NHPCO Facts and Figures

2022 EDITION

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NHPCO
National Hospice and Palliative Care Organization

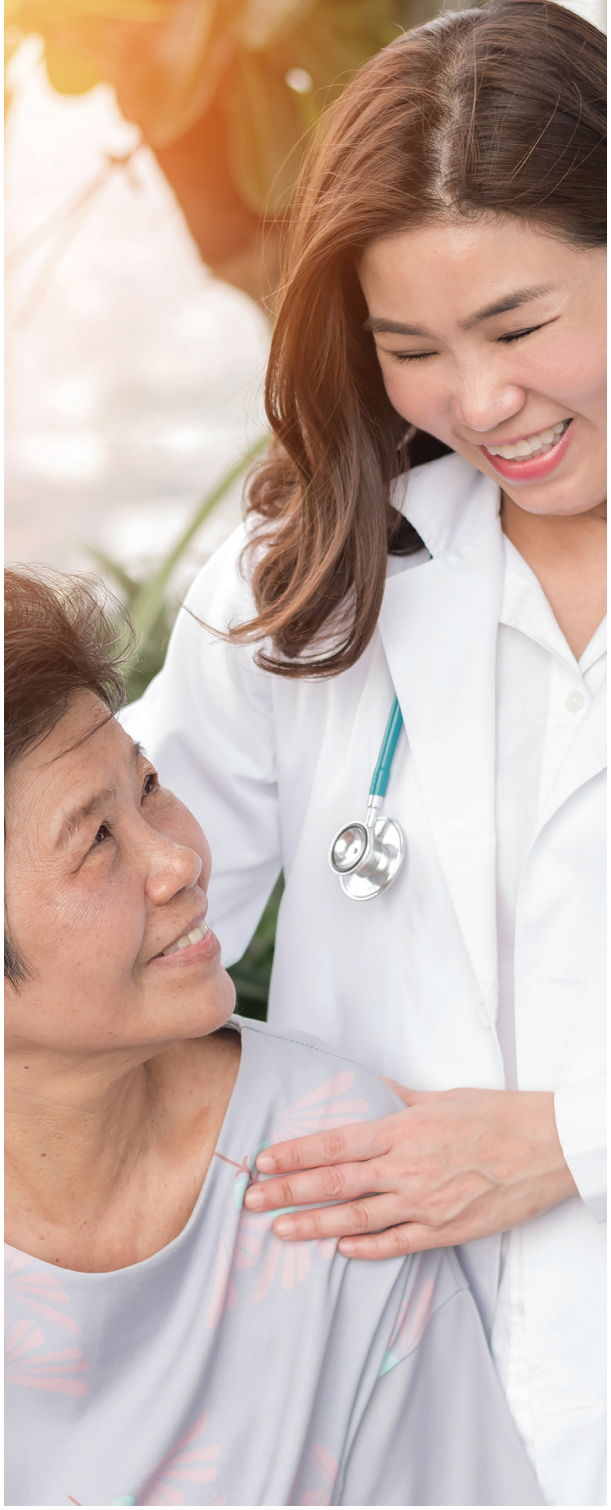


Table of Contents

Please see the Data Sources Section at the end of this report for details on the data sources used within this publication.

Section 1: Introduction

About this Report

NHPCO Facts and Figures provides an annual overview of hospice care delivery. This overview provides specific information on:

- Hospice patient characteristics
- Location and level of care
- Medicare hospice spending
- Hospice provider characteristics
- Volunteer and bereavement services

Currently, most hospice patients have their costs covered by Medicare, through the Medicare Hospice Benefit. The findings in this report reflect only those patients who received care through 2020, provided by the hospices certified by the Centers for Medicare and Medicaid Services (CMS) and reimbursed under the Medicare Hospice Benefit.

Impact of COVID-19

This year differs from years past as 2020 saw the effect of the COVID-19 pandemic along with various waivers to the traditional delivery of hospice care. These waivers included increased telehealth services. 2020 saw decreases in hospice usage in many areas due to death outpacing hospice use.

What is hospice care?

Considered the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's family as well.

Hospice focuses on caring, not curing. In most cases, care is provided in the patient's private residence, but may also be provided in freestanding

Introduction (continued)

hospice facilities, hospitals, nursing homes, or other long-term care facilities. Hospice services are available to patients with any terminal illness with a prognosis of six months or less to live if the illness follows its expected course. Hospices promote inclusiveness in the community by ensuring all people regardless of race, ethnicity, color, religion, gender, disability, sexual orientation, age, disease, or other characteristics have access to the hospice's programs and services.

How is hospice care delivered?

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff are on-call 24 hours a day, seven days a week.

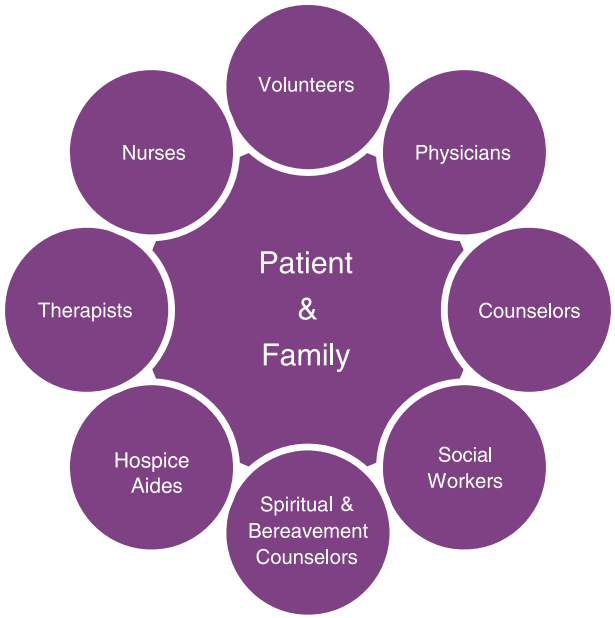
The hospice team develops a care plan to meet each patient's individual needs for pain management and symptom control. This interdisciplinary team, as illustrated in Figure 1, usually consists of the patient's personal physician; hospice physician or medical director; nurses; hospice aides; social workers; bereavement counselors; clergy or other spiritual counselors; trained volunteers; and speech, physical, and occupational therapists, if needed.

What services are provided?

The interdisciplinary hospice team:

- Manages the patient's pain and other symptoms
- Assists the patient and family members with the emotional, psychosocial, and spiritual aspects of dying
- Provides medications and medical equipment
- Instructs the family on how to care for the patient
- Provides grief support and counseling
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Delivers special services like speech and physical therapy when needed
- Provides grief support and counseling to surviving family and friends

Figure 1: Structure of the interdisciplinary team



Introduction (continued)

Location of Care

The majority of hospice care is provided in the place the patient calls home. In addition to private residences, this includes nursing homes and residential facilities. Hospice care may also be provided in freestanding hospice facilities and hospitals (see Levels of Care).

