

# **LETTER OF INTENT**



**State of Tennessee  
Health Facilities Commission**

502 Deaderick Street, Andrew Jackson Building, 9<sup>th</sup> Floor, Nashville, TN 37243

[www.tn.gov/hsda](http://www.tn.gov/hsda)

Phone: 615-741-2364

[hsda.staff@tn.gov](mailto:hsda.staff@tn.gov)

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## LETTER OF INTENT

The Publication of Intent is to be published in The Commercial Appeal which is a newspaper of general circulation in Fayette, Shelby, and Tipton Counties., Tennessee, on or before 03/15/2024 for one day.

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This is to provide official notice to the Health Facilities Commission and all interested parties, in accordance with T.C.A. §68-11-1601 et seq., and the Rules of the Health Facilities Commission, that Heart N Soul Hospice Memphis, a/an Hospice Agency owned by Heart N Soul Hospice Memphis LLC with an ownership type of Limited Liability Company and to be managed by itself intends to file an application for a Certificate of Need for The establishment of a hospice agency and the initiation of hospice services in the following counties: Fayette, Shelby, and Tipton.. The address of the project will be 1255 Lynnfield Road, Suite 258, Memphis, Shelby, Tennessee, 38119. The estimated project cost will be \$182,500.

The anticipated date of filing the application is 04/01/2024

The contact person for this project is Attorney Kim Looney who may be reached at K&L Gates LLP - 501 Commerce Street, Suite 1500, Nashville, TN 37203 – Contact No. 615-780-6727.

Kim Looney

03/15/2024

[kim.looney@klgates.com](mailto:kim.looney@klgates.com)

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**Signature of Contact**

**Date**

**Contact's Email Address**

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The Letter of Intent must be received between the first and the fifteenth day of the month. If the last day for filing is a Saturday, Sunday, or State Holiday, filing must occur on the next business day. Applicants seeking simultaneous review must publish between the sixteenth day and the last day of the month of publication by the original applicant.

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The published Letter of Intent must contain the following statement pursuant to T.C.A. §68-11-1607 (c)(1). (A) Any healthcare institution wishing to oppose a Certificate of Need application must file a written notice with the Health Facilities Commission no later than fifteen (15) days before the regularly scheduled Health Facilities Commission meeting at which the application is originally scheduled; and (B) Any other person wishing to oppose the application may file a written objection with the Health Facilities Commission at or prior to the consideration of the application by the Commission, or may appear in person to express opposition. Written notice of opposition may be sent to: Health Facilities Commission, Andrew Jackson Building, 9th Floor, 502 Deaderick Street, Nashville, TN 37243 or email at [hsda.staff@tn.gov](mailto:hsda.staff@tn.gov) .





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## **PUBLICATION OF INTENT**

**The following shall be published in the “Legal Notices” section of the newspaper in a space no smaller than two (2) columns by two (2) inches.**

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### **NOTIFICATION OF INTENT TO APPLY FOR A CERTIFICATE OF NEED**

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The contact person for this project is Attorney Kim Looney who may be reached at K&L Gates LLP - 501 Commerce Street, Suite 1500, Nashville, TN 37203 – Contact No. 615-780-6727.

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# **CRITERIA AND** **STANDARDS**

**Attachment 1N**  
**Criteria and Standards Narrative**

# **Hospice Services**

*Certificate of Need Standards and Criteria*



STATE OF TENNESSEE

**STATE HEALTH PLAN  
CERTIFICATE OF NEED STANDARDS AND CRITERIA**

*FOR*

**RESIDENTIAL HOSPICE SERVICES  
AND HOSPICE SERVICES**

The Health Services and Development Agency (HSDA) may consider the following standards and criteria for applications seeking to provide Residential Hospice and Hospice services. Existing providers of Residential Hospice and Hospice services are not affected by these standards and criteria unless they take an action that requires a new certificate of need (CON) for Residential Hospice and/or Hospice services.

These standards and criteria are effective immediately upon approval and adoption by the Governor of the State Health Plan updates for 2014. Applications to provide Residential Hospice and/or Hospice services that were deemed complete by HSDA prior to this date shall be considered under the Certificate of Need Standards and Criteria included in the State Health Plan updates for 2012.

Because of the unique nature of hospice services, the Division commits to reviewing these standards annually.

