Local Service Category:	**Hospice Services**
Amount Available**:**	**To be determined**
Unit Cost	
Budget Requirements or Restrictions:	Maximum 10% of budget for Administrative Cost
DSHS Service Category Definition:	Provision of end-of-life care provided by licensed hospice care providers to clients in the terminal stages of an HIV-related illness, in a home or other residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice care for terminal patients. Hospice services include, but are not limited to, the palliation and management of the terminal illness and conditions related to the terminal illness. Allowable Ryan White/State Services funded services are: • Room • Board • Nursing care • Mental health counseling, to include bereavement counseling • Physician services • Palliative therapeutics Ryan White/State Service funds may not be used for funeral, burial, cremation, or related expenses. Funds may not be used for nutritional services, durable medical equipment and medical supplies or case management services.
Local Service Category Definition:	Hospice services encompass palliative care for terminally ill clients and support services for clients and their families. Services are provided by a licensed nurse and/or physical therapist. Additionally, unlicensed personnel may deliver services under the delegation of a licensed nurse or physical therapist, to a client or a client's family as part of a coordinated program. A physician must certify that a patient is terminal, defined under Medicaid hospice regulations as having a life expectancy of 6 months or less. Services must include but are not limited to medical and nursing care, palliative care, and psychosocial support for the patient, as well as a mechanism for bereavement referral for surviving family members. Counseling services provided in the context of hospice care must be consistent with the (Ryan White) definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Program.
Target Population (age, gender, geographic, race, ethnicity, etc.):	People living with HIV and having a life expectancy of 6 months or less residing in the Houston HIV Service Delivery (HSDA).
Services to be Provided:	Services must include but are not limited to medical and nursing care,

	palliative care, psychosocial support and spiritual guidance for the patient, as well as a mechanism for bereavement referral for surviving family members. Counseling services provided in the context of hospice care must be consistent with the (Ryan White) definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Program. Allowable Ryan White/State Services funded services are: • Room • Board • Nursing care • Mental health counseling, to include bereavement counseling • Physician services • Palliative therapeutics Services NOT allowed under this category: • HIV medications under hospice care unless paid for by the client. • Medical care for acute conditions or acute exacerbations of chronic conditions other than HIV for potentially Medicaid eligible residents. • Funeral, burial, cremation, or related expenses. • Nutritional services, • Durable medical equipment and medical supplies. • Case management services. • Although Texas Medicaid can pay for bereavement counseling for family members for up to a year after the patient's death and can be offered in a skilled nursing facility or nursing home, Ryan White funding CANNOT pay for these services per legislation.
Service Unit Definition(s):	A unit of service is defined as one (1) twenty-four (24) hour day of hospice services that includes a full range of physical and psychological support to HIV patients in the final stages of AIDS.
Financial Eligibility:	Income at or below 300% Federal Poverty Guidelines.
Client Eligibility:	Individuals with an AIDS diagnosis and certified by his or her physician that the individual's prognosis is for a life expectancy of six (6) months or less if the terminal illness runs its normal course
Agency Requirements:	Agency/provider is a licensed hospital/facility and maintains a valid State license with a residential AIDS Hospice designation or is certified as a Special Care Facility with Hospice designation. Provider must inform Administrative Agency regarding issue of long-term care facilities denying admission for people living with HIV based on inability to provide appropriate level of skilled nursing care. Services must be provided by a medically directed interdisciplinary team, qualified in treating individual requiring hospice services.

	Staff will refer Medicaid/Medicare eligible clients to a Hospice Provider for medical, support, and palliative care. Staff will document an attempt has been made to place Medicaid/Medicare eligible clients in another facility prior to admission.
Staff Requirements:	All hospice care staff who provide direct-care services and who require licensure or certification, must be properly licensed or certified by the State of Texas.
Special Requirements:	These services must be: a) Available 24 hours a day, seven days a week, during the last stages of illness, during death, and during bereavement; b) Provided by a medically directed interdisciplinary team; c) Provided in nursing home, residential unit, or inpatient unit according to need. These services do not include inpatient care normally provided in a licensed hospital to a terminally ill person who has not elected to be a hospice client. d) Residents seeking care for hospice at Agency must first seek care from other facilities and denial must be documented in the resident's chart. Must comply with the **Houston HSDA Hospice Standards of Care**. The agency must comply with **the DSHS Hospice Standards of Care**. The agency must have policies and procedures in place that comply with the standards ***prior*** to delivery of the service.

FY 2021 RWPC "How to Best Meet the Need" Decision Process

Step in Process: **Council**		Date: **06/11/2020**
Recommendations:	Approved: Y:_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Steering Committee**		Date: **06/04/2020**
Recommendations:	Approved: Y:_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Quality Improvement Committee**		Date: **05/19/2020**
Recommendations:	Approved: Y:_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **HTBMTN Workgroup #3**	Date: **04/22/2020**
Recommendations:	Financial Eligibility:
1.	
2.	
3.	

HOSPICE SERVICES
2019 CHART REVIEW REPORT

PREFACE

DSHS Monitoring Requirements

The Texas Department of State Health Services (DSHS) contracts with The Houston Regional HIV/AIDS Resource Group, Inc. (TRG) to ensure that Ryan White Part B and State of Texas HIV Services funding is utilized to provide in accordance to negotiated Priorities and Allocations for the designated Health Service Delivery Area (HSDA). In Houston, the HDSA is a ten-county area including the following counties: Austin, Chambers, Colorado, Fort Bend, Harris, Liberty, Montgomery, Walker, Waller, and Wharton. As part of its General Provisions for Grant Agreements, DSHS also requires that TRG ensures that all Subgrantees comply with statutes and rules, perform client financial assessments, and delivery service in a manner consistent with established protocols and standards.

As part of those requirements, TRG is required to perform annual quality compliance reviews on all Subgrantees. Quality Compliance Reviews focus on issues of administrative, clinical, data management, fiscal, programmatic and quality management nature. Administrative review examines Subgrantee operating systems including, but not limited to, non-discrimination, personnel management and Board of Directors. Clinical review includes review of clinical service provision in the framework of established protocols, procedures, standards and guidelines. Data management review examines the Subgrantee's collection of required data elements, service encounter data, and supporting documentation. Fiscal review examines the documentation to support billed units as well as the Subgrantee's fiscal management and control systems. Programmatic review examines non-clinical service provision in the framework of established protocols, procedures, standards and guidelines. Quality management review ensures that each Subgrantee has systems in place to address the mandate for a continuous quality management program.

QM Component of Monitoring

As a result of quality compliance reviews, the Subgrantee receives a list of findings that must be address. The Subgrantee is required to submit an improvement plan to bring the area of the finding into compliance. This plan is monitored as part of the Subgrantee's overall quality management monitoring. Additional follow-up reviews may occur (depending on the nature of the finding) to ensure that the improvement plan is being effectively implemented.

Scope of Funding

TRG contracts one Subgrantee to provide hospice services in the Houston HSDA.

INTRODUCTION

Description of Service

Hospice services encompass palliative care for terminally ill clients and support services for clients and their families. Services are provided by a licensed nurse and/or physical therapist. Additionally, unlicensed personnel may deliver services under the delegation of a licensed nurse or physical therapist, to a client or a client's family as part of a coordinated program. A physician must certify that a patient is terminal, defined under Medicaid hospice regulations as having a life expectancy of 6 months or less.

Services must include but are not limited to medical and nursing care, palliative care, and psychosocial support for the patient, as well as a mechanism for bereavement referral for surviving family members. Counseling services provided in the context of hospice care must be consistent with the (Ryan White) definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Program.

Tool Development

The TRG Hospice Review tool is based upon the established local and DSHS standards of care.

Chart Review Process

All charts were reviewed by Bachelors-degree registered nurse experienced in treatment, management, and clinical operations in HIV of over 10 years. The collected data for each site was recorded directly into a preformatted computerized database. The data collected during this process is to be used for service improvement.

File Sample Selection Process

File sample was selected from a population of 46 (CPCDMS) who accessed hospice services in the measurement year. The records of 39 clients were reviewed, representing 85% of the unduplicated population. The demographic makeup of the provider was used as a key to file sample pull.

Demographics- Hospice

2018 Annual

Total UDC: 46

Age	Number of Clients	% of Total
Client's age as of the end of the reporting period		
Less than 2 years	0	0.00%
02 - 12 years	0	0.00%
13 - 24 years	1	2.17%
25 - 44 years	14	30.43%
45 - 64 years	28	60.87%
65 years or older	3	6.52%
Unknown	0	0.00%
	46	100.00%
Gender	**Number of Clients**	**% of Total**
"Other" and "Refused" are counted as "Unknown"		
Female	8	17.39%
Male	37	80.43%
Transgender FTM	0	0.00%
Transgender MTF	1	2.17%
Unknown	0	0.00%
	46	100.00%
Race/ Ethnicity	**Number of Clients**	**% of Total**
Includes Multi-Racial Clients		
White	19	41.30%
Black	27	58.70%
Hispanic	11*	23.91%
Asian	0	0.00%
Hawaiian/Pacific Islander	0	0.00%
Indian/Alaskan Native	0	0.00%
Unknown	0	0.00%
	46	100.00%

From 01/01/18 - 12/31/18

2019 Annual

Total UDC: 28

Age	Number of Clients	% of Total
Client's age as of the end of the reporting period		
Less than 2 years	0	0.00%
02 - 12 years	0	0.00%
13 - 24 years	0	0.00%
25 - 44 years	5	17.86%
45 - 64 years	18	64.29%
65 years or older	5	17.86%
Unknown	0	0.00%
	28	100.00%
Gender	**Number of Clients**	**% of Total**
"Other" and "Refused" are counted as "Unknown"		
Female	8	28.6%
Male	20	71.4%
Transgender FTM	0	0.00%
Transgender MTF	0	0.00%
Unknown	0	0.00%
	28	100.00%
Race/ Ethnicity	**Number of Clients**	**% of Total**
Includes Multi-Racial Clients		
White	15	41.30%
Black	13	58.70%
Hispanic	4*	23.91%
Asian	0	0.00%
Hawaiian/Pacific Islander	0	0.00%
Indian/Alaskan Native	0	0.00%
Unknown	0	0.00%
	28	100.00%

From 01/01/19 - 12/31/19

RESULTS OF REVIEW-2018

ADMISSION ORDERS AND ASSESSMENT

Percentage of client records that document attending physician certification of client's terminal illness.

	Yes	No	N/A
Client records that evidenced a Hospice Certificate Letter.	38	1	-
Clients in hospice services that were reviewed.	39	39	-
Rate	**97%**	**3%**	-

Percentage of client records that have admission orders

	Yes	No	N/A
Client records that showed evidence of an admission order.	39	0	-
Clients in hospice services that were reviewed.	39	39	-
Rate	**100%**	**0%**	-

Percentage of client records that have all scheduled and PRN medications, including dosage and frequency

	Yes	No	N/A
Client records that evidenced all medication orders	39	0	-
Clients in hospice services that were reviewed.	39	39	-
Rate	**100%**	**0%**	-

CARE PLAN AND UPDATES DOCUMENTAITON

Percentage of client records that have a completed initial plan of care within 7 days of admission.

	Yes	No	N/A
Client records that evidence a completed initial plan of care within 7 days of admission	39	0	-
Clients in hospice services that were reviewed.	39	39	-
Rate	**100%**	**0%**	-

Percentage of client records that have a completed plan of care reviewed and/or updated at least monthly.