Levels of Care

Hospice patients may require differing intensities of care during the course of their illness. While hospice patients may be admitted at any level of care, changes in their status may require a change in their level of care.

The Medicare Hospice Benefit affords patients four levels of care to meet their clinical needs: Routine Home Care, Continuous Home Care, Inpatient Respite Care, and General Inpatient Care. Payment for each covers all aspects of the patient's care related to the terminal illness, including all services delivered by the interdisciplinary team, medication, medical equipment, and supplies.

- **Routine Home Care (RHC)** is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their residence.
- **Continuous Home Care (CHC)** is care provided for between 8 and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be predominately nursing care, supplemented with caregiver and hospice aide services intended to maintain the terminally ill patient at home during a pain or symptom crisis.
- **Inpatient Respite Care (IRC)** is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long-term care facility that has enough 24-hour nursing personnel present.
- **General Inpatient Care (GIP)** is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or skilled nursing facility with a registered nursing available 24 hours a day to provide direct patient care.

Introduction (continued)

Volunteer Services

The U.S. hospice movement was founded by volunteers who continue to play an important and valuable role in hospice care and operations. Moreover, hospice is unique in that it is the only provider with a Medicare Conditions of Participation requirement for volunteers to provide.

Hospice volunteers provide service in three general areas:

- Spending time with patients and families ("direct support")
- Providing clerical and other services that support patient care and clinical services ("clinical support")
- Engaging in a variety of activities such as fundraising, outreach and education, and serving on a board of directors (general support).

Bereavement Services

Counseling or grief support for the patient and loved ones is an essential part of hospice care. After the patient's death, bereavement support is offered to families for at least one year. These services can take a variety of forms, including telephone calls, visits, written materials about grieving, phone or video calls, and support groups. Individual counseling may be offered by the hospice or the hospice may make a referral to a community resource.

Some hospices also provide bereavement services to the community as a whole, in addition to supporting patients and their families.

See appendix for details on methodology and data sources, including cited references within the report.

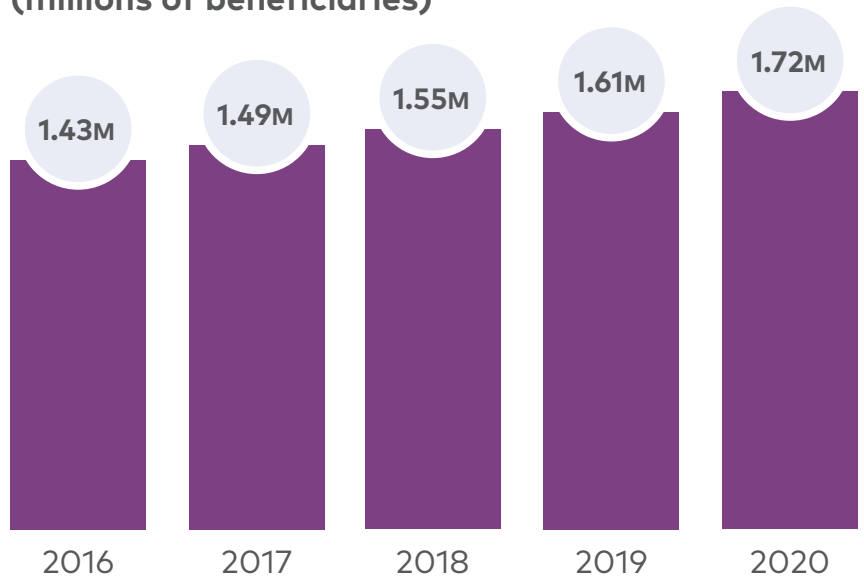
Section 2: Who Receives Hospice Care?

How many Medicare beneficiaries received care?

As seen in Figure 2, 1.72 million Medicare beneficiaries were enrolled in hospice care for one day or more in 2020. Per MedPAC analysis, this is a 6.8% increase from 2019. This is the largest increase in the number of Americans choosing hospice care in the last four years, both in absolute numbers and as a percentage. This includes patients who:

- Died while enrolled in hospice
- Were enrolled in hospice in 2019 and continued to receive care in 2020
- Left hospice care alive during 2020 (live discharges)

Figure 2: Number of Medicare hospice users (millions of beneficiaries)



***Includes all states, Washington, D.C., U.S. territories, and other**

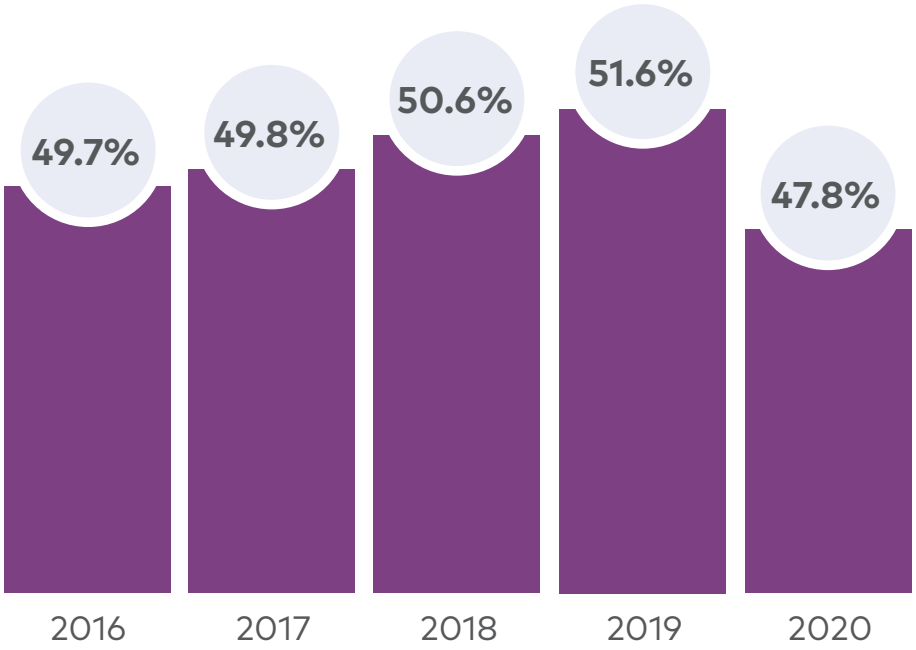
***Source:** MedPAC March 2022 Report to Congress, 11-6; MedPAC March 2021 Report to Congress, Table 11-3; MedPAC March 2020 Report to Congress, Table 11-3*

Who Receives Hospice Care? (continued)

What proportion of Medicare decedents were served by hospice?