**Definitions Applicable to both Residential Hospice Services and Hospice Services**

1. **"Deaths"** shall mean the number of all deaths in a Service Area less that Service Area's number of reported homicide deaths, suicide deaths, and accidental deaths (which includes motor vehicle deaths), as reported by the State of Tennessee Department of Health. The number of reported infant deaths includes neonatal and post neonatal deaths and is reported separately under the respective cause of death; therefore, in order to prevent overlap, the number of infant deaths is not included discretely.
2. **"Residential Hospice"**<sup>1</sup> shall have that meaning set forth in Tennessee Code Annotated

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<sup>1</sup> The Division recognizes the Guidelines for Growth's statement that "the purpose of residential hospice facilities is not to replace home care hospice services, but rather to provide an option to those patients who cannot be adequately cared for in the home setting." The Division also recognizes that Residential Hospice and Hospice providers may in

Section 68-11-201 or its successor.

3. **"Hospice"** shall refer to those hospice services not provided in a Residential Hospice Services facility.
4. **"Total Hospice"** shall mean Residential and Hospice Services combined.

#### STANDARDS AND CRITERIA APPLICABLE TO TOTAL HOSPICE

1. **Adequate Staffing:** An applicant should document a plan demonstrating the intent and ability to recruit, hire, train, assess competencies of, supervise, and retain the appropriate numbers of qualified personnel to provide the services described in the application. Importantly, the applicant must document that such qualified personnel are available for hire to work in the proposed Service Area. In this regard, an applicant should demonstrate its willingness to comply with the general staffing guidelines and qualifications set forth by the National Hospice and Palliative Care Organization.

**Rationale:** Health care professionals, including those who provide hospice services, are not uniformly located across the state, and rural areas showing some need for hospice services may not have a qualified hospice workforce. The Division believes that granting a CON for the provision of health care services without evidence that the applicant has a qualified workforce readily available to provide quality care to patients is not, in fact, providing access to quality health care.

**Response:** Heart N Soul Hospice Memphis ("Applicant") is seeking approval to establish a home care hospice agency dedicated to providing compassionate end-of-life care to all patients. We recognize the disparities in access to quality hospice care within African American and minority communities. Therefore, we place a particular emphasis on making our services accessible and culturally sensitive to these underserved populations. The hospice agency would provide services in Fayette, Shelby, and Tipton Counties, with an administrative office located in a leased 1500 sf in Memphis (Shelby County), TN.

Applicant understands that quality care is paramount. We will prioritize adequate, qualified staffing to ensure personalized, timely care for all patients. Our coordinated care plans promote smooth transitions and uninterrupted support, reducing stress and providing comfort during challenging times. We value community feedback and data analysis as tools to identify areas for improvement, making our care more responsive to the needs of those we serve. We are committed to ongoing data tracking and outcome monitoring to deliver the best possible care to patients and families. Our Community Health Accreditation Partner ("CHAP") accreditation reflects our dedication to excellence, giving consumers confidence in our standards. Finally, we comply with Medicare's four levels of care, guaranteeing access to the full spectrum of hospice services.

Applicant's commitment to quality care translates directly into benefits for consumers. Patients and families can expect personalized, culturally appropriate attention from qualified staff, seamless transitions in their care plans, and a focus on constant improvement for a positive hospice experience. Our CHAP accreditation offers peace of mind, and our adherence to Medicare guidelines ensures consumers have access to all necessary levels of support.

Applicant's staffing strategy is centered around attracting a skilled, compassionate team deeply connected to the Shelby, Fayette, and Tipton County communities. Applicant will implement a multi-pronged approach, prioritizing the following:

- **Local Recruitment:** Applicant's goal is to build a team that reflects the diversity and understands the cultural nuances of the populations it serves. Applicant will focus on:
  - **Community Engagement:** Partner with churches, community centers, and local organizations to host job fairs and targeted recruitment events.
  - **Online Outreach:** Utilize job boards, local social media groups, and professional networks specifically tailored to the healthcare field.
  
- **Educational Partnerships:** Applicant seeks to build relationships with nursing schools, allied health programs, and continuing education organizations within the region. This includes:
  - **Internship & Mentorship Programs:** Offer opportunities for hands-on experience and early career development, attracting passionate new graduates.
  - **Guest Lectures:** Contribute knowledge and expertise to nursing programs, raising our profile among prospective employees.
  
- **Contracted Specialists:** To ensure access to specialized care, Applicant has established a network of highly qualified, contracted professionals including a medical director, physical therapists, occupational therapists, speech therapists, and others, as needed.
  
- **Employee-Centric Culture:** Applicant recognizes that attracting top talent requires a commitment to employee well-being. This includes competitive salaries, flexible scheduling, and ongoing professional development. A key example is Applicant's dedicated nurse triage position, ensuring on-call nurses aren't overburdened by providing support during nights and weekends.