	Yes	No	N/A
Client records that evidenced a completed plan of care that was updated at least monthly.	12	0	27
Clients in hospice services that were reviewed.	12	39	39
Rate	**100%**	**0%**	**69%**

Percentage of client records that document palliative therapy as ordered by the referring provider

	Yes	No	N/A
Client records that showed evidence of palliative therapy as ordered.	33	3	3
Clients in hospice services that were reviewed.	36	36	39
Rate	**92%**	**8%**	**8%**

SERVICES

Percentage of client records that had bereavement counseling offered to family members upon admission to Hospice services

	Yes	No	N/A
Client records that showed evidence of bereavement counseling	3	27	9
Clients in oral health services that were reviewed.	30	30	39

Rate	**10%**	**90%**	**23%**

Percentage of client records that had dietary counseling

	Yes	No	N/A
Number of client records that evidenced dietary counseling	0	1	38
Clients in oral health services that were reviewed.	1	1	39
Rate	**0%**	**100%**	**97%**

Percentage of client records that had spiritual counseling

	Yes	No	N/A
Client records that evidenced spiritual counseling.	36	2	1
Clients in oral health services that were reviewed.	38	38	39
Rate	**95%**	**5%**	**3%**

Percentage of client records that had mental health counseling offered to family members upon admission

	Yes	No	N/A
Number of client records that evidence mental health counseling offered	0	0	39
Clients in oral health services that were reviewed.	39	39	39
Rate	**0%**	**0%**	**100%**

DISCHARGE

Percentage of client records that evidence all refusals of attending physician referrals by hospice providers with evidence indicating an allowable reason for the refusal

	Yes	No	N/A
Client records that evidenced appropriate refusal	6	0	33
Clients in hospice services that were reviewed.	6	39	39
Rate	**100%**	**0%**	**85%**

Percentage of client records that showed completed discharge documentation

	Yes	No	N/A
Client records that evidenced completed discharge documentation.	39	0	-
Clients in hospice services that were reviewed.	39	38	-
Rate	**100%**	**0%**	-

CONCLUSION

The review showed that Hospice Care continue to be delivered at a high standard. Seven of the thirteen Standard of Care data elements were scored at 100% compliance, including care plan, health assessment and discharge. Dietary and mental health counseling referrals to family members were below the threshold of 50% at 0% for each. These indicators are new to the review tool and will be documented in the future.

ZaggoCare

Improving Patient Engagement

Pros and Cons of Hospice Care

by **Zaggocare** on August 5, 2019 in **Hospice and Palliative Care**

No one likes to discuss end-of-life care and death. But it's worth having the difficult conversations because patients should be as comfortable as possible, receiving the level of treatment they desire. What are the pros and cons of hospice care? Take the time to learn more so you can make an informed decision about your care or the care of a loved one.

For many, the word hospice brings up negative thoughts of very sick people spending their last days and weeks in a depressing hospice facility. However, that is outdated thinking that should not stop you from considering hospice services. Rather, hospice is designed to provide comfort care that can make the end of life easier to bear and more comfortable.

What is hospice care?

Hospice care is a philosophy of treatment focused on caring, not curing. The goal is to help patients get the best quality of life in the time remaining. Hospice staff care for any type of physical and emotional symptoms that cause pain, discomfort and distress. The care is specifically designed around the patient's needs and wishes. The patient's loved ones receive support as well.

Hospice care is frequently provided in the patient's home, but patients can receive hospice care in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.

Importantly, patients in hospice can stop hospice service whenever they want.

The benefits of hospice care.

There are many benefits to the patient and family, including:

- Expert pain and symptom management, helping patients be as comfortable as possible.
- Emotional support for the patient and family.
- Following a patient's choices regarding their end-of-life care.
- Helping patients stay at home during their end-of-life.
- Help with practical tasks like bathing and feeding the patient. Additionally, hospice workers may help with household tasks and errands.
- Giving family caregivers a chance to take a break from caregiving tasks.

Additionally, studies have shown that hospice care can significantly lower hospitalization rates, ICU admissions, and the number of invasive procedures performed at the end of life. Finally, hospice care can significantly lower the total costs of care during the last year of life.

Hospice care for patients at home or in a long-term care facility.

- Hospices will arrange for the delivery of all the needed equipment and supplies, including a hospital bed, bedside commode, medications, etc.
- Hospice will send a variety of qualified staff to make the patient more comfortable. Staff can include a registered nurse, social worker, home health aides, and a chaplain.
- A trained hospice volunteer is usually available to provide non-medical support to patients and families, including running errands, staying with the patient to give family members a break, preparing light meals, and lending emotional support.
- Hospice care is available 24/7. If you need a nurse after normal business hours, most hospices have registered nurses who can respond to a call for help within minutes.

Who should receive hospice care?

In order to qualify for hospice care, two doctors must certify that the patient has a life-altering condition with a life expectancy of less than 6 months. However, it's important to understand that this expectation is a guess – there is no scientific way to know for certain how much time a person will live with a given set of medical conditions.

Many patients who could benefit from hospice don't receive it at all or enroll at the very end of their life, missing out on the benefits. Although end-of-life discussions are difficult, it's worth the time and effort to make sure the patient is as comfortable as possible until the end.

How do patients get hospice care?

If you think you or your loved one could benefit from hospice care, talk to your doctor. Doctors may not recommend hospice care unless patients/families specifically ask; it turns out that doctors are often uncomfortable talking about end of life issues. One survey found that 46% of doctors frequently or often felt unsure about what to say during end of life conversations, and only 29% had received formal training on how to have these difficult conversations. An additional roadblock can be determining when a patient can/should receive hospice care. Since Medicare and most private insurance companies only cover patients with less than 6 months, doctors may find it hard to determine if a patient qualifies, since all patients differ in their health trajectory.

Unfortunately, all of these stumbling blocks mean that many people who could benefit from weeks or months of hospice care are not getting the care until the last few days of their lives.

Is hospice care covered by insurance?

Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations cover hospice care,

paying all or most of the expense. But, you should check with your provider to learn the details of your coverage.

Because Medicare and Medicaid only cover hospice care in hospices they've approved, check eligibility before choosing a provider or facility.

What are the potential negatives of hospice care?

Hospice care is a rapidly growing industry with over 4,000 hospices in the US. Although some hospices provide safe, wonderful care, others provide dangerous, subpar care.

Problems with in-home hospice care.

A 2017 analysis by Kaiser Health News of 20,000 government inspection records found that "missed visits and neglect are common for patients dying at home". Families and caregivers filed over 3,200 complaints with state officials in the past five years. Subsequently, government inspectors found problems in 759 hospices; more than half were cited for missing visits or other services they had promised to provide.

Widespread issues exist at hospice facilities.

In July 2019, the Office of Inspector General (OIG), of the US Dept of Health and Human Services, released reports that illustrates widespread deficiencies at hospice facilities throughout the US. Sadly, the OIG found that 87% of 4,563 US hospices violated at least 1 of Medicare's safety requirement over a 5-year period. Additionally, for the same 5 years, the OIG found a tripling in the number of hospices which had severe complaints filed against them.

The issues identified can lead to poor care and can jeopardize patient safety.

What is the cause of problems?

According to the OIG report, the most common deficiencies involve:

- Poor care planning
- Mismanagement of aide services
- Inadequate assessments of patients

Additionally, hospices had other problems that also posed risks to patients, including:

- Improperly vetting of staff
- Inadequate quality control

How bad can these problems get?

Bad. Very bad.

The OIG report provides examples of harm caused by serious lapses in care found in 2016 at hospice facilities. Here are a few examples:

- One hospice failed to treat a patient's wounds, which then became gangrenous. As a result, the patient needed an amputation of the lower left leg.
- Inspectors found maggots around the insertion site of a patient's feeding tube.
- One patient didn't receive his needed respiratory therapy, leading to difficulty breathing and increased fatigue.
- Although there were signs of injuries on the patient's pelvic area and other body parts, a hospice failed to recognize signs of a possible sexual assault.

How to choose a hospice?

Because the risk of problems is high, do your research before choosing a provider or facility:

- First of all, ask your doctor, friends and family for referrals. A personal recommendation is likely the best way to make a choice.
- Call your state hospice organization (find contact information for your state at Medicare.gov/contacts).
- Visit Medicare.gov/HospiceCompare to learn about services provided and quality of care. However, it's important to realize that for legal reasons, these reports do not contain data on deficiencies gathered by private accrediting organizations. Therefore, some important quality data is missing.
- If you plan on in-patient care at a hospice facility, a family member/trusted adult should visit in person. How do the staff interact with and treat the patients? Do the patients look well cared for? Are the facilities clean?
- Use the helpful worksheet provided by the National Hospice and Palliative Care Organization to help you evaluate the hospices available in your area.

Want to learn more?

Visit these sites to learn more:

- Centers for Medicare and Medicaid Services booklet on hospice
- Compassion and Choices
- Hospice Foundation of America
- National Hospice and Palliative Care Organization
- The Conversation Project

My final thoughts on the pros and cons of hospice care…

Although the OIG and other investigations found serious, concerning issues, hospice remains a helpful service for patients at the end of life and their families. Personally, when my teenage son Zach was near the end of his life, the services we received from hospice (and palliative care) were very helpful and appreciated. So, if you, or a loved, one is near the end of life, I suggest you consider hospice care. But do your homework before choosing a provider!

Healthy Lifestyle

End of life

Hospice care might be an option if you or a loved one has a terminal illness. Understand how hospice care works and how to select a program.

By Mayo Clinic Staff

If you or a relative has a terminal illness and you've exhausted all treatment options, you might consider hospice care. Find out how hospice care works and how it can provide comfort and support.

Hospice care is for people who are nearing the end of life. The services are provided by a team of health care professionals who maximize comfort for a person who is terminally ill by reducing pain and addressing physical, psychological, social and spiritual needs. To help families, hospice care also provides counseling, respite care and practical support.

Unlike other medical care, the focus of hospice care isn't to cure the underlying disease. The goal is to support the highest quality of life possible for whatever time remains.

Hospice care is for a terminally ill person who's expected to have six months or less to live. But hospice care can be provided for as long as the person's doctor and hospice care team certify that the condition remains life-limiting.

Many people who receive hospice care have cancer, while others have heart disease, dementia, kidney failure or chronic obstructive pulmonary disease.

Enrolling in hospice care early helps you live better and live longer. Hospice care decreases the burden on family, decreases the family's likelihood of having a complicated grief and prepares family members for their loved one's death. Hospice also allows a patient to be cared for at a facility for a period of time, not because the patient needs it, but because the family caregiver needs a break. This is known as respite care.

Most hospice care is provided at home — with a family member typically serving as the primary caregiver. However, hospice care is also available at hospitals, nursing homes, assisted living facilities and dedicated hospice facilities.

No matter where hospice care is provided, sometimes it's necessary to be admitted to a hospital. For instance, if a symptom can't be managed by the hospice care team in a home setting, a hospital stay might be needed.

If you're not receiving hospice care at a dedicated facility, hospice staff will make regular visits to your home or other setting. Hospice staff is on call 24 hours a day, seven days a week.

A hospice care team typically includes:

- **Doctors.** A primary care doctor and a hospice doctor or medical director will oversee care. Each patient gets to choose a primary doctor. This can be your prior doctor or a hospice doctor.
- **Nurses.** Nurses will come to your or your relative's home or other setting to provide care. They are also responsible for coordination of the hospice care team.
- **Home health aides.** Home health aides can provide extra support for routine care, such as dressing, bathing and eating.
- **Spiritual counselors.** Chaplains, priests, lay ministers or other spiritual counselors can provide spiritual care and guidance for the entire family.
- **Social workers.** Social workers provide counseling and support. They can also provide referrals to other support systems.
- **Pharmacists.** Pharmacists provide medication oversight and suggestions regarding the most effective ways to relieve symptoms.
- **Volunteers.** Trained volunteers offer a variety of services, including providing company or respite for caregivers and helping with transportation or other practical needs.
- **Other professionals.** Speech, physical and occupational therapists can provide therapy, if needed.
- **Bereavement counselors.** Trained bereavement counselors offer support and guidance after the death of a loved one in hospice.

Medicare, Medicaid, the Department of Veterans Affairs and private insurance typically pay for hospice care. While each hospice program has its own policy regarding payment for care, services are often offered based on need rather than the ability to pay. Ask about payment options before choosing a hospice program.

To find out about hospice programs, talk to doctors, nurses, social workers or counselors, or contact your local or state office on aging. Consider asking friends or neighbors for advice. The National Hospice and Palliative Care Organization also offers an online provider directory.

To evaluate a hospice program, consider asking:

- Is the hospice program Medicare-certified? Is the program reviewed and licensed by the

state or certified in some other way? Is the hospice program accredited by The Joint Commission?

- Who makes up the hospice care team, and how are they trained or screened? Is the hospice medical director board certified in hospice and palliative care medicine?
- Is the hospice program not-for-profit or for profit?
- Does the hospice program have a dedicated pharmacist to help adjust medications?
- Is residential hospice available?
- What services are offered to a person who is terminally ill? How are pain and other symptoms managed?
- How are hospice care services provided after hours?
- How long does it take to get accepted into the hospice care program?
- What services are offered to the family? What respite services are available for the caregiver or caregivers? What bereavement services are available?
- Are volunteer services available?
- If circumstances change, can services be provided in different settings? Does the hospice have contracts with local nursing homes?
- Are hospice costs covered by insurance or other sources, such as Medicare?