Of all Medicare decedents in 2020, 47.8% received one day or more of hospice care and were enrolled in hospice at the time of death. This is the lowest share of decedents using hospice since 2013 where 47.3% of decedents received one or more days of hospice care. This decrease was due to death outpacing the growth in hospice enrollment.

Figure 3: Share of Medicare decedents who used hospice (percentage)



Source: *MedPac March 2022 Report to Congress, Table 11-2*

Utah Medicare beneficiaries had the highest utilization of hospice with 60.7% of Medicare deaths occurring on hospice; whereas, New York had the lowest utilization with 24.7%.

Figure 4: Hospice utilization by state (percentage)

Rank	State	
1	Utah	60.7%
2	Florida	56.2%
3	Ohio	54.8%
4	Wisconsin	54.7%
5	Arizona	54.7%
6	Oregon	54.5%
7	Idaho	54.1%
8	Minnesota	53.6%
9	Maine	52.9%
10	Iowa	52.7%
11	Kansas	52.1%
12	Delaware	51.9%
13	Rhode Island	51.2%
14	Colorado	50.4%
15	South Carolina	50.1%
16	Michigan	49.8%
17	Texas	49.8%
18	Nebraska	48.3%
19	New Hampshire	48.3%
20	Georgia	48.3%
21	Oklahoma	48.3%
22	Hawaii	48.0%
23	North Carolina	47.9%
24	Missouri	47.5%
25	Indiana	47.3%
26	Illinois	47.1%
27	National	46.7%
28	Louisiana	46.7%
29	Alabama	46.6%
30	Nevada	46.4%
31	Virginia	46.2%
32	Pennsylvania	46.1%
33	Arkansas	45.7%
34	Washington	45.5%
35	New Mexico	45.4%
36	Massachusetts	45.1%
37	Tennessee	45.0%
38	Vermont	44.5%
39	Maryland	44.4%
40	Connecticut	43.8%
41	West Virginia	42.4%
42	California	42.3%
43	Mississippi	42.3%
44	Kentucky	42.1%
45	Montana	41.2%
46	South Dakota	40.7%
47	New Jersey	39.5%
48	Wyoming	33.1%
49	North Dakota	31.6%
50	Alaska	30.1%
51	District of Columbia	25.8%
52	New York	24.7%

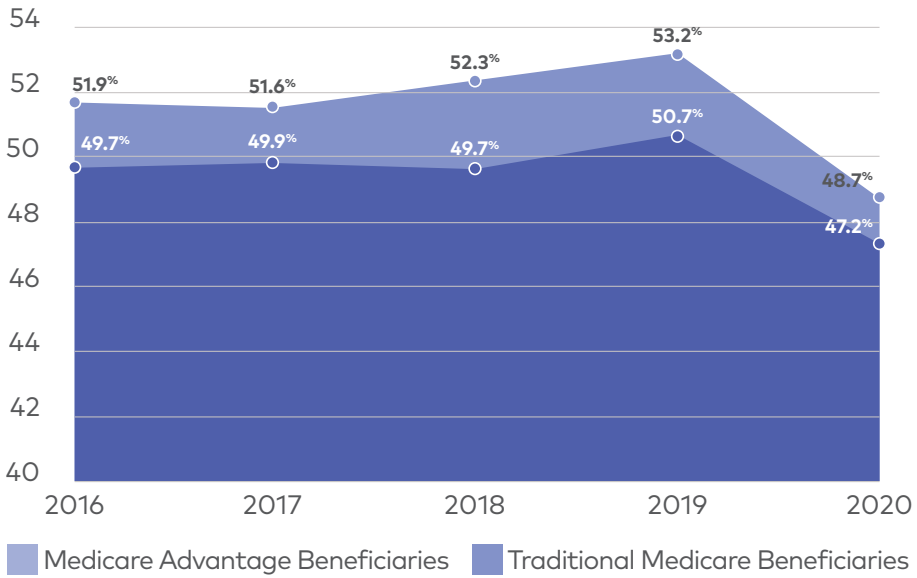
Source: *Hospice Analytics*

Who Receives Hospice Care? (continued)

What percent of hospice patients were enrolled in Medicare Advantage within the year?

As demonstrated in Figure 4, utilization of the hospice benefit remains slightly higher among decedents enrolled in Medicare Advantage (MA) plans than among traditional Medicare users, while the trendline for hospice usage decreased in both groups. The share of MA decedents who utilized the hospice benefit decreased from 53.2% in 2019 to 48.7% in 2020. During the same period, traditional Medicare decedents utilizing the hospice benefit decreased from 50.7% in 2019 to 47.2% in 2020.

Figure 5: Utilization of hospice by MA & Traditional Medicare



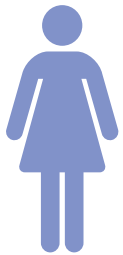
Source: *MedPac March 222 Report to Congress, Table 11-3; various years*

What are the characteristics of Medicare beneficiaries who received hospice care?

Patient Gender

In 2020, when presented with a binary question, beneficiaries who identified as female and died in 2020, 52.7% used hospice. Among beneficiaries who identified as male and died in 2020, 42.9% used hospice. Both groups saw a drop in usage of more than three percentage points.

Figure 6: Patient Gender



Among Medicare decedents who identified as female

52.7%

used hospice

Among Medicare decedents who identified as male

42.9%

used hospice

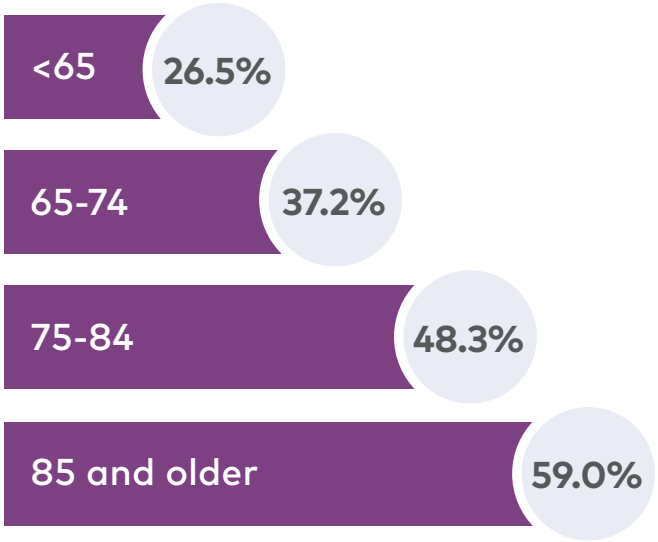
Source: *MedPac March 2022 Report to Congress, Table 11-3*

Who Receives Hospice Care? (continued)