### **Ongoing Development**

Applicant remains adaptable, continuously monitoring its staffing needs as its patient census grows. Applicant will explore additional recruitment strategies and partnerships based on local resources and the evolving healthcare landscape in the proposed service area.

While Applicant is seeking approval for a new hospice agency in Shelby, Fayette, and Tipton County area, Applicant's commitment to this region runs deep. Several members of Applicant's leadership team are long-time Tennessee residents, providing a strong foundation for understanding the state's healthcare landscape and the unique needs of the communities that Applicant aims to serve. Applicant recognizes that attracting a compassionate, skilled hospice team requires integrating ourselves into the fabric of these communities. Applicant has begun to establish relationships with healthcare providers in the proposed service area and has attended local health fairs to raise its visibility and connect with potential staff.

Additionally, Applicant has proactively researched the hospice staffing market. Applicant's findings indicate there is a pool of qualified nurses, social workers, and chaplains within the region. Applicant understands the competitive landscape and is prepared to offer attractive compensation packages that align with industry standards for the area. Applicant recognizes recruitment may present some challenges and has developed specific strategies such as flexible scheduling and potential sign-on incentives to attract qualified staff to these areas.

Applicant's commitment to building a successful hospice agency in Shelby, Fayette, and Tipton counties extends beyond providing care – Applicant is dedicated to becoming an integral part of the community and a respected employer within the hospice field. Applicant is excited by the prospect of building a dedicated team that shares our mission of providing exceptional end-of-life care.

Applicant is currently in the process of identifying a highly qualified Medical Director for its hospice agency. Applicant understands the crucial role this individual plays in ensuring excellent medical oversight and patient care. Applicant is actively seeking a physician who possesses the following:

- **Specialized Expertise:** Board certification in hospice and palliative medicine is ideal. If not board-certified, Applicant seeks a physician with extensive experience in this field.
- **Community Understanding:** Preference will be given to candidates who are already practicing within the Shelby, Fayette, and Tipton region and demonstrate an understanding of local healthcare resources and needs.
- **Collaborative Spirit:** Applicant's ideal Medical Director will be a team player, working closely with our interdisciplinary team to guide care plans and support Applicant's staff.

Applicant is confident that the region offers a pool of skilled physicians who align with Applicant's mission. Applicant is committed to finding the best possible candidate to lead Applicant's medical team.

2. **Community Linkage Plan:** The applicant should provide a community linkage plan that demonstrates factors such as, but not limited to, relationships with appropriate health care system providers/services and working agreements with other related community services assuring continuity of care focusing on coordinated, integrated systems. Letters from physicians in support of an application should detail specific instances of unmet need for hospice services.

**Response:** Principals of Applicant have developed a relationship with many area providers and community agencies to ensure appropriate continuity of care. This is also manifested in the applicant's connection to key faith-based community entities. The applicant believes, as a minority owned entity, it will be successful because to serve the African American population requires a collaborative relationship with the religious community and other community providers and leaders in both an educational way and a service rendering, which it is uniquely positioned to provide.

Please see list of Applicant's established relationships with the specific community institutions, faith-based community entities and healthcare providers in the service area detailed in response to Item 4N.

3. **Proposed Charges:** The applicant should list its benefit level charges, which should be reasonable in comparison with those of other similar facilities in the Service Area or in adjoining service areas.

**Response:** Applicant is committed to promoting economic efficiencies within the healthcare system. We understand that our proposed charges should align with those of other similar

facilities. Additionally, we believe educating the healthcare community about hospice services can lead to more informed decision-making with regards to end-of-life care, potentially reducing unnecessary costs. This education component also supports our goal of recruiting, developing, and retaining a qualified healthcare workforce.

Our proposed per diem rates directly align with the 2024 Medicare final rule reimbursement rates: Routine Home Care: \$192.39; Continuous Care: \$1356.56; Inpatient Respite: \$451.96; and General Inpatient: \$1014.40. This ensures transparency and financial responsibility while adhering to established Medicare guidelines. Since all hospices receive standardized reimbursement for Medicare and Medicaid patients, these rates are consistent across providers.

Our rates align with existing hospices in the region, as seen in Attachment 1N (Criteria and Standards Data), promoting fair competition and ensuring patients have access to quality care within a predictable reimbursement structure.

- 4. Access:** The applicant must demonstrate an ability and willingness to serve equally all of the Service Area in which it seeks certification. In addition to the factors set forth in HSDA Rule 0720-11-.01(1) (listing the factors concerning need on which an application may be evaluated), the HSDA may choose to give special consideration to an applicant that is able to show that there is limited access in the proposed Service Area.