Remember, hospice stresses care over cure. The goal is to provide comfort during the final months and days of life.

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Jan. 30, 2019
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NHPCO Facts and Figures

2018 EDITION *(REVISION 7-2-2019)*

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.

Introduction

About this Report

NHPCO Facts and Figures: Hospice Care in America 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 2017, provided by the Medicare Hospice Benefit by the hospices certified by the Centers for Medicare and Medicaid Services (CMS) to care for them.

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.

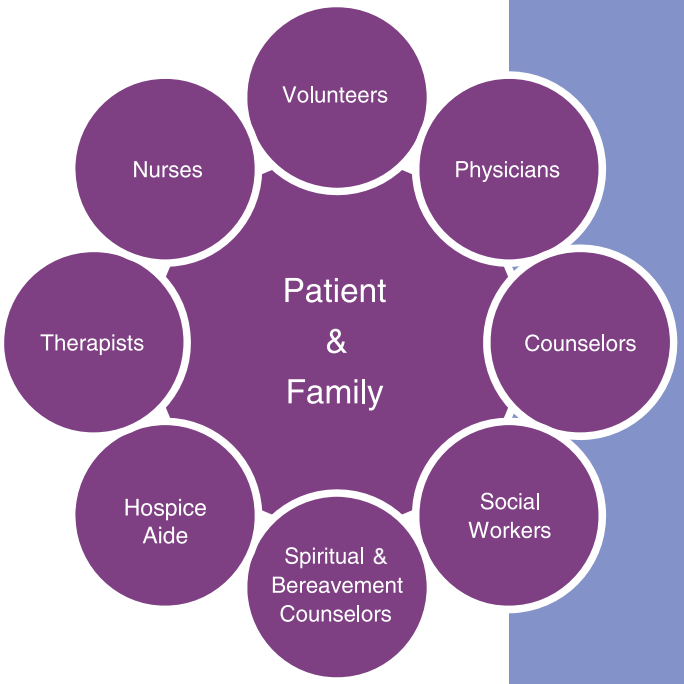
Hospice focuses on caring, not curing. In most cases, care is provided in the patient's home but may also be provided in freestanding hospice facilities, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients with any terminal illness or of any age, religion, or race.

Introduction (continued)

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 is on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets 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.



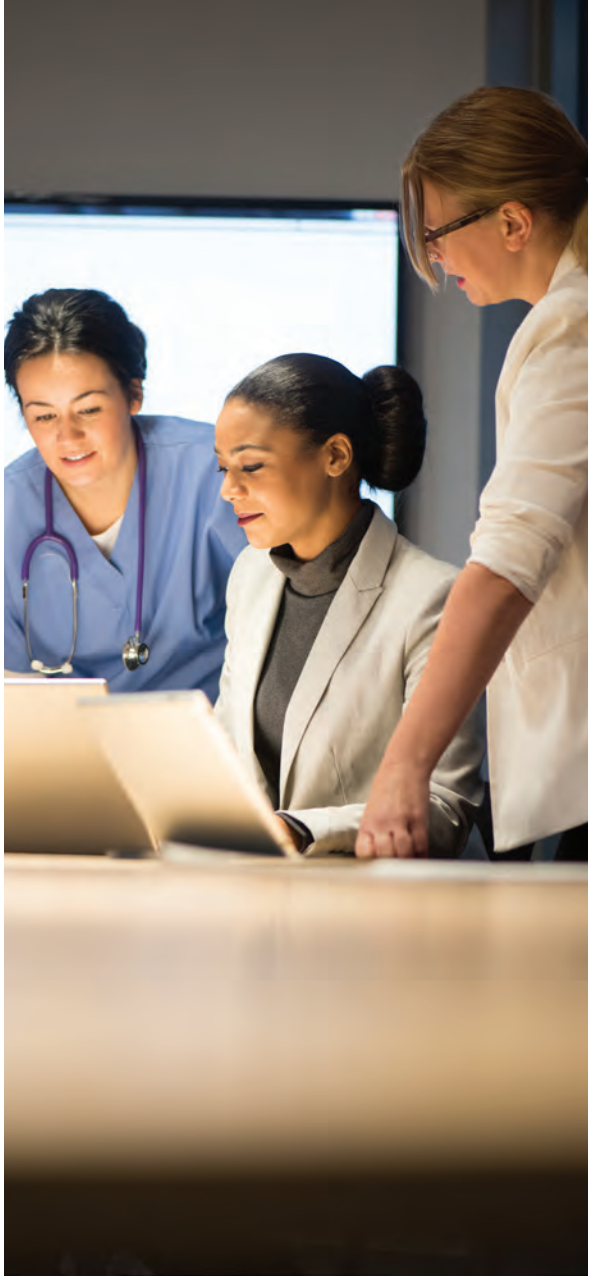
What services are provided?

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.

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).



Introduction (continued)

Levels of Care

Hospice patients may require differing intensities of care during the course of their disease. 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, General Inpatient Care, Continuous Home Care, and Inpatient Respite 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 Hospice 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 and are 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 sufficient 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 nursing facility that has 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 and continues to play an important and valuable role in hospice care and operations. Moreover, hospice is unique in that it is the only provider with Medicare Conditions of Participation (CoPs) requiring volunteers to provide at least 5% of total patient care hours.

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, 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 at large.

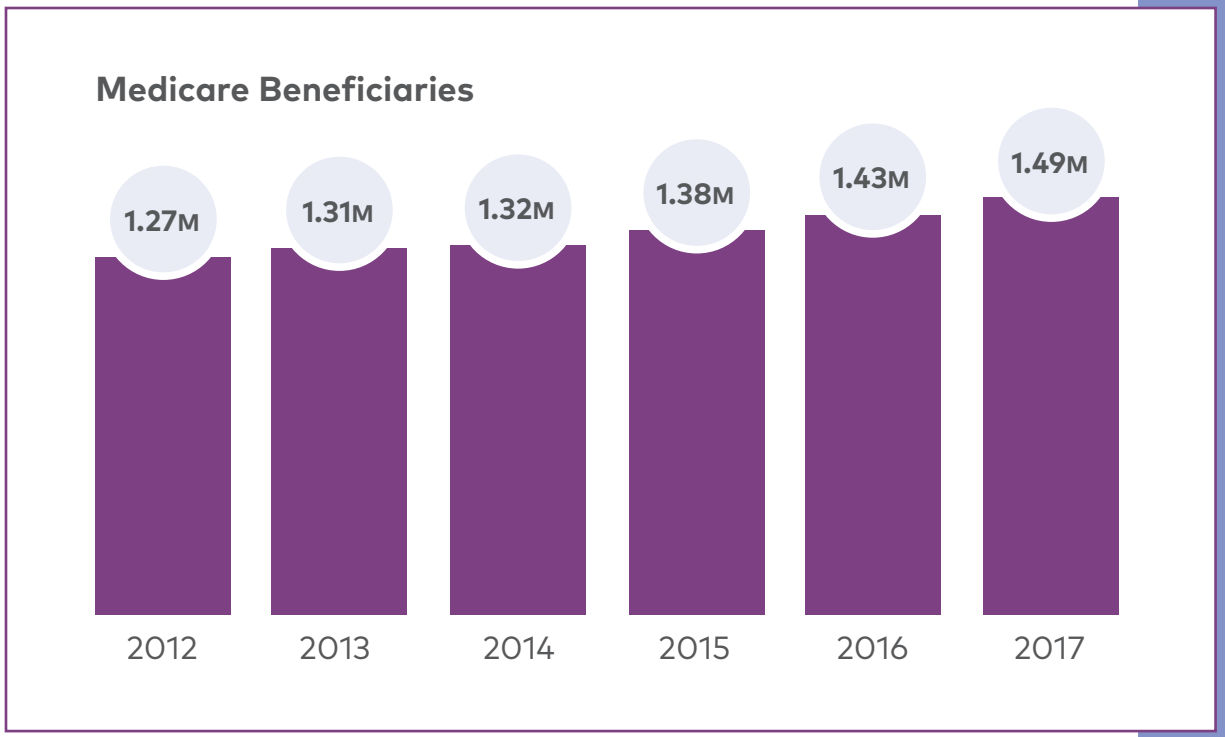
Who Receives Hospice Care

How many Medicare beneficiaries received hospice care in 2017?

1.49 million Medicare beneficiaries, a 4.5% increase from prior year, were enrolled in hospice care for one day or more in 2017*. This includes patients who:

- Died while enrolled in hospice
- Were enrolled in hospice in 2016 and continued to receive care in 2017
- Left hospice care alive during 2017 (live discharges)

*includes all states, Washington, D.C., U.S. territories, and Other.

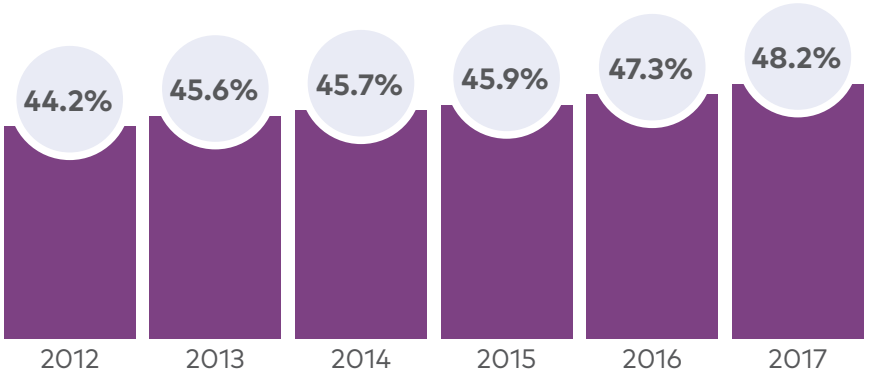


Who Receives Hospice Care (continued)

What proportion of Medicare decedents were served by hospice in 2017?

Of all Medicare decedents in 2017, 48.2% received one day or more of hospice care and were enrolled in hospice at the time of death.

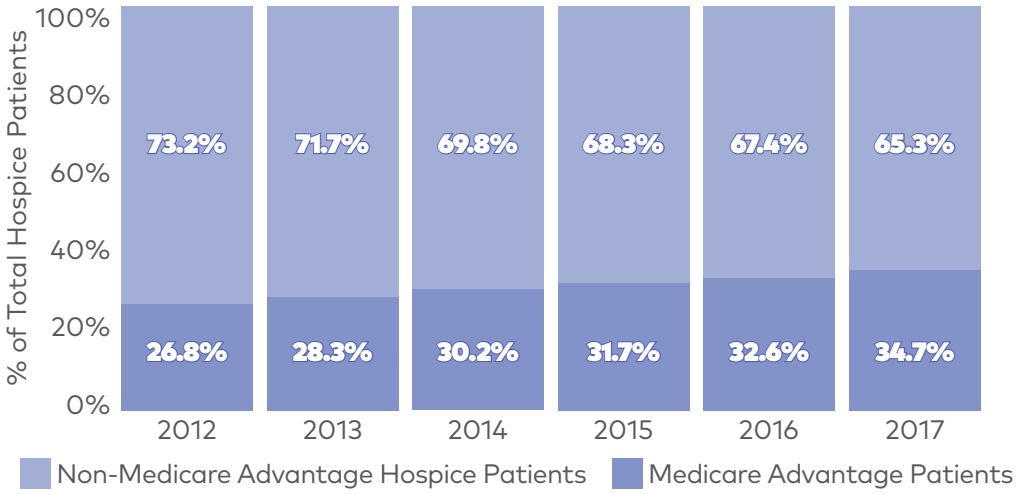
Medicare Decedents Receiving 1 or more Days of Hospice Care



What % of Hospice Patients Enrolled in Medicare Advantage within the Year?

The number of individuals who enrolled in a Medicare Advantage plan within the same year that they utilized the hospice benefit rose from 26.8% of Medicare hospice patients in 2012 to 34.7% in 2017. The increase in hospice beneficiaries with MA enrollment is consistent with the overall increase in MA enrollment over this period.

