the patient was admitted to the agency and provided services by the agency, CONTINUE this interview. According to's medical records, what were's primary and other diagnoses at the time of discharge –	00 🗌 No diagnosis 01 🗋 Same as 9a Primary: 1 Others: 2 3
	that is, on (Date of discharge)? PROBE: Any other diagnoses?	4 5 6

<b></b>			
9c.	anv diagnostic o	.'s medical record, did have or surgical procedures that were admission to this agency?	00 🗌 No procedures
ł			01 🗌 Yes 1
			2
	HAND FLASHCAR	D 4.	01 □ Goals met
d.	Why was disc	charged?	
	Mark (X) only one	box	
			04 🗌 Family/friends resumed care
	If the respondent a determine which a	answers "01 – Goals met", PROBE to of the boxes "02–06" you should mark.	os □ Services no longer needed
		,	06 🗌 Other – <i>Specify</i>
			07 □ Moved out of area 08 □ Admitted to hospital
			99 Admitted to nursing home
			10 🗆 Benefits exhausted
			11 Charged/transferred home health/hospice agency
	÷.		
			13 □ Other – <i>Specify</i>
10	What type of ear	e was receiving at the time of	
10.	discharge? Was i	it home health care or hospice care?	01 Home health care
			02
11a.	Did have a pr agency)?	rimary caregiver (outside of this	01 🗌 Yes
			03 🗌 Don't know 🌔 INSTRUCTION BOX
b.	Did usually li caregiver?	ive with (his/her) primary	01 🗌 Yes
	calegiver		02 🗆 No
			03 🗌 Don't know
	HAND FLASHCAR	D 5.	01 🖸 Spouse
c.	What was the rel	lationship of the primary	02 🗆 Parent
	caregiver to?	,	
	Mark (X) only one	box.	04 □ Daughter-in-law/Son-in-law 05 □ Other relative – <i>Specify</i>
			of □ Neighbor
			07 🗆 Friend
			₀ 08 🔲 Volunteer group
			09 🗌 Other – Specify
	····	·	10 🗌 Don't know
	STRUCTION	For items 12 through 19, use the phrase (discharge on date of discharge)" if the	se "THE LAST TIME SERVICE WAS PROVIDED PRIOR TO e patient was discharged alive. Use the phrase "THE LAST
BC	DX	TIME SERVICE WAS PROVIDED PRIOR	TO (death)" if the patient was discharged dead.
	HAND FLASHCAR	D 6.	₀₀ □ No aids used
12.		lestions refer to the patient's	01 🗌 Bedside commode
		me service was provided prior to te of discharge/death).	02 Brace (any type)
		0	<sup>1</sup> 03 □ Cane 1 04 □ Crutches
		vice was provided prior to te of discharge/death), which of	05 □ Dentures (full or partial)
	these aids did	. regularly use?	06 Eyeglasses (including contact lenses)
	Mark (X) all that a	pply.	07 🗌 Hearing aid
	PROBE: Any othe	v aide7	08 Hospital bed
	Thobe. Any one	1 4143.	09 □ Orthotics 10 □ Shower chair
	x		
			12 Wheel chair – Manually operated
			13 🗌 Wheel chair – Motorized
			14 🗌 Other – <i>Specify</i>

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Figure III. Discharge Patient Questionnaire—Con.