**Response:** Applicant believes in equitable access to hospice care. We will serve all patients in our area without discrimination and have clear plans for caring for low-income and marginalized patients. Our focused outreach to underserved communities, particularly minority populations, aims to improve awareness of hospice benefits. We strive to empower consumers from all backgrounds to make informed choices about their end-of-life care.

Patients without Medicare or Medicaid coverage will be carefully evaluated during the intake process. For those with commercial insurance, Applicant will verify eligibility and benefits. If a patient is found to be indigent, Applicant will adhere to its established eligibility process and, in line with traditional Medicare guidelines, admit and provide care if the patient qualifies for hospice services.

The Applicant is not seeking special consideration. However, the Applicant strongly feels it will be providing services to a minority patient population that is not being served at the same rate as its white counterparts. As is demonstrated in the application and elsewhere in these supplemental responses, particularly in the discussion on hospice penetration rates, the black population clearly does not receive hospice services at the same rate as the white population does. The black population penetration rate for hospice services is significantly lower than that of the white population penetration rate for hospice services in Shelby County.

- 5. Indigent Care:** The applicant should include a plan for its care of indigent patients in the Service Area, including:
- a. Demonstration of a plan to work with community-based organizations in the Service Area to develop a support system to provide hospice services to the indigent and to conduct outreach and education efforts about hospice services.
  - b. Details about how the applicant plans to provide this outreach.



- c. Details about how the applicant plans to fundraise in order to provide indigent and/or charity care.

**Response:** Ministers and other community leaders are frequently in a position of influence with the elderly population, including the indigent and African American population, and provide them with relevant literature so that they can be in a position to understand themselves and to explain the benefits of hospice services to both patients and their family members. Applicant has cultivated relationships with such individuals, which will help to develop a support system to provide hospice services to the indigent.

Because the majority of hospice patients are 65 and older, they are covered by Medicare. If they are also indigent, they will generally qualify for TennCare. Because of the existence of such payor sources, the applicant does not anticipate needing to fundraise for the provision of care for the patients.

Applicant is firmly committed to providing compassionate hospice care to all residents of Shelby, Fayette, and Tipton counties, regardless of their ability to pay. Applicant recognizes this as a core responsibility of operating a hospice service. To support this, Applicant is developing a comprehensive plan for indigent care, and will use the foundation dedicated to this mission.

**a. Community Collaboration:**

- **Partnership Identification:** Applicant has begun proactively identifying community-based organizations, including faith-based groups, social service agencies, and healthcare providers, that serve low-income populations and align with our mission.
- **Needs Assessment:** Applicant will work collaboratively with these organizations to perform a comprehensive needs assessment, pinpointing specific barriers to hospice access for indigent patients.
- **Outreach & Education:** Together with those partners, Applicant will develop culturally sensitive outreach and educational programs designed to increase awareness and understanding of hospice within underserved communities.

**b. Outreach Strategies:**

- **Targeted Events:** Collaborate with community partners to host health fairs and informational sessions in areas with high concentrations of indigent populations.
- **Train-the-Trainer Model:** In concert with our community educators Applicant will equip leaders in community organizations with the knowledge and tools to educate their own members about hospice benefits and eligibility.
- **Diverse Materials:** Develop multilingual and culturally appropriate brochures, presentations, and resources for distribution through community partners.

**c. Fundraising for Indigent Care:**

- **Dedicated Foundation:** Applicant's foundation will focus specifically on securing resources to support the care of indigent patients.
- **Grant Seeking:** Actively pursue grants from foundations, government agencies, and philanthropic organizations committed to expanding healthcare access for underserved populations.

- **Community Events:** Organize fundraising events (e.g., walks, auctions, dinners) in collaboration with community partners, fostering awareness and support.
- **Individual Donations:** Create a simple, accessible platform for individuals in the community to make direct donations in support of indigent care.

6. **Quality Control and Monitoring:** The applicant should identify and document its existing or proposed plan for data reporting, quality improvement, and outcome and process monitoring system. Additionally, the applicant should provide documentation that it is, or intends to be, fully accredited by the Joint Commission, the Community Health Accreditation Program, Inc., the Accreditation Commission for Health Care, another accrediting body with deeming authority for hospice services from the Centers for Medicare and Medicaid Services (CMS) or CMS licensing survey, and/or other third party quality oversight organization. The applicant should inform the HSDA of any other hospice agencies operating in other states with common ownership to the applicant of 50% or higher, or with common management, and provide a summary or overview of those agencies' latest surveys/inspections and any Department of Justice investigations and/or settlements.