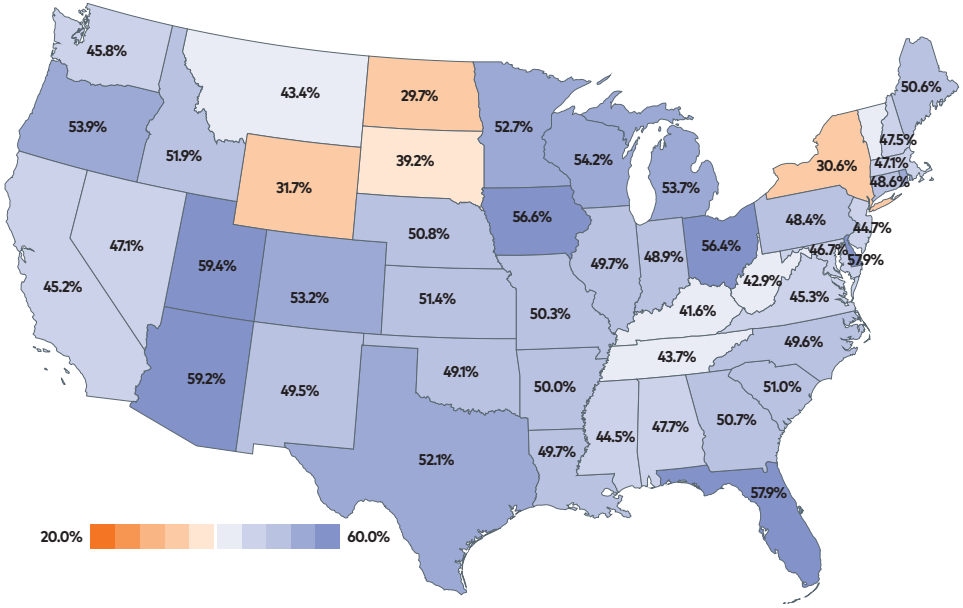
Growth of Medicare Advantage Hospice Patients



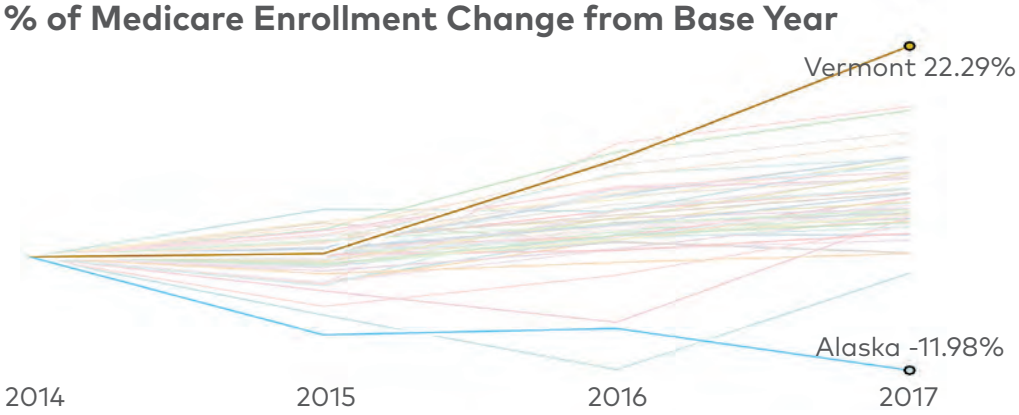
Who Receives Hospice Care (continued)

As illustrated on this page, the proportion of Medicare decedents enrolled in hospice at the time of death varied from a low of 13% (other) to a high of 59.4% (UT). Vermont and Alaska had the greatest % increase/decrease in decedents enrolled in hospice at the time of death since 2014.

% of Medicare Decedents Services by Hospice and Aligns to Graphic at Right



% of Medicare Enrollment Change from Base Year



2017 State Rank For Decedent Medicare Enrollment %

Rank	State	
1	Utah	59.4%
2	Arizona	59.2%
3	Florida	57.9%
4	Delaware	57.9%
5	Iowa	56.6%
6	Ohio	56.4%
7	Rhode Island	55.0%
8	Wisconsin	54.2%
9	Oregon	53.9%
10	Michigan	53.7%
11	Colorado	53.2%
12	Minnesota	52.7%
13	Texas	52.1%
14	Idaho	51.9%
15	Kansas	51.4%
16	South Carolina	51.0%
17	Nebraska	50.8%
18	Georgia	50.7%
19	Maine	50.6%
20	Missouri	50.3%
21	Arkansas	50.0%
22	Illinois	49.7%
23	Louisiana	49.7%
24	North Carolina	49.6%
25	New Mexico	49.5%
26	Oklahoma	49.1%
27	Indiana	48.9%
28	Connecticut	48.6%
29	Pennsylvania	48.4%
30	Alabama	47.4%
31	New Hampshire	47.5%
32	Massachusetts	47.1%
33	Nevada	47.1%
34	Maryland	46.7%
35	Hawaii	46.1%
36	Washington	45.8%
37	Virginia	45.3%
38	California	45.2%
39	New Jersey	44.7%
40	Mississippi	44.5%
41	Tennessee	43.7%
42	Montana	43.4%
43	West Virginia	42.9%
44	Vermont	42.9%
45	Kentucky	41.6%
46	South Dakota	39.2%
47	District of Columbia	32.0%
48	Wyoming	31.7%
49	New York	30.6%
50	North Dakota	29.7%
51	Alaska	22.5%
52	Other	13.9%

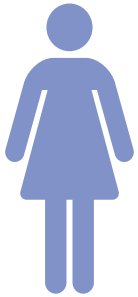
Who Receives Hospice Care (continued)

What are the characteristics of Medicare beneficiaries who received hospice care in 2017?

Patient Gender

In 2017, more than half of hospice Medicare beneficiaries were female.

58.4% were **female** in 2017

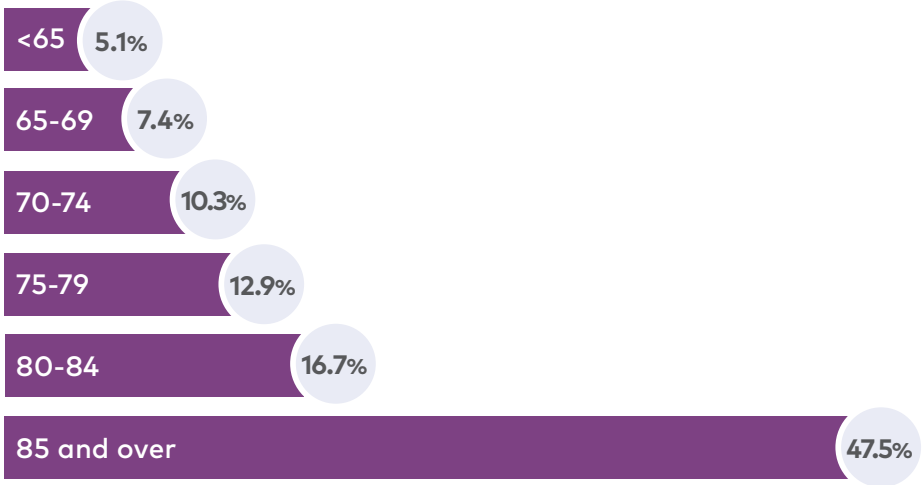


41.6% were **male** in 2017

Patient Age

In 2017, about 64.2% of Medicare hospice patients were 80 years of age or older.

% of Patients by Age for 2017



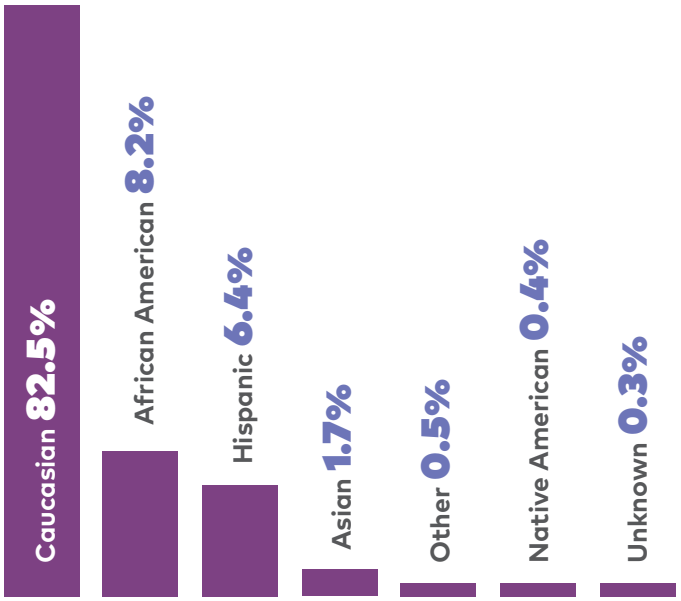
Who Receives Hospice Care (continued)

What are the characteristics of Medicare beneficiaries who received hospice care in 2017?

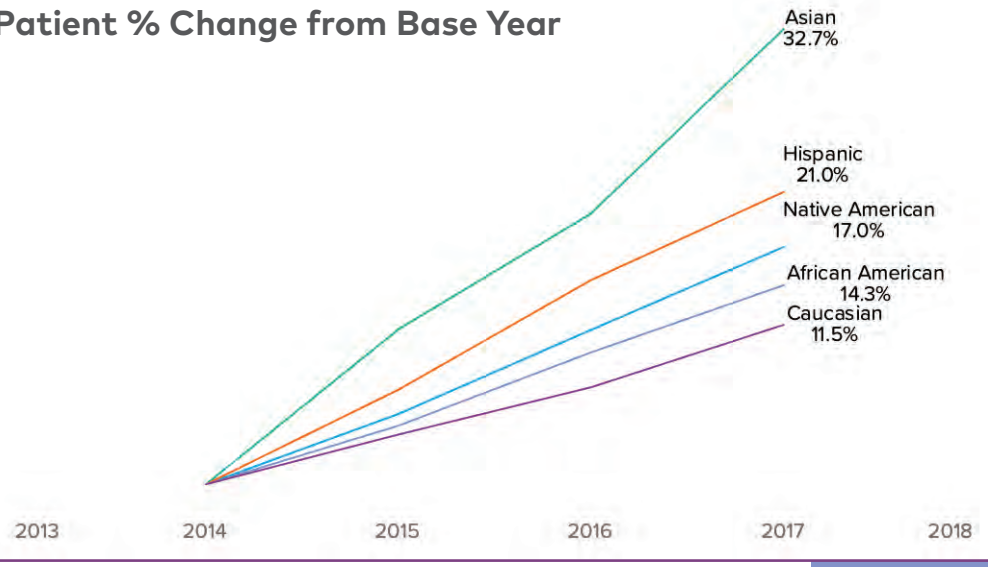
Patient Race*

In 2017 a substantial majority of Medicare hospice patients were Caucasian. However, since 2014 Patients identified as Asian and Hispanic increased by 32% and 21% respectively.

% of Patients by Race for 2017

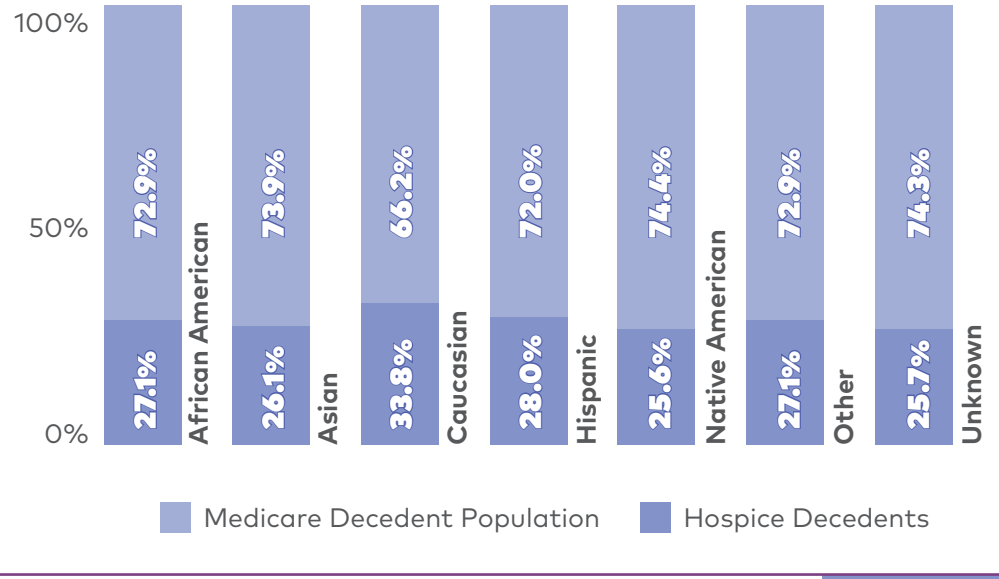


Patient % Change from Base Year



** Categories correspond to those used by CMS in the Hospice Limited Data Set*

Death Service Ratio by Race for 2017



**Percentage of Medicare decedents who died under hospice care by race.*

Who Receives Hospice Care (continued)

What are the characteristics of Medicare beneficiaries who received hospice care in 2017?