Patient Age

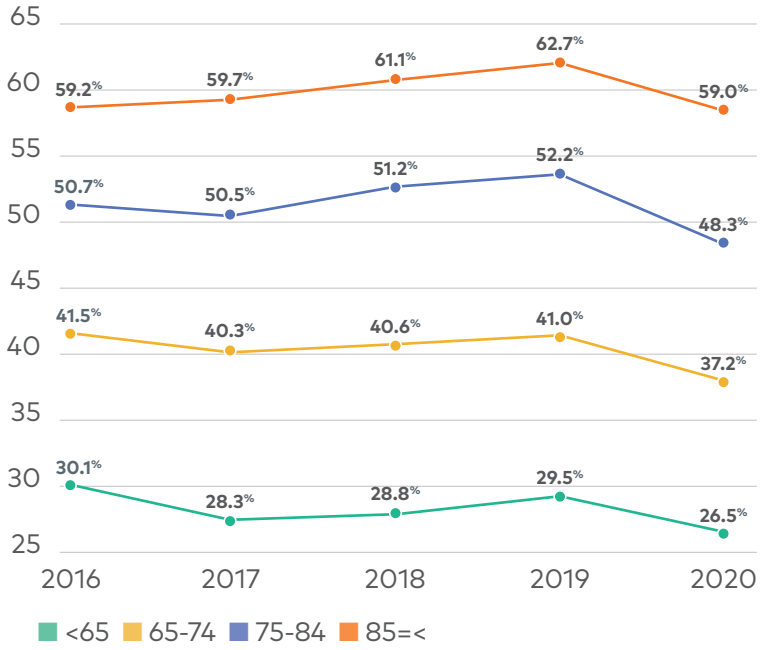
In 2020, as shown in Figure 7, 59% of Medicare decedents age 85 years and older utilized the Medicare hospice benefit, while progressively smaller percentages of decedents in younger age groups received hospice care. Figure 8 continues to highlight the drop in hospice usage in 2020 with all four Medicare beneficiary age groups seeing at least a 3 percentage point drop in usage from 2019 to 2020.

Figure 7: Share of Medicare decedents who used hospice, by age 2020 (percentage)



Source: *MedPAC March 2022 Report to Congress, Table 11-3*

Figure 8: Share of Medicare decedents who used hospice, by age 2016-20



Source: *MedPAC March 2022 Report to Congress, Table 11-3 & MedPAC March 2021 Report to Congress, Table 11-2*

Who Receives Hospice Care? (continued)

Patient Race/Ethnicity

2020 Medicare data present combined information on patient race and ethnicity. In 2020, 50.8% of White Medicare decedent beneficiaries used the Medicare hospice benefit. 36.1% of Asian American Medicare beneficiaries and 35.5% of Black Medicare beneficiaries enrolled in hospice in 2020. More than 33 percent of Hispanic and American Indian/Alaska Native Medicare decedents used hospice in 2020.

Figure 10 shows the decrease in hospice use from 2019 to 2020 with Hispanic beneficiaries seeing the largest decrease (9.4 percentage points) whereas White beneficiaries saw the smallest decrease (3.0 percentage points). Black beneficiaries saw a decrease of usage of 5.3 percentage points, North American Native beneficiaries saw a 5.0 percentage points decrease, and Asian American beneficiaries saw 3.7 percentage points decrease.

Figure 9: Share of Medicare decedents who used hospice, by race

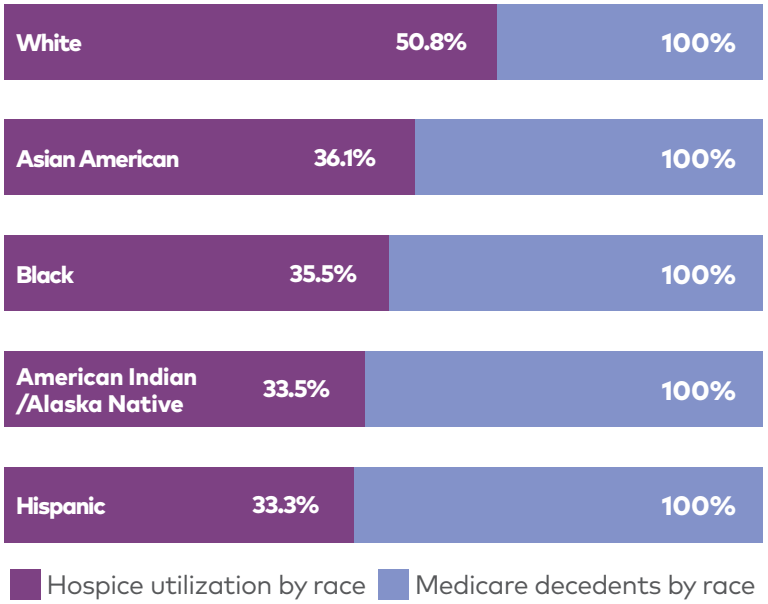
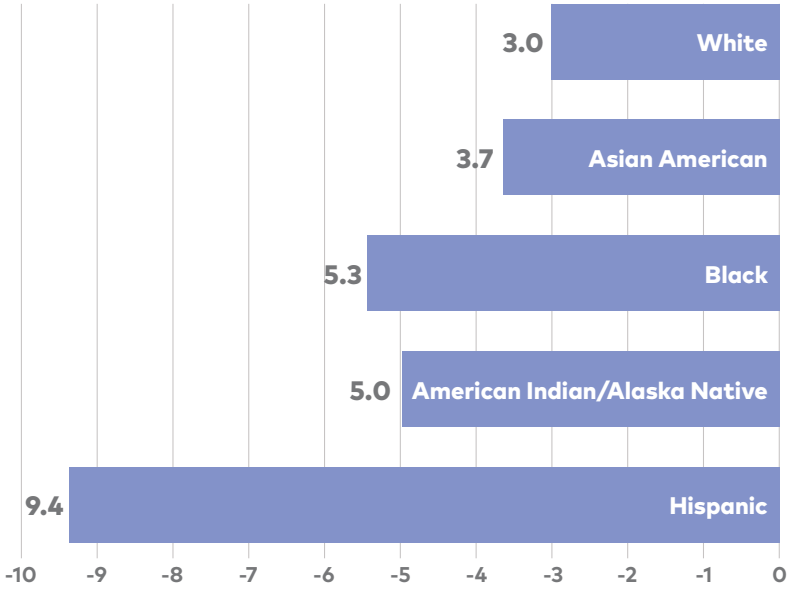


Figure 10: Percentage point change of decedents who use hospice, by race



Source: *MedPAC March 2022 Report to Congress, Table 11-3*

Who Receives Hospice Care? (continued)

Principal Diagnosis

The principal hospice diagnosis is the diagnosis used to determine the most contributory to the patient's terminal prognosis. Specific diagnoses have been collapsed into major disease groupings in Figures 11 and 12. Although a decrease from 2019, Alzheimer's/Dementias/ Parkinson's remained the largest group of primary diagnoses for Medicare hospice beneficiaries (18.5%), while cancer diagnosis remained stable at 7.5%. COVID-19, although it may be contributory to deaths of beneficiaries with other principal diagnoses, accounted for only 0.9% of principal diagnosis.