**Rationale:** This information will help inform the HSDA about the quality of care the applicant's common ownership and/or management provides in other states and the likelihood of its providing similar quality of care in Tennessee.

**Response:** Applicant understands that quality care is paramount. We will prioritize adequate, qualified staffing to ensure personalized, timely care for all patients. Our coordinated care plans promote smooth transitions and uninterrupted support, reducing stress and providing comfort during challenging times. We value community feedback and data analysis as tools to identify areas for improvement, making our care more responsive to the needs of those we serve. We are committed to ongoing data tracking and outcome monitoring to deliver the best possible care to patients and families. Our CHAP accreditation reflects our dedication to excellence, giving consumers confidence in our standards. Finally, we comply with Medicare's four levels of care, guaranteeing access to the full spectrum of hospice services.

Neither the Applicant, nor any of its principals, has an ownership interest of 50% or greater in any hospice agencies in other states.

Applicant plans to be accredited by CHAP and will follow its quality standards. CHAP divides its Standards of Excellence into three key areas: patient centered care, safe care delivery, and sustainable organizational structure. Each key performance area has standards and evidence guidelines. Applicant will also provide the HFC with such information as it reasonably requests related to quality.

Heart and Soul Hospice, LLC is fully accredited and had half of the number of deficiencies on its last state survey as it understands hospice providers usually have (6 versus 13). It has no DOJ investigations or settlements.

7. **Data Requirements:** Applicants should agree to provide the Department of Health and/or the Health Services and Development Agency with all reasonably requested information and statistical data related to the operation and provision of services and to report that data in the time and format requested. As a standard of practice, existing data reporting

streams will be relied upon and adapted over time to collect all needed information.

**Response:** The Applicant agrees to provide the Department of Health and/or the Health Facilities Commission with all such information as is reasonably requested.

8. **Education:** The applicant should provide details of its plan in the Service Area to educate physicians, other health care providers, hospital discharge planners, public health nursing agencies, and others in the community about the need for timely referral of hospice patients.

**Response:** Applicant believes educating the healthcare community about hospice services can lead to more informed decision-making with regards to end-of-life care, potentially reducing unnecessary costs. This education component also supports our goal of recruiting, developing, and retaining a qualified healthcare workforce.

Applicant recognizes the importance of community education and outreach for hospice services in Shelby, Fayette, and Tipton counties. To address this need, Applicant will hire dedicated community educators who will be solely focused on this region. Applicant's educators will utilize guided tools and resources to effectively engage with diverse populations, including:

- **Physicians & Healthcare Providers:**
  - Develop targeted educational materials highlighting hospice eligibility guidelines, emphasizing early referral benefits for the target population.
  - Conduct in-service presentations and workshops at hospitals, clinics, and long-term care facilities, fostering open conversations about end-of-life care choices.
- **Hospital Discharge Planners:**
  - Establish strong relationships with discharge planners, providing information that supports hospice referrals for patients meeting eligibility criteria, particularly within the target population.
  - Offer guidance on how hospice services can facilitate smoother transitions from hospital to home.
- **Public Health Nursing Agencies:**
  - Collaborate closely to identify potentially eligible patients within the target population, sharing resources and coordinating referrals.
  - Offer joint educational sessions for public health nurses to deepen their understanding of hospice care and its benefits for underserved communities.
- **Community Outreach:**
  - Partner with faith-based organizations, community centers, and advocacy groups serving the target population to address specific cultural, linguistic, and informational needs about hospice.
  - Develop culturally sensitive materials in relevant languages to dispel myths and provide clear information about the benefits of hospice care.

## **RESIDENTIAL HOSPICE SERVICES**

### **DEFINITIONS**

**9. "Service Area"** shall mean the county or contiguous counties represented on an application as the reasonable area in which a health care institution intends to provide Residential Hospice Services and/or in which the majority of its service recipients reside. A radius of 50 miles and/or a driving time of up to 1 hour from the site of the residential hospice services facility may be considered a "reasonable area;" however, full counties shall be included in a Service Area. Only counties with a Hospice Penetration Rate that is less than 80 percent of the Statewide Median Hospice Penetration Rate may be included in a proposed Service Area.

**10. "Statewide Median Hospice Penetration Rate" (SMHPR)** shall mean the number equal to the Hospice Penetration Rate (as described in the following Need Formula) for the median county in Tennessee.

#### ADDITIONAL SPECIFIC STANDARDS AND CRITERIA FOR RESIDENTIAL HOSPICE SERVICES

Note that, while a "need formula" is set forth below, the decision to approve a CON application hereunder should be determined by the cumulative weight of all standards and criteria, including those set forth earlier herein.