Principal Diagnosis

The principal hospice diagnosis is the diagnosis that has been determined to be the most contributory to the patient's terminal prognosis. 2017 continued to show that more Medicare hospice patients had a principal diagnosis of cancer than any other disease.

Stroke, circulatory/heart, Respiratory, and other CCS diagnosis grew the most since 2014.

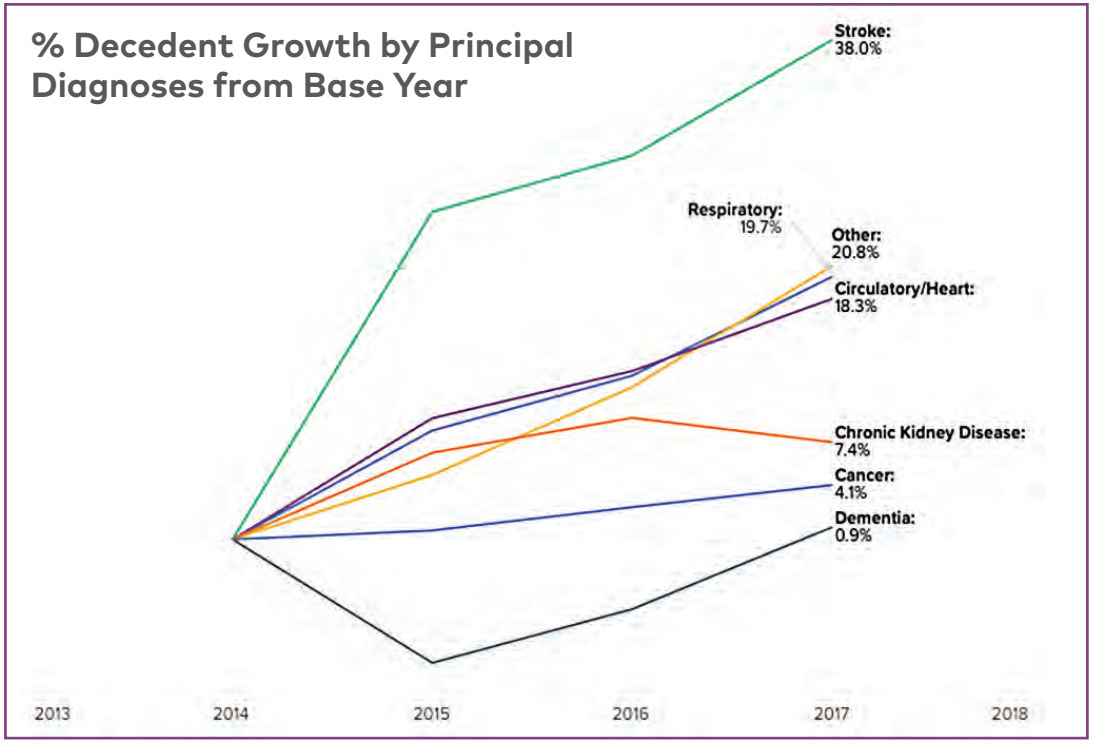
% of Hospice Decedents by Principal Diagnosis for 2016 & 2017

CCS Code	2016	2017
Cancer	31.1%	30.1%
Circulatory/Heart	17.6%	17.6%
Dementia	15.4%	15.6%
Other	13.5%	13.9%
Respiratory	10.9%	11.0%
Stroke	9.2%	9.4%
Chronic Kidney Disease	2.4%	2.3%

No. of Hospice Decedents by Principal Diagnosis for 2016 & 2017

CCS Code	2016	2017
Cancer	327,344	332,718
Circulatory/Heart	185,483	194,512
Dementia	161,983	172,643
Other	142,191	153,963
Respiratory	114,356	122,004
Stroke	97,074	103,684
Chronic Kidney Disease	25,382	24,953

% Decedent Growth by Principal Diagnoses from Base Year



How Much Care Is Received?

Length of Service*

The average length of service (ALOS) for Medicare patients enrolled in hospice in 2017 was 76.1 days. The median length of service (MLOS) was 24 days.

Average Levels of Service

Year	Patients	Total Days	Avg. Days of Care
2012	1.3M	98.7M	77.6
2013	1.3M	103.7M	79.0
2014	1.3M	100.7M	76.1
2015	1.4M	102.6M	74.5
2016	1.4M	108.2M	75.7
2017	1.5M	113.6M	76.1

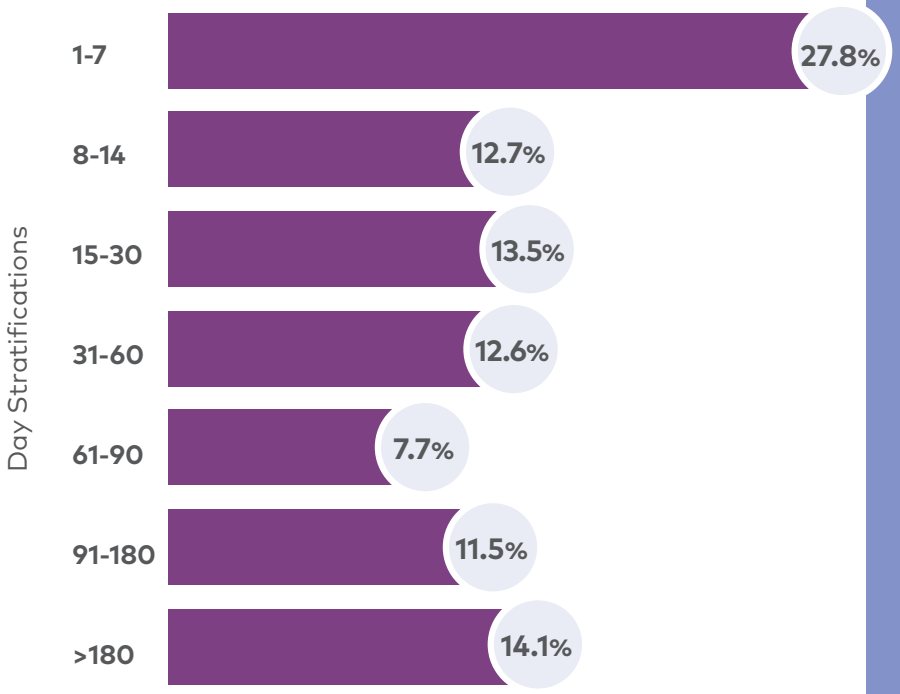
** LOS calculation is based on the total days of care for patients who received care in 2017. Also included in the calculation are days from 2014 and 2015 for patients who received care in those years as well as in 2016.*

Days of Care

In 2017 hospice patients received a total of 113.6 million days of care paid for by Medicare.

A greater proportion of Medicare patients (27.8%) were enrolled in hospice a total of seven days or fewer compared to all other length of service categories.

% of Patients by Days of Care for 2017



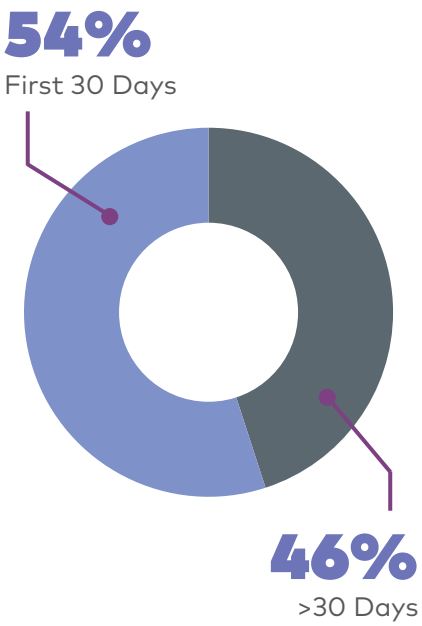
**These values are computed using only days of care that occurred in 2017. Days of care occurring in other years are not included. Days of care have been combined for patients who had multiple episodes of care in 2017.*

How Much Care Is Received (continued)

Days of Care

In 2017 over half (54%) of patients were enrolled in hospice for 30 or fewer days.