Figure 11: Medicare Decedents Using Hospice by Top 20 Principal Diagnoses (percentage)

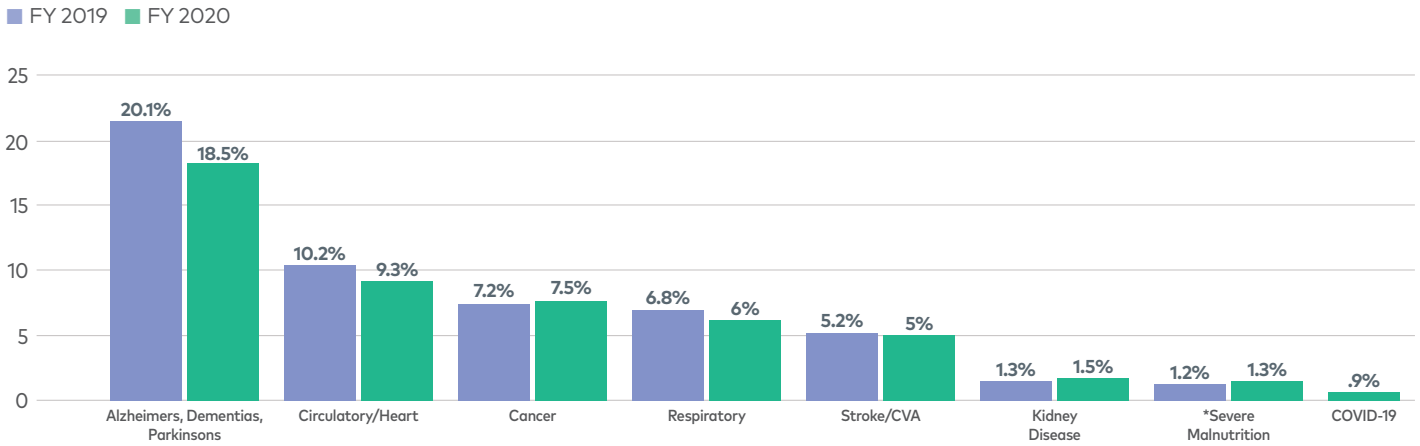
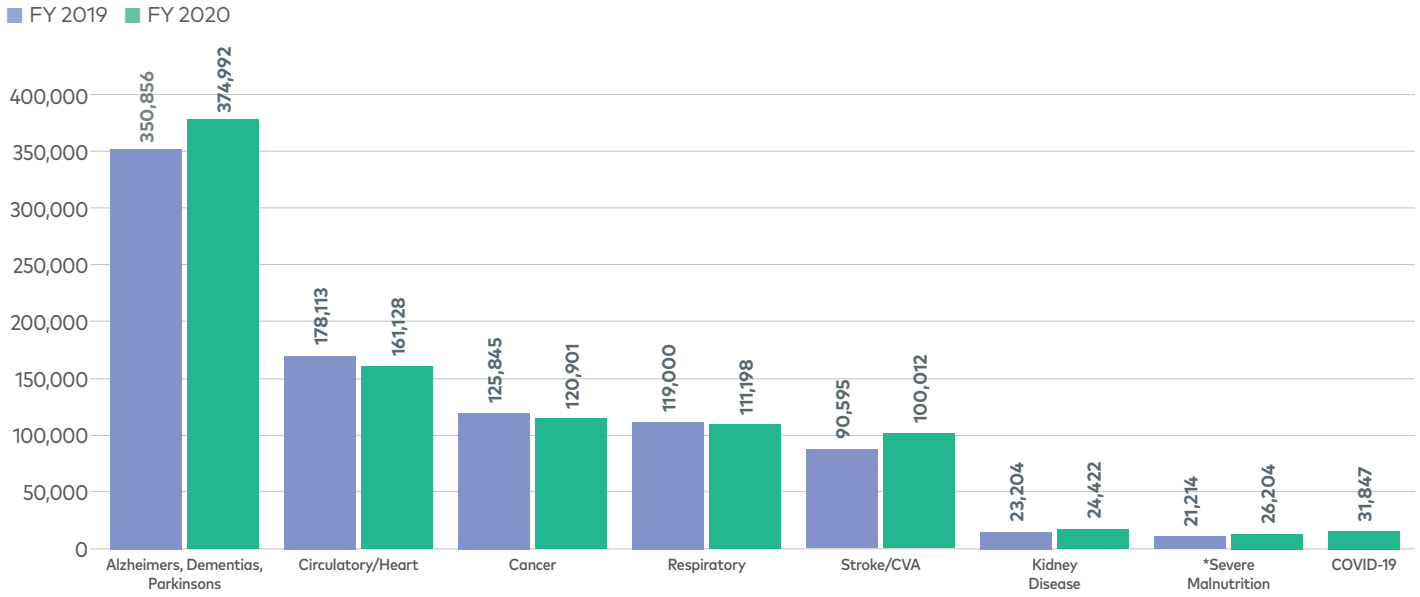


Figure 12: Medicare Decedents Using Hospice by Top 20 Diagnoses (number)



Note: *Only the top 20 diagnoses were included in these groupings. Additional diagnosis that could fall under these groupings are outside of the top 20 diagnoses.*
Source: *Hospice Analytics*

Section 3: How Much Care Is Received?

Length of Stay

The average Length of Stay (LOS) for Medicare patients enrolled in hospice in 2020 was 97.0 days; the largest increase in the previous five years. The median length of stay (MLOS) was 18 days which has been consist over the previous five years.

Table 1: Average Lifetime Length of Stay

Year	Total Days (in millions)	Average Length of Stay	Median Length of Stay	Number of Patients (in millions)
2016	101.2	87.8	18	1.43
2017	106.3	89.3	18	1.49
2018	113.5	90.3	18	1.55
2019	121.8	92.5	18	1.61
2020	127.8	97.0	18	1.72

Note: *"Lifetime length of stay" is calculated for decedents who were using hospice at the time of death or before death and reflects the total number of days the decedent was enrolled in the Medicare hospice benefit during their lifetime. The data displayed in the table are rounded.*