**11. Need Formula:** The need for Residential Hospice Services should be determined by using the following Hospice Need Formula, which should be applied to each county in Tennessee:

$A / B = \text{Hospice Penetration Rate}$

Where:

A = the mean annual number of Hospice unduplicated patients served in a county for the preceding two calendar years as reported by the Tennessee Department of Health;

and

B = the mean annual number of Deaths in a county for the preceding two calendar years as reported by the Tennessee Department of Health.

Note that the Tennessee Department of Health Joint Annual Report for Hospice defines "unduplicated patients served" as "number of patients receiving services on day one of reporting period plus number of admissions during the reporting period."

Need is established in a county (thus, enabling an applicant to include it in the proposed Service Area) if its Hospice Penetration Rate is less than 80% of the Statewide Median Hospice Penetration Rate; further, existing Residential Hospice Services providers in a proposed Service Area must show an average occupancy rate of at least 85%.

The following formula to determine the demand for additional hospice service recipients should be applied to each county included in the proposed service area, and the results for each county's calculation should be aggregated for the proposed service area:

(80% of the SMHPR — County Hospice Penetration Rate) x B

**Rationale:** The use of an SMHPR is a methodology employed by many states; the Division paid particular attention to the Kentucky model (which employs an 80% rate), as Kentucky's population is similar geographically and culturally to that of Tennessee. The Division considered ranges from 70-85%, but felt that the results of rates lower than 80% were too restrictive. Only three additional counties showed need using the 85% rate as opposed to the 80% one, and those had low single-digit-need numbers. Thus, the 80% rate is proposed. The Division believes that using the median county rate supports the view that rural counties cannot quickly reach the higher penetration rates of Tennessee's metropolitan areas. The underlying purpose is to help encourage orderly growth by using an SMHPR that ratchets upward across the state as hospice providers strive to exceed 80% of the median county's hospice penetration rate. Thus, utilization should continue to increase, albeit gradually, and provide the opportunity in the underutilizing counties for more hospice services by agencies that can expect a market to exist for those services.

**Response:** Please see applicable need formula chart in Attachment 1N (Criteria and Standards Data).

**12. Types of Care:** An applicant should demonstrate whether or not it will have the capability to provide general inpatient care, respite care, continuous home care, and routine home care to its patients. If it is not planning to provide one or more of these listed types of care, the applicant should explain why.

**Response:** Not applicable.

**13. Continuum of Care Regarding the Expansion from Non-Residential Hospice Services:** An applicant for Residential Hospice Services that provides Hospice Services should explain how the Residential Hospice Services will maintain or enhance the Hospice Services' continuum of care to ensure patients have access to needed services. An applicant should provide assurances that it understands and will comply with any existing Medicare reimbursement requirements (e.g., the provision of different levels of hospice care, including any total patient care day allowances) and evidence that there are a sufficient number of potential hospice service recipients that will enable it to so comply.

**Rationale:** Currently<sup>2</sup>, Medicare pays nearly 90% of all hospice claims. The Medicare hospice benefit produces an incentive to recruit as many new patients as possible and to keep them on the service as long as possible. Unlike other segments of the health care industry, where revenues and costs can vary widely, Medicare pays a set daily rate for each person in hospice care, with higher allowances for patients that require more attention.

As part of its interest in ensuring that hospice programs serve only patients who are eligible and appropriate for hospice care, Medicare limits the total number of days of inpatient care (the sum of general inpatient care (GIP) and inpatient respite care days) for which a hospice may be reimbursed. The cap is set at 20 percent of the hospice's total patient care days. The Department of Health and Human Services' Office of Inspector General (OIG), in a May 3, 2013, memo to Marilyn Tavenner, Acting Administrator for

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<sup>2</sup> As of January 9, 2015.

Centers for Medicare & Medicaid Services (CMS), stated that CMS staff "have expressed concerns about possible misuse of GIP" by hospice programs and noted a \$2.7 million settlement with a hospice program for allegedly having billed for GIP when patients actually received routine home care (which has a lower reimbursement rate). "Long lengths of stay and the use of GIP in inpatient units need further review to ensure that hospices are using GIP as intended and providing the appropriate level of care. OIG is committed to looking into these issues further and will conduct a medical record review that will assess the appropriateness of GIP provided in different settings." The Division adds the above requirement as a way to ensure that the HSDA and applicants understand the importance that an applicant provide hospice services appropriately. The Division believes that the HSDA, through its application of appropriately developed CON standards and criteria, can serve an important role in reducing opportunities for Medicare/Medicaid fraud and abuse in Tennessee.