	For items 13a–14b, refer to item 12.	01 🗌 Yes
13a.	The last time service was provided prior to	02 No
	(discharge on date of discharge/death), did have any difficulty in seeing (when wearing glasses)?	$1  04 \square \text{ Don't know} \dots \dots$
	HAND FLASHCARD 7.	01  Partially impaired
Ь.	Was's sight (when wearing glasses) partially,	02 🗌 Severely impaired
-	severely, or completely impaired as defined on this card?	03 Completely lost, blind
<u> </u>		04 🗌 Don't know
14a.	The last time service was provided prior to (discharge on date of discharge/death), did have	01 🗌 Yes
	any difficulty in hearing (when wearing a hearing aid)?	02 □ No
	uru/:	$04 \square$ Don't know
	HAND FLASHCARD 8.	01  Partially impaired
h	Was 's hearing (when wearing a hearing aid)	02 Severely impaired
	partially, severely, or completely impaired, as	03 Completely lost, deaf
	defined on this card?	04 🗌 Don't know
15.	HAND FLASHCARD 9.	
	Ask questions 15a through 15k in <b>PART I FIRST</b> . As you ask or respondent time to refer to the flashcard. Mark (X) the "Yes" be	ov for each item the reasondant cause the metions
	nad in his/her home. Then, <b>GO TO PART II</b> , and ask the ques	tion for each item marked "Yes" in Part I.
PAR	T I The following questions refer to the patient's status the last time service was provided prior to (discharge on date of discharge/death).	PART II Did receive assistance from your agency staff in caring for or using:
	The last time service was provided prior to	
	(discharge on <i>date of discharge</i> /death), which of the following items did have in (his/her) home?	
a	Oxygen, respiratory therapy equipment?	
	(1) Ventilator/Respirator	01 ∐ Yes 02 ∐ No 03 ∐ Don't know
	<ul> <li>(2) Liquid oxygen delivery system</li></ul>	1 01 ∐ Yes 02 ∐ No 03 ∐ Don't know
	(4) Gaseous oxygen delivery system 01 🗌 Yes	01 ∐ Yes 02 ∐ No 03 ∐ Don't know
	(5) Nebulizer	01 └ Yes 02 └ No 03 └ Don't know
	(6) Humidifier	「 01 ∐ Yes 02 ∐ No 03 ∐ Don't know
	(7) Suction equipment	1 01 ∐ Yes 02 ∐ No 03 ∐ Don't know
	(8) Tracheostomy	01 └── Yes 02 └── No 03 └── Don't know
b.	Intravenous therapy equipment?	
	(1) Peripheral catheter	01 🗆 Yes 02 🗀 No 03 🗆 Don't know
	(2) Midline catheter	01 □ Yes 02 □ No 03 □ Don't know
		1 01 □ Yes 02 □ No 03 □ Don't know
	(4) Infusion pumps 01 🗌 Yes	01 🗆 Yes 02 🗆 No 03 🗆 Don't know
c.	Decubitus ulcer prevention/treatment equipment?	
	(1) Air mattress/air fluidized bed	
	(2) Foam mattress (egg-crate mattress) 01 🗌 Yes	01 □ Yes 02 □ No 03 □ Don't know
d.	Enteral nutrition equipment?	
	(1) Nasogastric tube	
	(2) Gastrostomy/jejunostomy tube	
		01 □ Yes 02 □ No 03 □ Don't know 01 □ Yes 02 □ No 03 □ Don't know
	CONTINUED ON NEXT PAGE	CONTINUED ON NEXT PAGE

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Figure III. Discharge Patient Questionnaire—Con.

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15.	PART I - Continued	15. PART II - Continued
•••		
	The last time service was provided prior to (discharge on date of discharge/death), which of the following items did have in (his/her) home?	Did receive assistance from your agency staff in caring for or using:
e.	Dialysis equipment?	 
	(1) Peritoneal Dialysis – Manual (continuous) 01 🗌 Yes	¦ 01 □ Yes 02 □ No 03 □ Don't know
	(2) Peritoneal Dialysis – Automated (intermittent/continuous cyclic)	
	(3) Peritoneal – unspecified	01 🗆 Yes 02 🗆 No 03 🗆 Don't know
	(4) Hemodialysis 01 🗆 Yes	01 □ Yes 02 □ No 03 □ Don't know
f.	Blood glucose monitor?	। Ⅰ 01 □ Yes 02 □ No 03 □ Don't know
g.	Drainage devices?	01 ☐ Yes 02 ☐ No 03 ☐ Don't know
	(1) Wound/bile duct/ureteral drainage catheter 01 🗌 Yes	I I 01 □ Yes 02 □ No 03 □ Don't know
	(2) Foley catheter	I I 01 □ Yes 02 □ No 03 □ Don't know
	(3) Intermittent bladder catheterization $\ldots$ . 01 $\Box$ Yes	l 1 01 □ Yes 02 □ No 03 □ Don't know
	(4) External urinary collection devices (e.g. condom catheter)	
	(5) Urostomy	1
	(6) Ileostomy/Colostomy	
Ь	Protective restraints (e.g. vests, belts)? 01 [] Yes	1
1.	Pediatric care? 01 🗌 Yes	
	(1) Apnea monitor	
	(2) Phototherapy lights/equipment	
	Prenatal uterine monitoring? 01 🗌 Yes	
k.	<b>Other?</b> – <i>Specify</i> 01 🗆 Yes	I 01 □ Yes 02 □ No 03 □ Don't know
16.	The last time service was provided prior to (discharge on <i>date of discharge</i> /death), did have any difficulty in controlling (his/her) bowels?	01
	The last time service was provided prior to (discharge on date of discharge/death), did have any difficulty in controlling (his/her) bladder?	01 ☐ Yes 02 ☐ No 03 ☐ Not applicable (e.g. infant, had an indwelling catheter, had an ostomy) 04 ☐ Don't know
NOTE	ES	