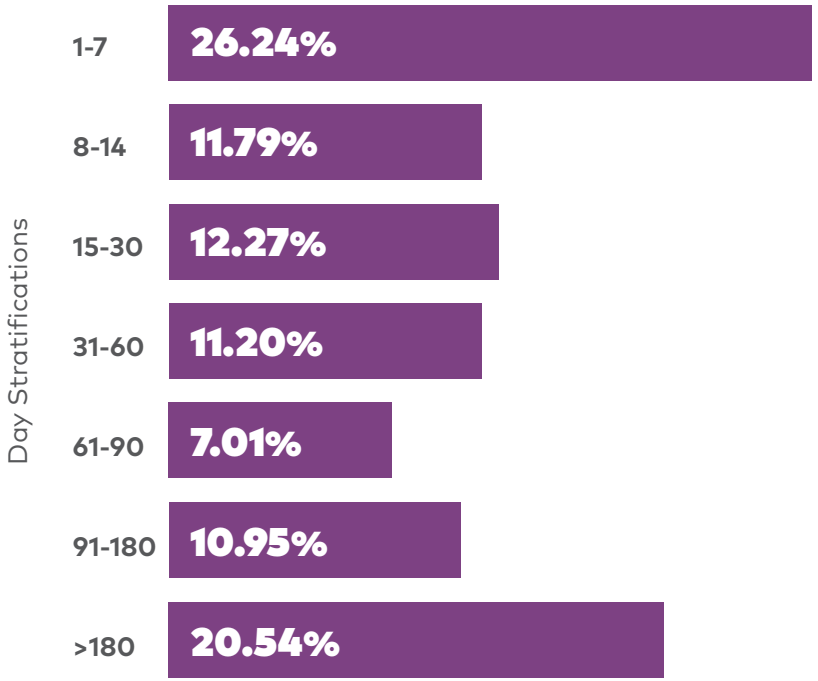
% of Patients by Days of Care for 2017



Days of Care

Days of care over multiple years by percentage of patients*

Days of Care Between 2015-2017 by % of Patients



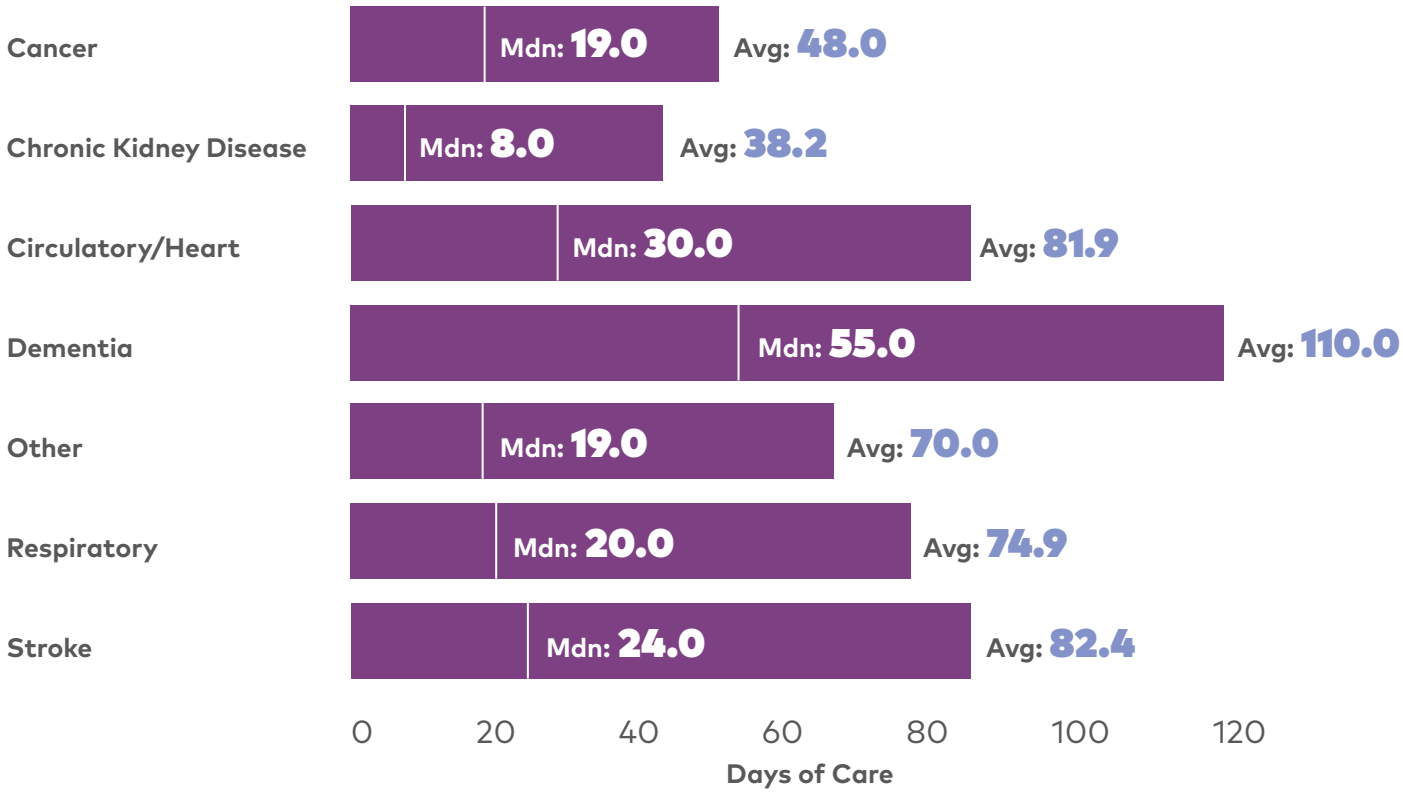
These values are computed using all days of care that occurred between 2015 through 2017 highlighting extended care beyond 180 days that covered multiple years vs just 2017.

How Much Care Is Received? (continued)

Days of Care

Patients with a principal diagnosis of dementia had the largest number of days of care on average in 2017.

Days of Care by Principal Diagnosis for 2017



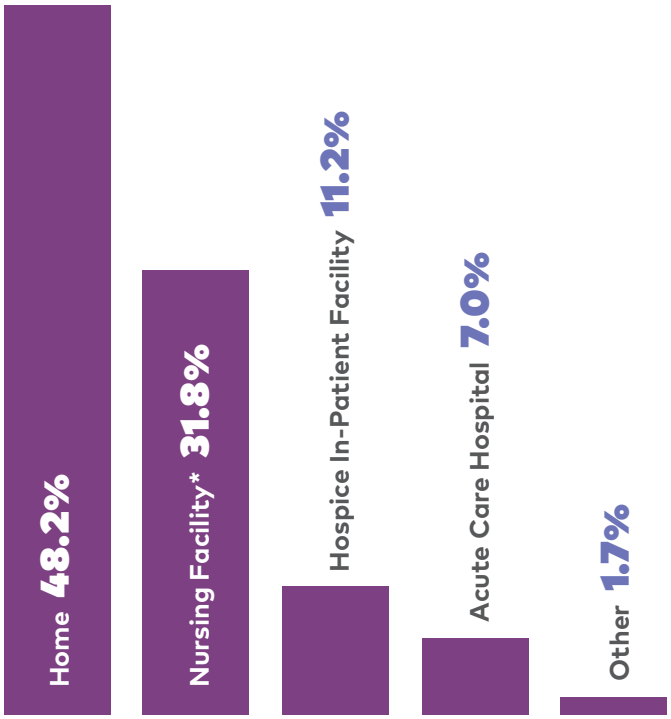
**These values are computed using only days of care that occurred in 2017. Days of care have been combined for patients who had multiple episodes of care in 2017. Days of care occurring in other years are not included.*

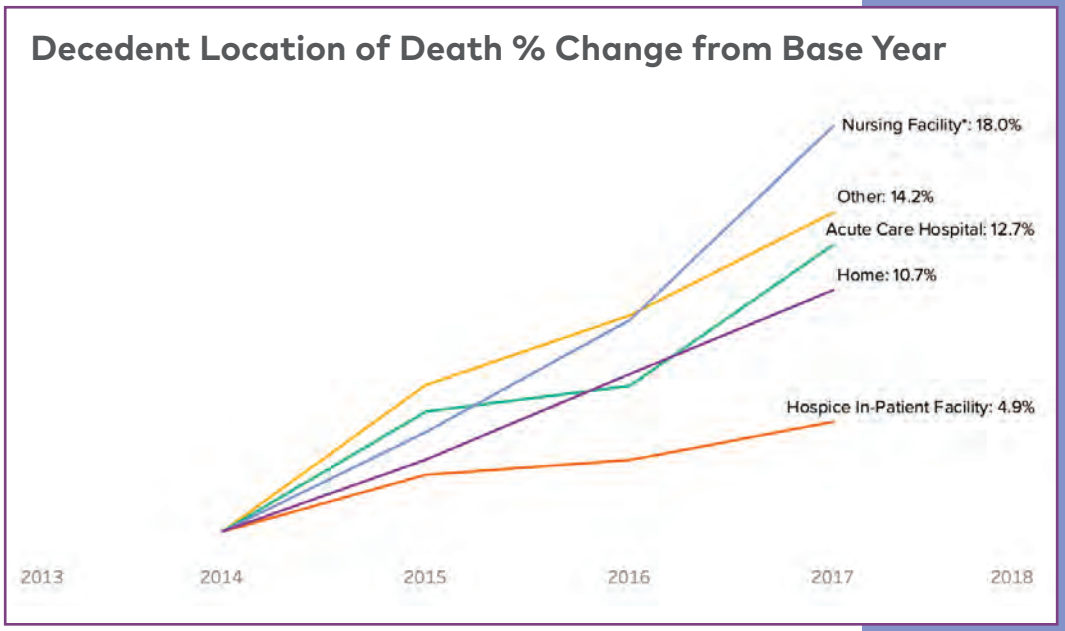
How Much Care Is Received? (continued)

Deaths

In 2017 1.1 million Medicare beneficiaries died while enrolled in hospice care. 48.2 % of deaths occurred in the home, and almost a third in nursing facilities. Nursing facilities have continued to grow the most since 2014 at 18% followed acute care and other facilities.

Decedent % by Location of Death





** Includes skilled nursing facilities, nursing facilities, assisted living facilities, and long-term care facilities.*

How Much Care Is Received? (continued)

Discharges and Transfers

In 2017, there were 1.3M discharges. Live discharges comprised 17% of all Medicare hospice discharges with patient and hospice initiated discharges being about equal.

Discharge by Type for 2017

Deaths	Decedents	82.9%
Patient Initiated-Live Discharges	Revocations	6.5%
	Transfers	2.1%
Hospice Initiated-Live Discharges	No Longer Terminally Ill	6.7%
	Moved Out of the Service Area	1.4%
	Discharges for Cause	0.3%

**Calculations are based on total number of discharges which includes patients who were discharged more than one time in 2017.*

Level of Care

In 2016 the vast majority of days of care were at the Routine Homecare (RHC) level.

Level of Care by % of Days of Care

LOC Metrics	2012	2013	2014	2015	2016	2017
RHC Days	97.6%	97.8%	97.8%	97.9%	98.1%	98.2%
CHC Days	0.3%	0.3%	0.3%	0.3%	0.2%	0.2%
IRC Days	0.3%	0.3%	0.3%	0.3%	0.3%	0.3%
GIC Days	1.8%	1.6%	1.5%	1.5%	1.4%	1.3%

Location of Care

In 2017, most of days of care were provided at a private residence followed by Nursing Facilities. Since 2014, Nursing Facilities have grown by over 14% and Home by 12.3%.

Location of Care by % of Days of Care for 2017

Home	55.7%
Nursing Facility*	42.2%
Hospice In-Patient Facility	0.8%
Acute Care Hospital	0.3%
Other	1.1%

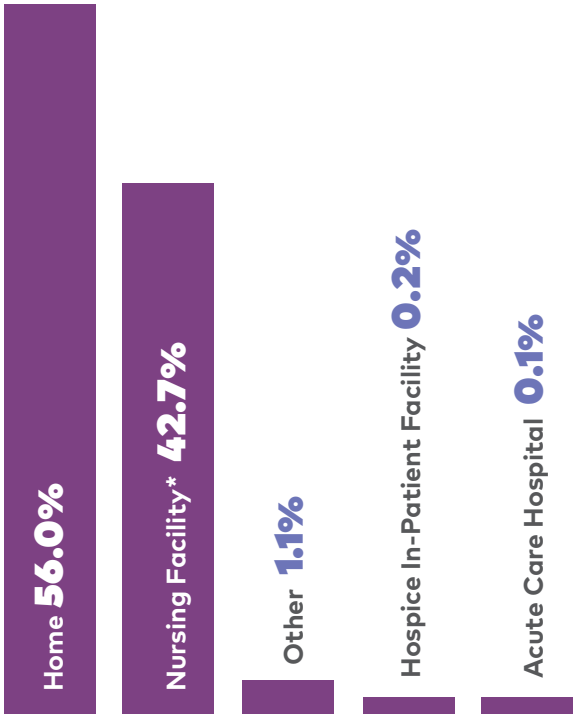
** Includes skilled nursing facilities, nursing facilities, assisted living facilities, and RHC days in a hospice inpatient facility.*

How Much Care Is Received? (continued)

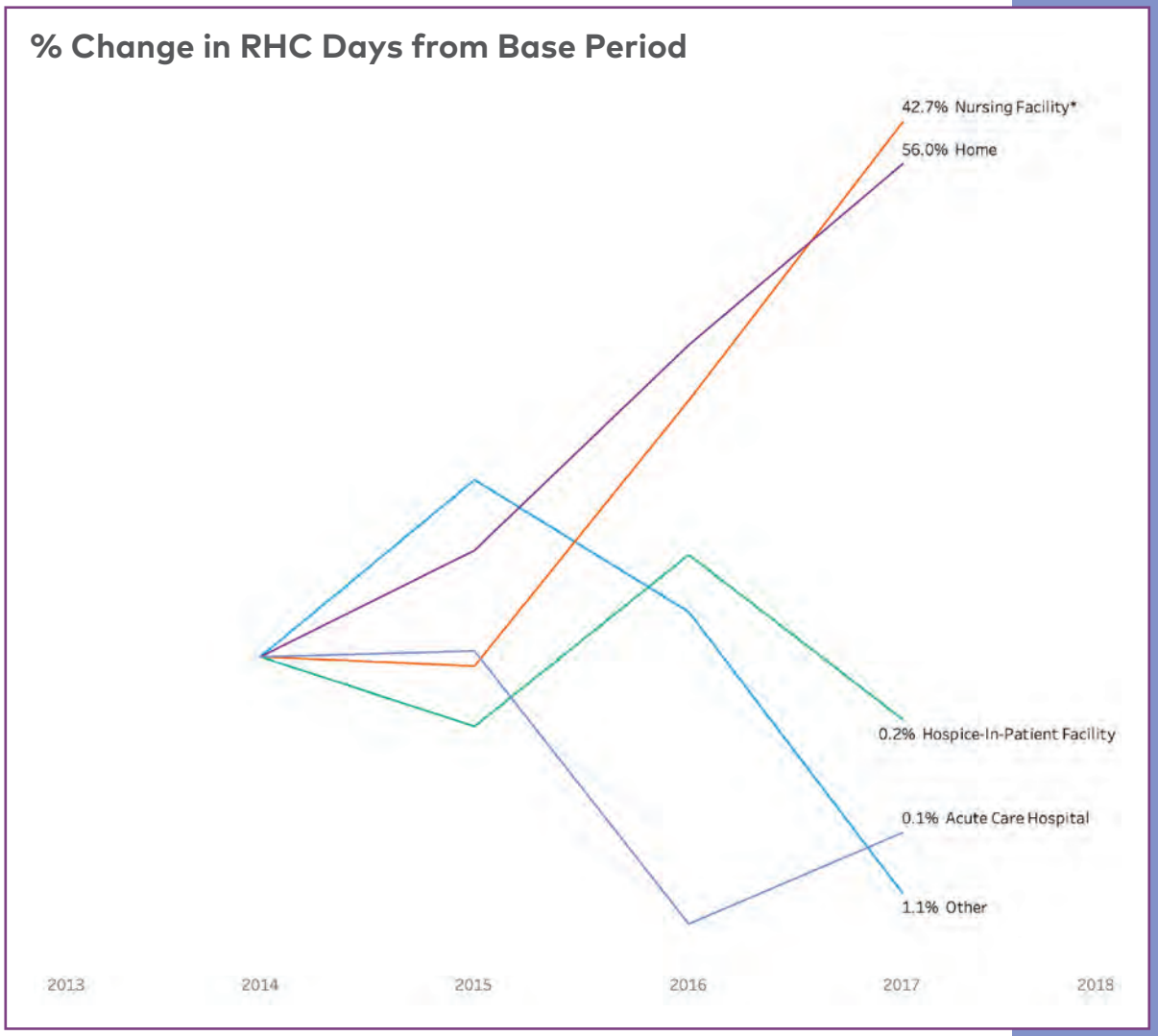
Location of RHC Days

56% of RHC days of care occurred in a private residence. RHC days in nursing facilities and home care have grown since 2014 by more than 42% while use of hospice inpatient facilities have declined.