**Response:** Not applicable.

- 14. Assessment Period:** After approval by the HSDA of a residential hospice services CON application, no new residential hospice services CON application — whether for the initiation of services or for the expansion of services — should be considered for any county that is added to or becomes part of a Service Area until JAR data for residential hospice services can be analyzed and assessed by the Division to determine the impact of the approval of the CON.

**Assessment Period Rationale:** This Standard is designed to ensure that the impact of the provision of hospice services as a result of the approval of a new CON is accounted for in any future need calculations for a Service Area.

**Response:** Not applicable.

## HOSPICE SERVICES

### DEFINITIONS

- 15. "Service Area"** shall mean the county or contiguous counties represented on an application as the area in which an applicant intends to provide Hospice Services and/or in which the majority of its service recipients reside.

- 16. "Statewide Median Hospice Penetration Rate" (SMHPR)** shall mean the number equal to the Hospice Penetration Rate (as described below) for the median county in Tennessee.

### ADDITIONAL SPECIFIC STANDARDS AND CRITERIA FOR HOSPICE SERVICES

Note that, while a "need formula" is set forth below, the decision to approve a CON application hereunder should be determined by the cumulative weight of all standards and criteria, including those set forth earlier herein.

- 17. Need Formula:** The need for Hospice Services should be determined by using

the following Hospice Need Formula, which should be applied to each county in Tennessee:

$A / B = \text{Hospice Penetration Rate}$

Where:

A = the mean annual number of Hospice unduplicated patients served in a county for the preceding two calendar years as reported by the Tennessee Department of Health;

and

B = the mean annual number of Deaths in a county for the preceding two calendar years as reported by the Tennessee Department of Health.

Note that the Tennessee Department of Health Joint Annual Report of Hospice Services defines "unduplicated patients served" as "number of patients receiving services on day one of reporting period plus number of admissions during the reporting period."

Need should be established in a Service Area as follows:

a. For a hospice that is initiating hospice services:

i. The Hospice Penetration Rate for the entire proposed Service Area is less than 80% of the SMHPR;

AND

ii. There is a need shown for at least 100 total additional hospice service recipients in the proposed Service Area, provided, however, that every county in the Service Area shows a positive need for additional hospice service recipients.

Preference should be given to applications that include in a proposed Service Area only counties with a Hospice Penetration Rate that is less than 80% of the SMHPR; however, an application may include a county or counties that meet or exceed the SMHPR if the applicant provides good reason, as determined by the HSDA, for the inclusion of any such county and: 1) if the HSDA finds that such inclusion contributes to the orderly development of the healthcare system in any such county, and 2) the HSDA finds that such inclusion is not intended to include a county or counties that meet(s) or exceed(s) the SMHPR solely for the purpose of gaining entry into such county or counties. Letters of support from referring physicians in any such county noting the details of specific instances of unmet need should be provided by the applicant.

b. For a hospice that is expanding its existing Service Area:

i. There is a need shown of at least 40 additional hospice service recipients in each of the new counties being added to the existing Service Area.

Taking into account the above guidelines, the following formula to determine the demand for additional hospice service recipients should be applied to each county, and the results should be aggregated for the proposed service area:

(80% of the Statewide Median Hospice Penetration Rate — County Hospice Penetration Rate) x B

**Rationale 17a:** The Division believes that hospice services in Tennessee are underutilized, most likely as a result of community and societal norms and a need for more education to the general public on the benefits of hospice. Consequently, the Division believes that hospice services should be encouraged, within reason, in Tennessee and that providing broader opportunities for these services will help educate the public as to their value. Under 17a, the ability to include within a Service Area a county that meets or exceeds the SMHPR should assist in the grouping of counties within a Service Area, thus providing more hospice services opportunities, provided that there is no detriment to the orderly development of the healthcare system as a result.

The Tennessee Hospice Association and other stakeholders provided information that 120 hospice service recipients is a larger than necessary number to ensure economic sufficiency of a hospice that is initiating hospice services. Consensus opinion appears to agree that 100 hospice service recipients is a sufficient number.

**Response:** Please find attached a revised Attachment 1NR (Criteria and Standards Data) that includes 2021-2022 data for Criteria #14 and Criteria #17.