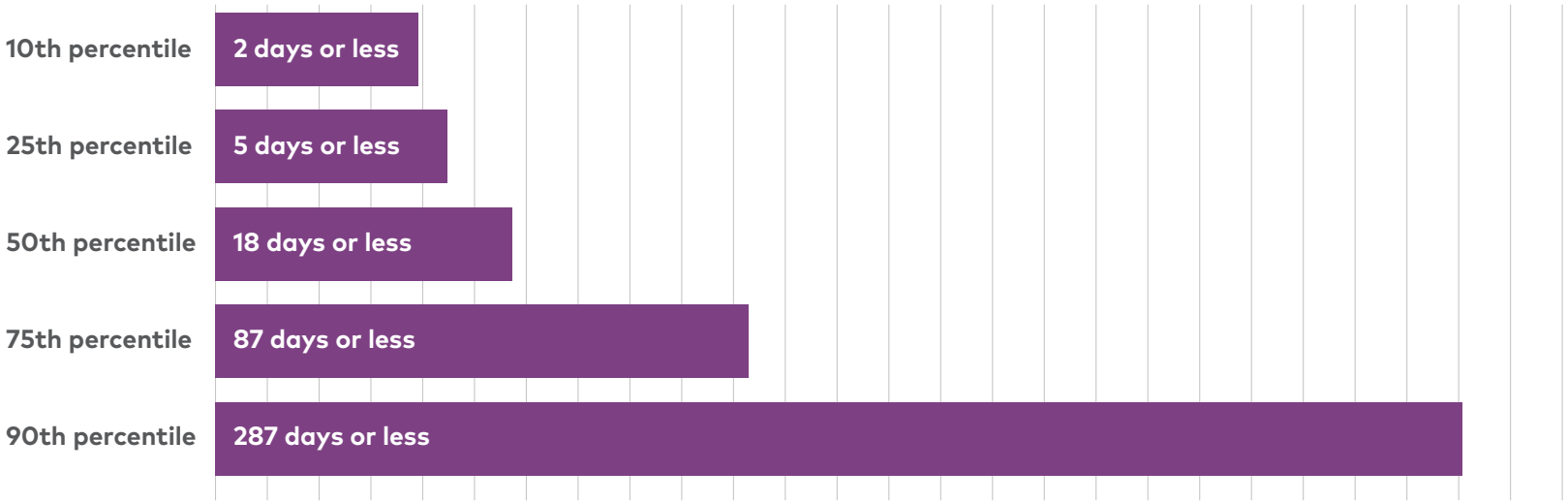
Source: *MedPAC March 2022 Report to Congress, Table 11-6; MedPAC 2021 Report to Congress, Table 11-3*

How Much Care Is Received? (continued)

Days of Care by Lifetime Length of Stay in 2019

- 10% of patients were enrolled in hospice for 2 days or less.
- 25% of patients were enrolled in hospice for 5 days or less.
- 50% of patients were enrolled for 18 days or less.
- 75% of patients were enrolled for 87 days or less.
- Only 10% of patients were enrolled for more than 287 days.

Figure 13: Days of Care by Lifetime Length of Stay (in days), 2020



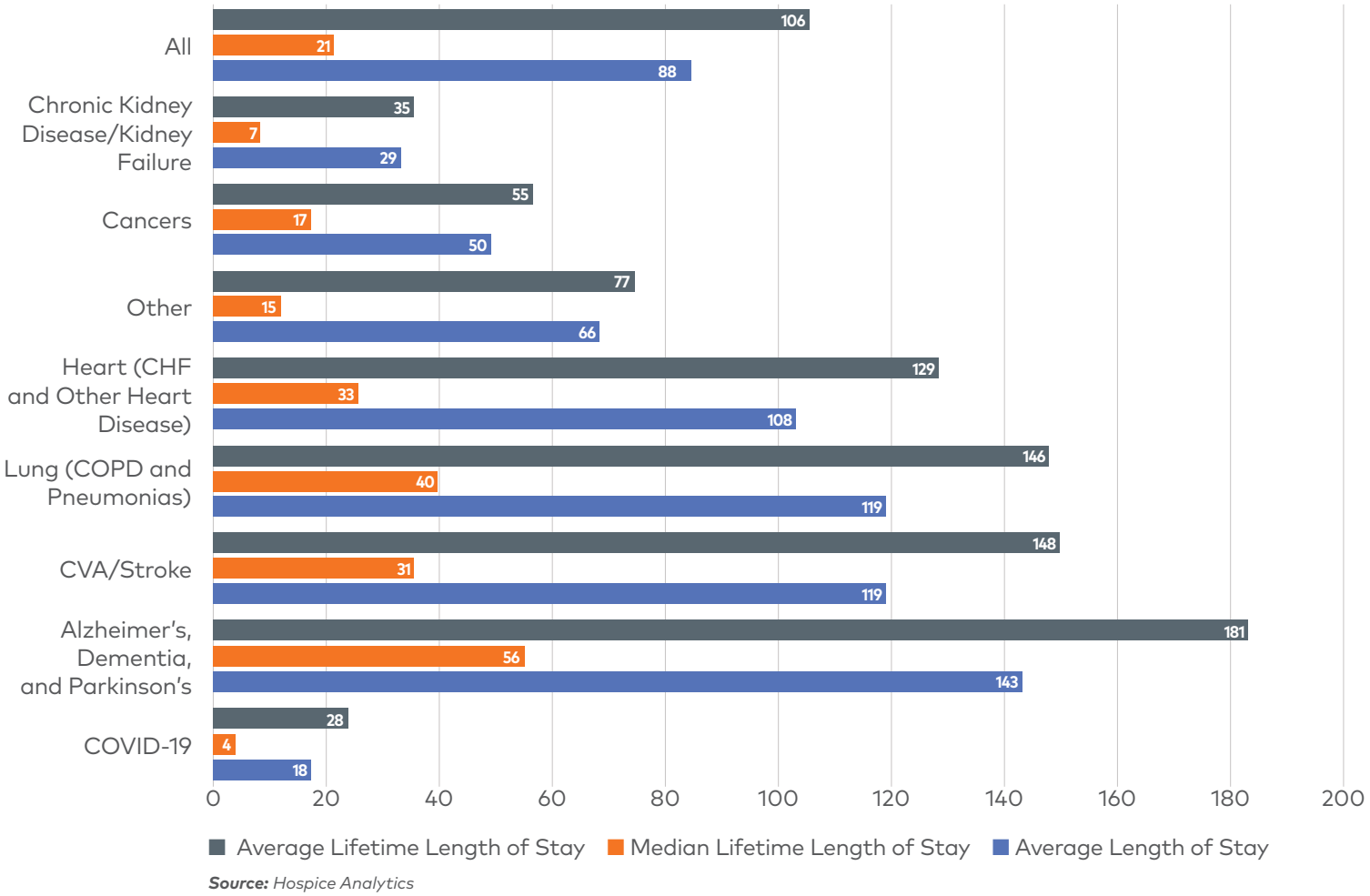
Source: *MedPAC July Data Book, 2022, Chart 11-13*

How Much Care Is Received? (continued)

Days of Care

Figure 14 depicts the average and median lifetime length of stay for major hospice disease categories. Neurological and stroke/CVA have the longest average lifetime (181, 148 respectively) whereas neurological and respiratory had the longest median lifetime (56, 40 respectively). Per CMS, average length of stay means the number of hospice days during a single hospice election at the time of live discharge or death; the median lifetime length of stay represents the 50th percentile, and; average lifetime length of stay includes the sum of all days of hospice care across all hospice elections.