Location of RHC Days for 2017



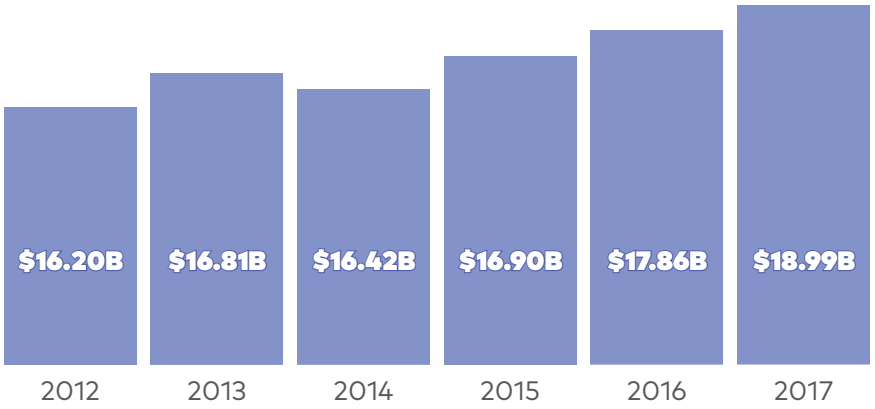
% Change in RHC Days from Base Period



How Does Medicare Pay for Hospice?

Medicare paid hospice providers a total of $18.99 billion dollars for care provided in 2017, representing an increase of 6.3% over the previous year.

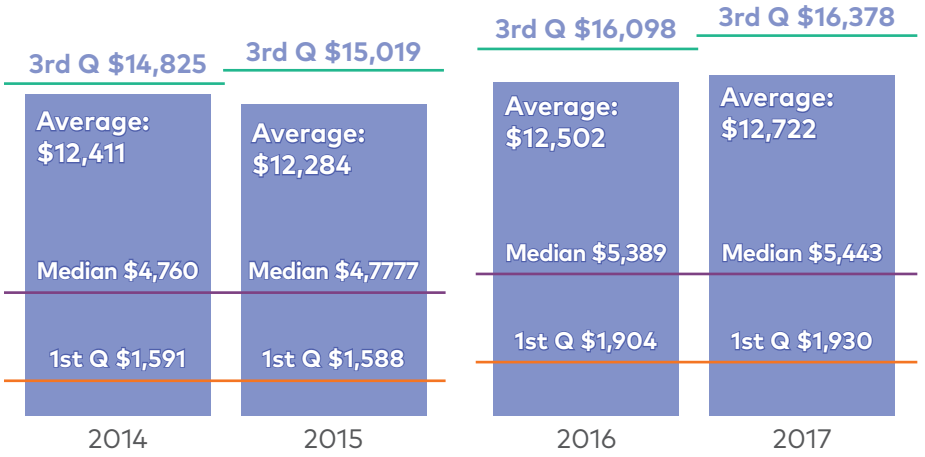
Medicare Spending



Spending Per Patient

The average spending per Medicare hospice patient was $12,722.

Average Medicare Spending Per Patient



Spending by Days of Care

In 2017, only 26.2% of Medicare spending for hospice care was for patients who had received 180 or fewer days of care.*

Medicare Payments by Days of Care Stratified from 2012-2017

Day Stratifications	2012	2013	2014	2015	2016	2017
1-7	97.6%	97.8%	97.8%	97.9%	98.1%	98.2%
8-14	0.3%	0.3%	0.3%	0.3%	0.2%	0.2%
15-30	0.3%	0.3%	0.3%	0.3%	0.3%	0.3%
31-60	1.8%	1.6%	1.5%	1.5%	1.4%	1.3%
61-90	0.3%	0.3%	0.3%	0.3%	0.2%	0.2%
91-180	0.3%	0.3%	0.3%	0.3%	0.3%	0.3%
>180	1.8%	1.6%	1.5%	1.5%	1.4%	1.3%

** Includes days of care that spanned between the years of 2012 through 2017.*

How Does Medicare Pay for Hospice? (continued)

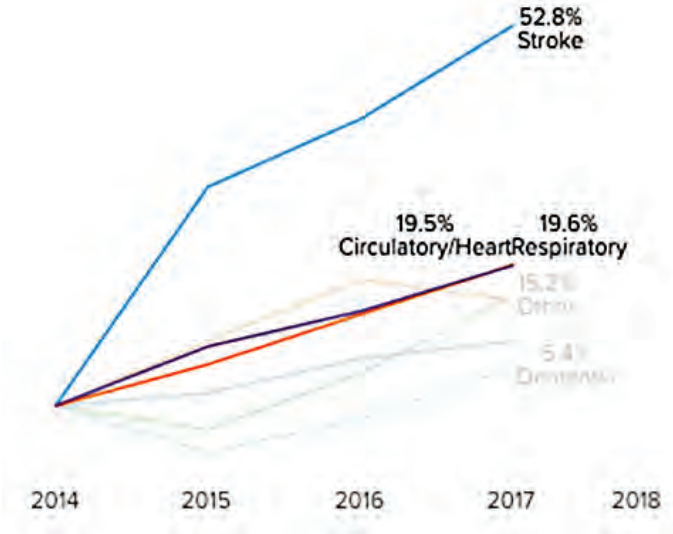
Spending by Diagnosis

In 2017, patients with a principal diagnosis of dementia continued to lead Medicare hospice spending at 25.4%. Stroke, circulatory/heart, and respiratory related diagnosis grew the most since 2014.

% of Medicare Spending by Principal Diagnosis

CCS	2017
Dementia	25.4%
Circulatory/Heart	20.0%
Cancer	18.4%
Other	13.3%
Respiratory	10.9%
Stroke	10.9%
Chronic Kidney Disease	1.1%

Medicare Spending % Change from Base Period



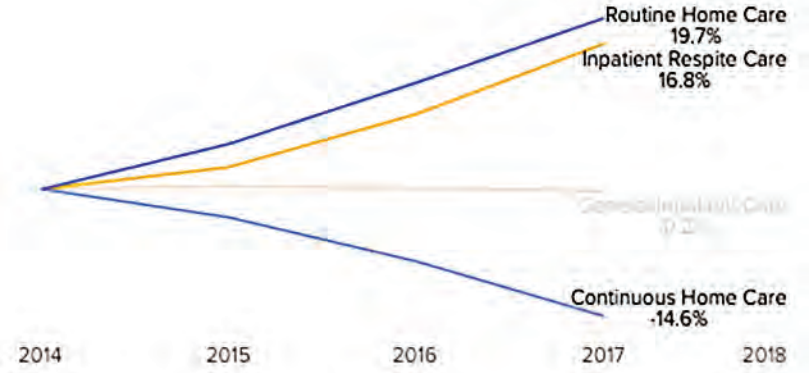
Spending by Level of Care

In 2017, the vast majority of Medicare spending for hospice care was for care at the routine home care level. This has grown 20% since 2014, followed by inpatient respite care. Continuous home care has declined 14% over the same period.

Spending by Level of Care

Level of Care	2017
Routine Home Care	89.31%
General Inpatient Care	7.14%
Inpatient Respite Care	1.78%
Continuous Home Care	1.77%

LOC Spending % Change from Base Period

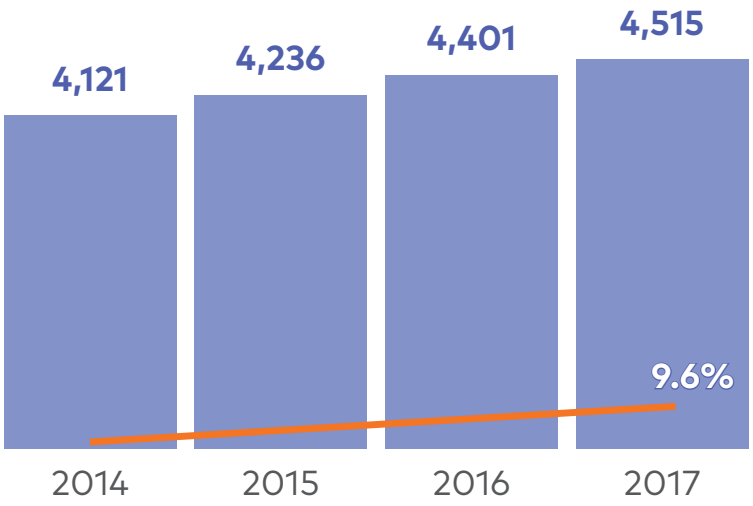


Who Provides Care?

How many hospices were in operation in 2017?

Over the course of 2017, there were 4,515 Medicare certified hospices in operation based on claims data. This represents an increase of 9.6% since 2014.

Number of Operating Hospices

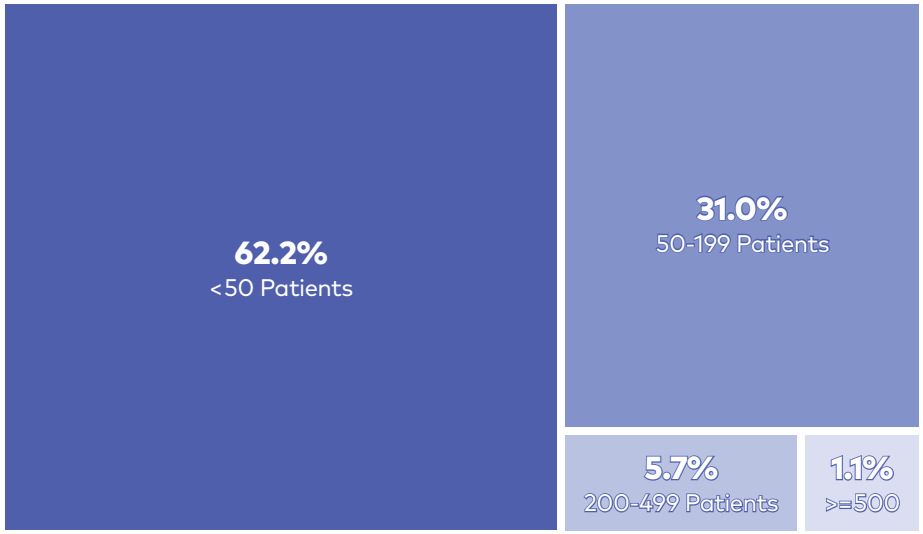


Hospice Size

One indicator of hospice size is the average daily census (ADC) or more specifically the number of patients cared for by a hospice on average each day.

In 2017 the mean ADC was 63 and the median 31. 62% of hospices had an ADC of less than 50 patients.