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<u> </u>		· · · · · · · · · · · · · · · · · · ·		····-	·····
18.	HAND FLASHCARD 10. The last time service was provided prior to (discharge on date of discharge/death), did receive personal help from this agency in any of the	I I Yes	No	Don't know	Not applicable (e.g., patient was bedfast)
	following activities as defined on this card	I			
	Mark (X) one box for each activity.	1			
a.	Bathing or showering?	01	02 🗌	03 🗌	04 🗆
b.	Dressing?	   01 🗌	02 🗌	03 🗆	04 🗌
<u>c.</u>	Eating?		02 🗌	03 🗌	04 🗌
d.	Transferring in or out of beds or chairs?	01	02	03 🗌	04 🗌
е.	Walking?	01	02 🗌	03 🗌	04 🗆
f.	Using the toilet room?	01	02 🗌	03 🗌	04 🗌
	HAND FLASHCARD 11.				Not
19.	The last time service was provided prior to (discharge on date of discharge/death), did receive personal help from your agency in any of the following activities -	Yes	No	Don't know	applicable (e.g., patient was bedfast)
	Mark (X) one box for each activity.	I 			
a.	Doing light housework?	01	02 🗌	03 🗌	04 🗌
b.	Managing money?	01 🗌	02 🗌	03 🗆	04 🗌
c.	Shopping for groceries or clothes?	01	02 🗌	03 🗖	04 🗌
d.	Using the telephone (dialing or receiving calls)?	01.	02 🗌	03 🗌	04 🗌
e.	Preparing meals?	01	02 🗌	03 🗌	04 🗔
f.	Taking medications?	I 01 🗌	02 🗌	03 🗌	04
	HAND FLASHCARD 12.		Lene		I
	During the 30 days prior to discharge, which of these services were provided to BY YOUR AGENCY? Mark (X) all that apply. PROBE: Any other services?	<ul> <li>00 None</li> <li>01 Continuous home care</li> <li>02 Counseling</li> <li>03 Homemaker-household services</li> <li>04 Medications</li> <li>05 Mental health services</li> <li>06 Nursing services</li> <li>07 Nutritionist services</li> <li>08 Occupational therapy</li> <li>09 Physical therapy</li> <li>10 Physician services</li> <li>11 Social services</li> <li>12 Speech therapy/Audiology</li> <li>13 Transportation</li> <li>14 Volunteers</li> <li>15 Other services - Specify z</li> </ul>			
NOTE	S				FORM HHCS-5 (3-29-96)

HAND FLASHCARD 13.		· · · · · · · · · · · · · · · · · · ·	
20b. During the 30 days prior to discharge, wh these service providers FROM YOUR AGE visited?	ich of NCY 00 □ None 1 01 □ Chaplain 02 □ Dieticians/Nutritionists 03 □ Home health aides		
Mark (X) all that apply.	04 Homemakers/Personal ca	aretakers	
PROBE: Any other providers?	<ul> <li>05 Licensed practical or voc</li> <li>06 Nursing aides and attend</li> <li>07 Occupational therapists</li> <li>08 Physical therapists</li> <li>09 Physicians</li> <li>10 Registered nurses</li> <li>11 Respiratory therapists</li> <li>12 Social workers</li> <li>13 Speech pathologists/aud</li> <li>14 Volunteers</li> <li>15 Other providers - Specif</li> </ul>	ational nurses lants iologists	
HAND FLASHCARD 14.		Home Health	Hospice
		Care	Care
21. What was the PRIMARY expected source o payment for 's entire episode of care? Mark (X) only one source.	f 01		01 🗌 02 🛄
For the source of payment ask: Was the (source of payment) for home health	03 🗆 Supplemental Security	03	03 🗌
care or hospice care?	04 🗌 Medicare	04 🗌	04 🗖
	05 🗌 Medicaid	05	05 🗌
	06 Cher government medic assistance	al 06 🗌	06 🗌
	07  Religious organizations, foundations, agencies	07 🗌	07 🗌
	08 🗌 VA contract, pensions, or other VA compensation	- 08 🗌	08 🗌
	09 🗌 No charge made for care	09 🗖	09 🗖
	10 Payment source not yet determined	10 🗌	10 🗖
	I 11 □ Other – Specify 🖌	11 🗖	11 🗋
	12 🗆 Don't know		
NOTES			

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		Home Health Care	Hospice Care
22. What were ALL the secondary sources of 01	Private insurance	01	01
payment for 's entire episode of care?       02         Mark (X) all that apply.       02	Own income, family support, Social Security benefits, retirement funds, or welfare	02 🗌	02
	Supplemental Security	03 🗌	03 🗌
For the source of payment ask:	Income (SSI)	04 🗌	04
Was the (source of normant) for home health	☐ Medicaid	05	05
06[	Other government medical assistance	06 🗌	06 🗌
07 [	Religious organizations, foundations, agencies	07 🗌	07 🗌
08 [	VA contract, pensions, or other VA compensation	08 🗌	08 🗌
	☐ No charge made for care	09 🔲	09 🗌
10	Payment source not yet determined	10 🗔	10 🗌
	Other – Specify Z	11 🗌	11 🗌
	Don't know		
23. When was the last time service was provided?	onth Day Year		
FILL SECTION C ON THE COVER OF T WITH THE NEXT DISCHARGED PA			
NOTES			

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