Figure 14: Average lifetime lengths of stay, median lifetime lengths of stay, and average length of Stay, 2020



Source: *Hospice Analytics*

How Much Care Is Received? (continued)

Discharges

In 2020, 15.4% percent of all Medicare hospice discharges were discharged alive, which was a 2 percentage point decrease from 2019. All hospice discharges saw a decrease in 2020 except for discharge for cause, which did not change.

Table 2: Rates of hospice live discharge and reported reason for discharge, 2018–2020 (percentage)

Reason for Discharge	2018	2019	2020
All discharges	17.0%	17.4%	15.4%
Patient-Initiated Live Discharges			
Revocation	6.6	6.5	5.7
Transferred hospice providers	2.2	2.3	2.2
Hospice-Initiated Live Discharges			
No longer terminally ill	6.3	6.5	5.6
Moved out of service area	1.6	1.7	1.6
Discharge for cause	0.3	0.3	0.3

Calculations are based on total number of discharges which includes patients who were discharged more than one time in 2019.

Source: *MedPAC March 2022 Report to Congress, Table 11-13*

How Much Care Is Received? (continued)

Location of Care

In 2020, Medicare beneficiaries received the most days of care at private residences followed by nursing facilities and assisted living facilities.

Average days by location of care as shown in Figure 15 were 90 days at a private residence, 133 days in nursing facilities, and 172 days in assisted living facilities. Median length of stay by location of care, shown in Figure 16, were 23 days at a private residence, 26 days in nursing facilities, and 59 days in assisted living facilities. In both the average and median length of stay, there was a decrease from 2019 in private residences but an increase for nursing facilities and assisted living facilities.

Table 3: Location of Care by Average and Median Days of Care, 2020

	Average	Median
Private Residence	90	23
Nursing Facility	133	26
Assisted Living Facility	172	59

Source: *MedPAC March 2022 Report to Congress, Table 11-7; MedPAC March 2021 Report to Congress, Table 11-4*

Figure 15: Average Days by Location of Care

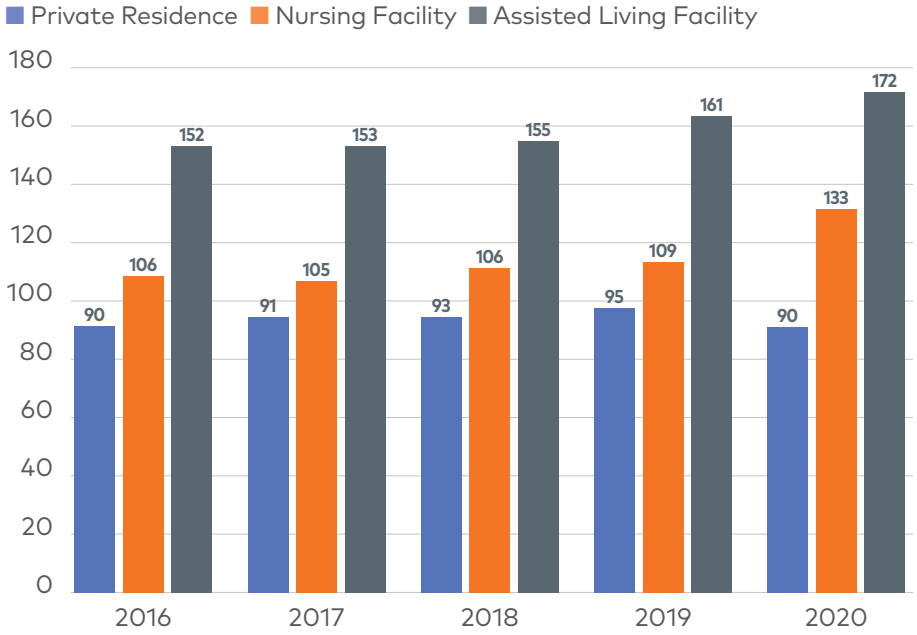
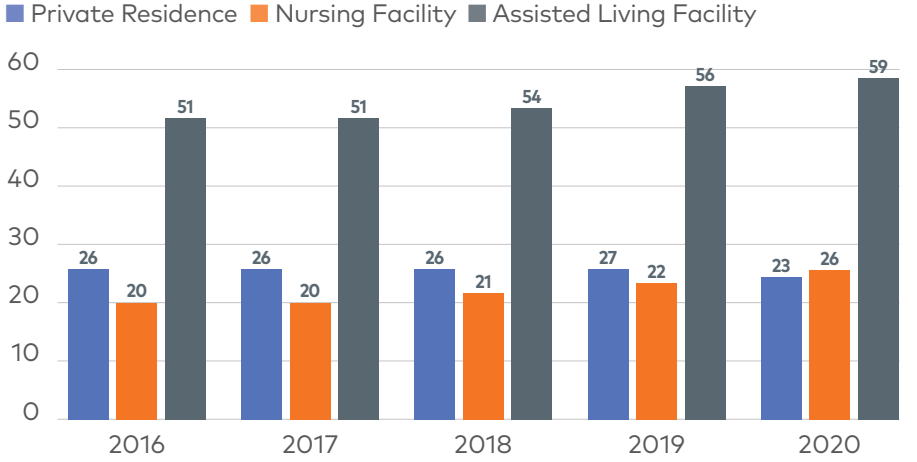


Figure 16: Median Days by Location of Care

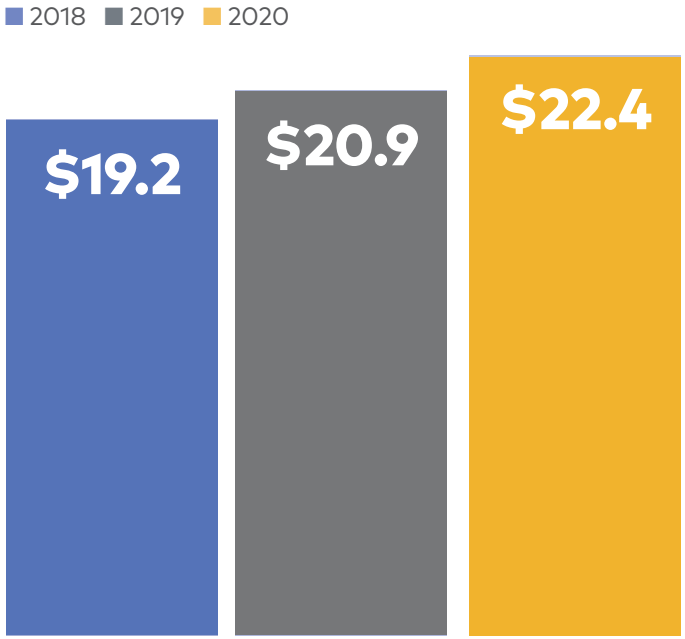


Source: *Source: MedPAC March 2022 Report to Congress, Table 11-7; MedPAC March 2021 Report to Congress, Table 11-4*

Section 4: How Does Medicare Pay for Hospice?