Hospice Average Daily Census for 2017



ADC Support Stats

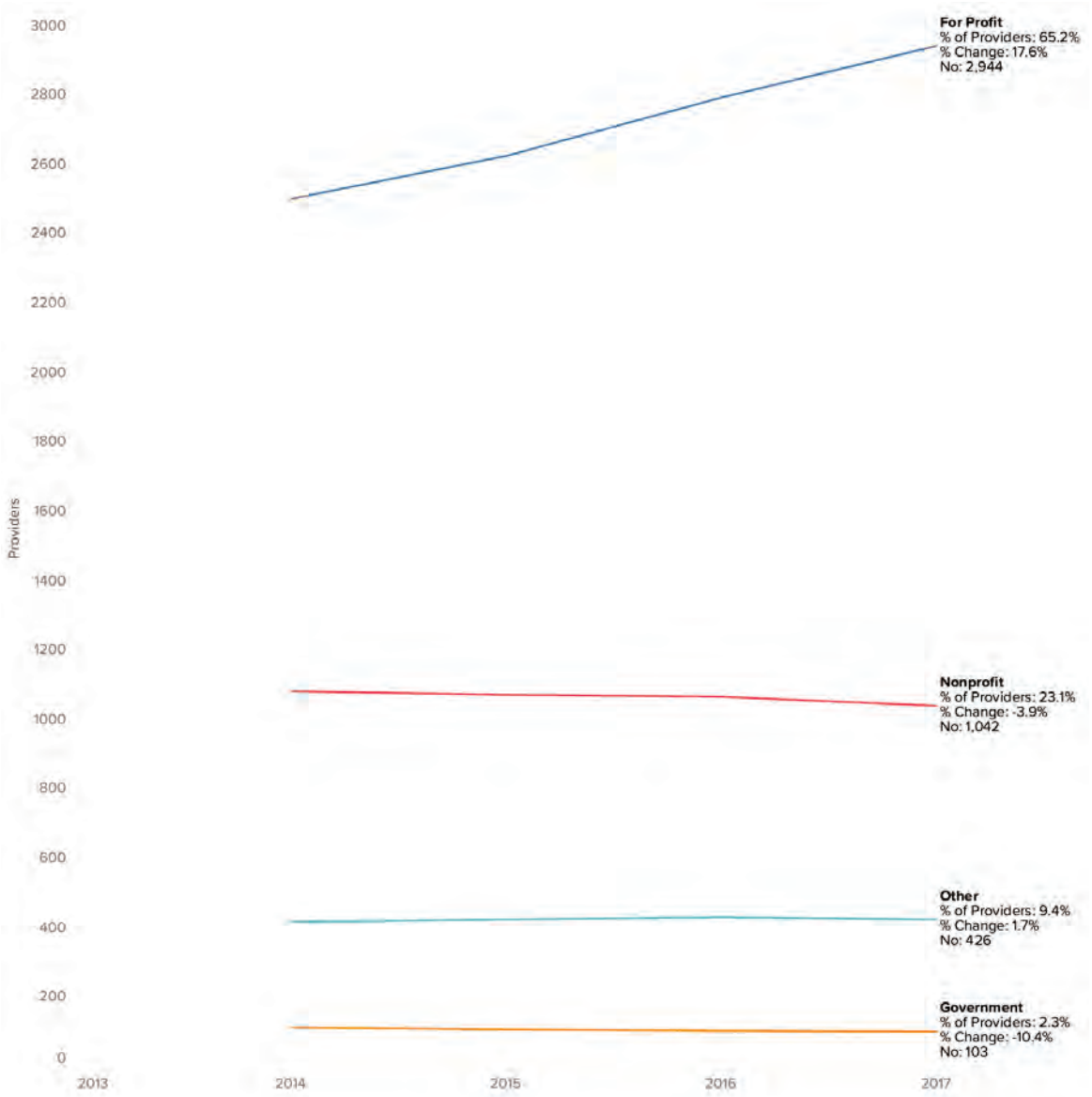
Year	Providers	Mean Census	Median Census	10th Percentile Census	25th Percentile Census	75th Percentile Census	90th Percentile Census
2014	4,121	66.9	33.5	4.1	12.8	75.3	150.3
2015	4,236	66.3	33.2	4.0	13.2	74.5	146.5
2016	4,401	67.3	33.1	3.1	12.1	75.9	153.5
2017	4,515	68.9	33.2	3.6	12.2	78.3	157.6

Who Provides Care? (continued)

Tax Status

62.2% of active Medicare provider numbers were assigned to hospice providers with for-profit tax status and 23.1% with not-for-profit status. For-profit hospice providers grew more than 17% since 2014 while non-profit hospice providers retracted 3.9%. Government-owned hospice providers comprised only 2.3% and has also declined.

Providers by Type

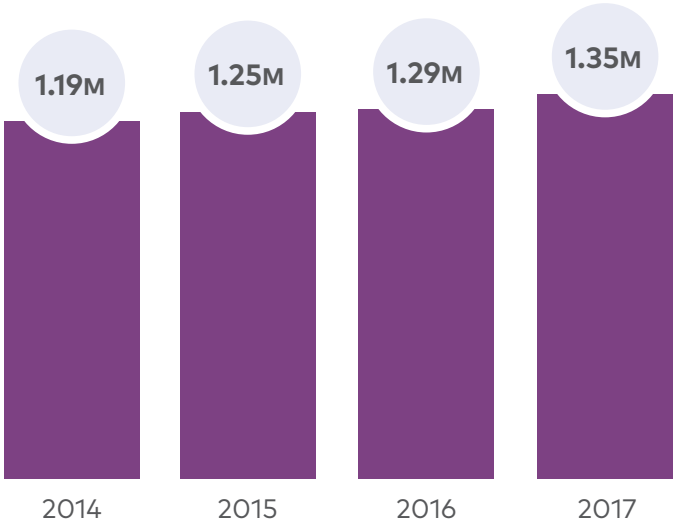


Who Provides Care? (continued)

Patient Volume First Admissions

In 2017 hospice providers performed a total 1.3 million unduplicated admissions* of Medicare hospice patients representing a 13.1% increase since 2014.

First Admissions

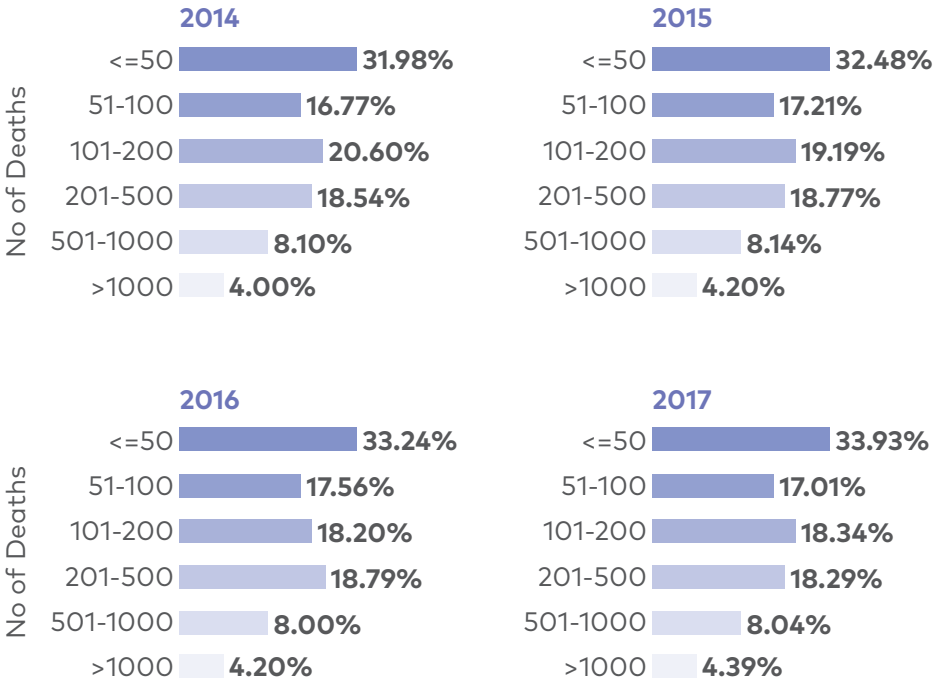


**Unduplicated admissions include patients who were part of the census at the end of 2016, carried over into 2017, discharged in 2016 and readmitted within the year.*

Volume of Deaths

In 2017, the highest number of hospice providers served 50 or fewer patients who died while enrolled in hospice care.

% of Hospice Providers by Decedent Count



Who Provides Care? (continued)

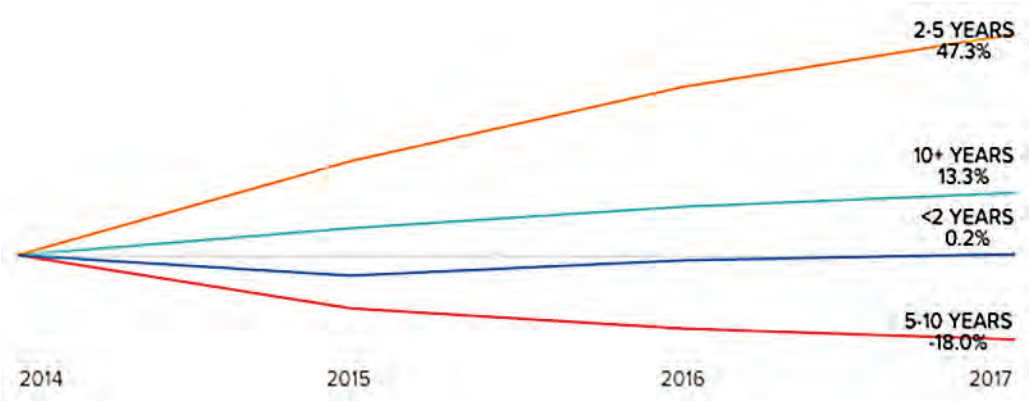
Provider Medicare Certification

More than 55% of all providers have been certified for 10 or more years highlighting the maturity of the industry. The biggest growth of provider certification since 2014 have been on newer providers certified for 2-5 years highlighting new entrants within the industry.

Provider Certification

Years Certified	2012	2013	2014	2015	2016	2017
< 2 Years	9.6%	11.0%	11.1%	10.3%	10.3%	10.1%
2-5 Years	12.5%	12.3%	13.3%	15.5%	16.9%	17.9%
5-10 Years	25.7%	24.8%	21.8%	18.8%	17.2%	16.3%
10 + Years	52.1%	51.9%	53.8%	55.4%	55.6%	55.7%
N/A	0.1%	0.1%	0.0%	0.0%	0.0%	0.0%

% of Medicare Certified Providers Change from Base Year



Data Sources

The primary data source used for the findings in this report is CMS Research Identifiable Files (RIF) Medicare Fee-for-Service (FFS) claims data including 100% of Medicare Part A from 2012-2017. The CMS 2018 Provider of Service (POS) file is used to provide further information on facilities certified to provide care to Medicare beneficiaries. The Healthcare Cost and Utilization Project (HCUP) Clinical Classification Software (CCS) was used to classify patients into diagnosis categories based on their primary ICD-9 or ICD-10 diagnosis. The FY 2018 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements is the source for the tax status statistics.

Methodology Note

All claims are analyzed within the calendar year with the date assigned based on the claim through date, the last date on the billing statement for services covered to a beneficiary. The methods used to aggregate hospice claims were based on those outlined in the Centers for Medicare and Medicaid Services' Medicare Hospice Utilization &Payment Public Use File: A Methodological Overview. Results may differ from other reports such as Medpac's publications that look within a fiscal year or across multiple years for patients that have lengths of stay that cross many years. Unless otherwise specified, the denominator is all hospice beneficiaries who had any services covered within the calendar year, regardless of the discharge status code for the last service rendered. This differs from other analyses that may restrict to patients who were discharged (live discharges and/or decedents).

CMS Research Identifiable Files (RIF) Data Set

The Medicare FFS RIFs used for this report contain all Medicare Part A claims related to payment made directly towards hospice services. All beneficiaries with at least one hospice claim paid through Medicare are included in this file (2.5% of all Medicare beneficiaries in 2017). Selected variables within the files are encrypted, blanked, or ranged. The RIF Medicare claims used for Facts and Figures include the following data files:

- Hospice File: Hospice Fee-for-Service claims submitted by Medicare certified hospice providers (see documentation for detailed information on hospice files)
- Member Beneficiary Summary File (MBSF): Medicare beneficiary enrollment information via Medicare Parts A, B, C, and D (see documentation for detailed information on MBSF)

CMS 2018 Provider of Service (POS) Data Set

The POS file contains information of health care providers who are certified to provide care to Medicare beneficiaries.

Healthcare Cost and Utilization Project (HCUP) Clinical Classification Software (CCS)

The CCS tool was used to group patients into diagnosis groups based off ICD-9 or ICD-10 diagnosis.

Questions May Be Directed To:

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