Medicare paid hospice providers a total of $22.4 billion dollars for care provided in 2020, representing an increase of 7.4% over the previous year.

Figure 17: Medicare Spending (billions of US Dollars)



Source: *MedPAC March 2022 Report to Congress, table 11-6*

Spending by Level of Care

In 2020, the vast majority of Medicare days of care were at the routine home care (RHC) level with a slight increase from previous years. General inpatient (GIP) level saw a slight decrease from 2019 (1.2 to 1.0).

Table 4: Spending by Level of Care

Percent of Days by Spending	
Routine Home Care (RHC)	92.7%
General Inpatient Care (GIP)	5.6%
Inpatient Respite Care (IRC)	0.6%
Continuous Home Care (CHC)	1.1%

Source: *Hospice Analytics*

Table 5: Percent of Days by Level of Care

Percent of Days by Level of Care	2016	2017	2018	2019	2020
Routine home care	98.0%	98.0%	98.2%	98.3%	98.7%
General inpatient care	1.6%	1.3%	1.2%	1.2%	1.0%
Inpatient respite care	0.3%	0.3%	0.3%	0.3%	0.2%
Continuous home care	0.3%	0.2%	0.2%	0.2%	0.2%

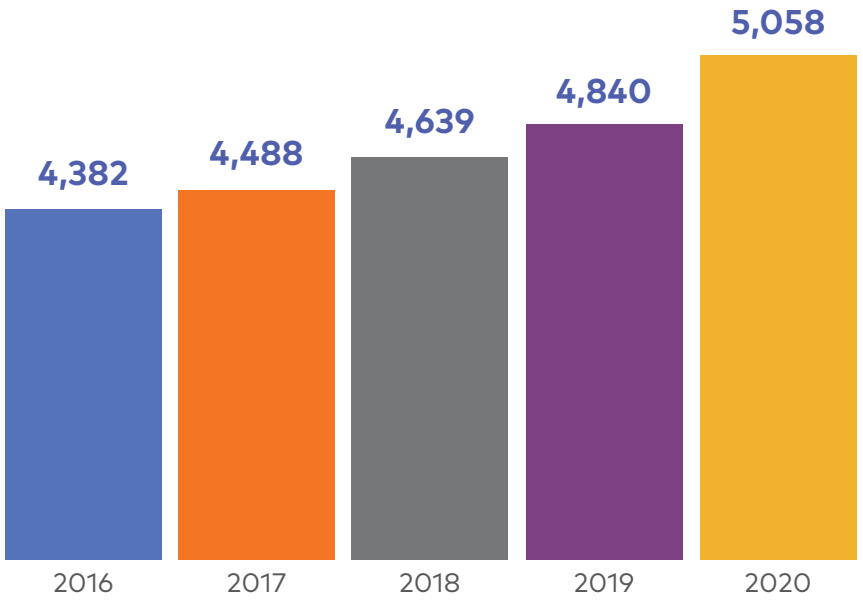
Source: *MedPAC March Report to Congress, various years; Hospice Analytics*

Section 5: Who Provides Care?

How many hospices were in operation in 2020?

Over the course of 2020, there were 5,058 Medicare certified hospices in operation based on claims data. This represents an increase of 4.50% since 2019.

Figure 18: Number of Operating Hospices

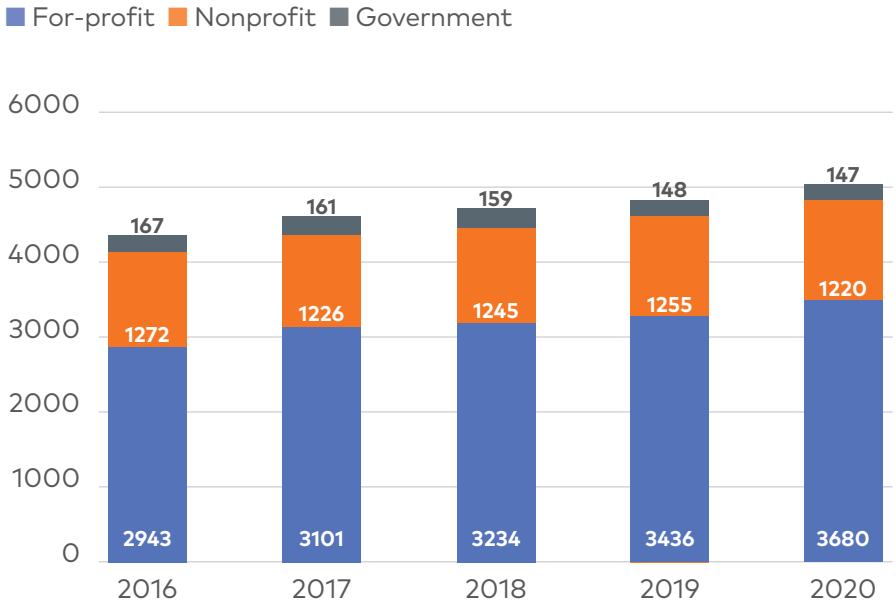


Source: *MedPAC March 2022 Report to Congress, Table 11-1; MedPAC March 2021 Report to Congress, Table 11-1*

Tax Status

As shown in Figure 19, the growth in hospice ownership is being driven by the growth in for-profit ownership. As reported by MedPAC in the March 2022 Report to Congress, between 2019 and 2020, the number of for-profit hospices continued to increase (7.1% since 2019), while the number of nonprofit hospices decreased by 2.8 % and government owned hospices declined by 0.7%. As of 2020, over 72% of hospices were for profit, approximately 24% were nonprofit, while just under 3% were government owned.

Figure 19: Providers by Type



Source: *MedPAC March 2022 Report to Congress, Table 11-1; MedPAC March 2021 Report to Congress, Table 11-1*

Appendix: Data Sources and Methodology

The data sources primarily used for this report are from the MedPAC March Report to Congress (various years). See cited sources throughout the report for each table and figure. For data references provided by MedPAC, the March Report to Congress from various years or the FY2022 MedPAC Data Book are used. They can be found at www.medpac.gov. In addition, Hospice Analytics provided additional data.

Questions May Be Directed To:

National Hospice and Palliative Care Organization

Attention: Communications

Phone: 703.837.1500

Web: www.nhpco.org/hospice-care-overview/hospice-facts-figures/

Email: Communications@nhpco.org

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