As stated in the discussion on the penetration formula in the application, even if the penetration rate is greater than the statewide median hospice penetration rate, an applicant may be able to provide good reason why the proposed service area counties should be included provided that the HFC determines that the inclusion of such county/counties contributes to the orderly development of health care. The application goes on to state that “[t]he Division believes that hospice services in Tennessee are underutilized, most likely as a result of community and societal norms and a need for more education to the general public on the benefits of hospice.” Applicant agrees that hospice services in Tennessee are underutilized, particularly for the African American population. Although penetration rates provide one way to determine need, another method for determining need for this particular application is to look at the extent to which African American and white patients receive hospice services. As previously noted, NHPCO studies report that the share of Medicaid decedents who used hospice services by race are as follows: (i) white Americans – 50%; (ii) African Americans – 35.6%. Instead, African Americans are more likely than white Americans to choose aggressive, life-sustaining interventions, including resuscitation and mechanical ventilation, even when there is little chance of survival. (see Association of American Medical Colleges, “Family, Fear, and Faith: Helping Black Patients with End-of-Life Decisions,” (July 2022)). At the root of the resistance, say researchers and African American physicians, is a toxic distrust of a health care system stemming from the “infamous Tuskegee syphilis experiment... gravediggers who exhumed the bones of enslaved people for anatomy lessons [and] researchers who used Henrietta Lacks’ cells without her consent.” (Id.). A hospice like the one Applicant proposes will work to educate the African American community in the proposed service area on the benefits of hospice.



**Rationale 17b:** Other states provide for the ability of an existing hospice to expand its Service Area where positive need is shown at 40-50% of the criterion required for a new hospice to institute services, thus a number of 40 additional hospice service recipients is suggested. Existing agencies are presumed to have the infrastructure in place for such expansion.

**Response:** Not applicable.

**18. Assessment Period:** After approval by the HSDA of a hospice services CON application, no new hospice services CON application — whether for the initiation of services or for the expansion of services — should be considered for any county that is added to or becomes part of a Service Area until JAR data for hospice services can be analyzed and assessed by the Division to determine the impact of the approval of the CON.

**Assessment Period Rationale:** This Standard is designed to ensure that the impact of the provision of hospice services as a result of the approval of a new CON is accounted for in any future need calculations for a Service Area.

**Response:** Not applicable.

It is our understanding that licensure for PruittHealth is pending so it has not yet started serving patients.

## **Additional Comments and Rationale Statements for Revised and Updated Standards and Criteria for Hospice Services**

### **Definitions**

**Deaths:** The Division of Health Planning patterns its need formula off the Kentucky certificate of need formula that takes into account all deaths, instead of using a type of cancer death weighted formula that appeared in the Guidelines for Growth. Cancer patient utilization of hospice services has lessened in relation to non-cancer patients, while the utilization of hospice services continues to grow.

**Residential Hospice and Hospice:** The Division recognizes that residential hospice services and hospice services are able to perform the same level of services and has thus not distinguished between the need for hospice services based on the two types of service providers. However, certain standards and criteria, such as service area, provide for a difference in consideration of an application.

### **Standards and Criteria**

**Quality of Care:** Providing for adequate and qualified staffing is an important part of providing quality care to patients, and is one of the State Health Plan's Principles for Achieving Better Health. A community linkage plan that assures continuity of care also falls within this Principle. Letters from physicians in support of an application should detail specific instances of unmet need for hospice services. Quality improvement, data reporting,

and outcome and process monitoring fall under this Principle as well, as does accreditation/quality oversight of the hospice service program. Finally, it should be noted that Medicare currently requires all four levels of hospice care for reimbursement (which also supports the third Principle regarding Economic Efficiencies).

**Access:** The second Principle for Achieving Better Health in the State Health Plan focuses on access to care. Accordingly, the applicant must demonstrate an ability and willingness to serve equally all of the Service Area in which it seeks certification and provide a plan for its care of indigent patients. As well, in addition to the factors set forth in HSDA Rule 0720-11.01(1) (listing the factors concerning need on which an application may be evaluated), the HSDA may choose to give special consideration to an applicant that is able to show that there is limited access in the proposed Service Area. The revisions to the need formula in 17b are meant to encourage the provision of hospice services in counties that otherwise do not meet the need formula, thus providing better access for the community.

**Economic Efficiencies:** The third Principle for Achieving Better Health focuses on encouraging economic efficiencies in the health care system. The new standards and criteria provide that the applicant's proposed charges should be reasonable in comparison with those of other similar facilities in the Service Area or in adjoining service areas. Educating the health care community on hospice services also falls within this Principle; the education component also addresses the fifth Principle of recruiting, developing, and retaining a sufficient qualified health care workforce.

**Data Needs:** The Division recognizes that hospice patients known as "general inpatients" receive hospice services in locations other than their homes, such as nursing homes and hospitals, and that these patients are not separately identified on the Joint Annual Report. The Division aims to correct this omission in the future to better account for the total utilization of hospice services.

**NOTE:** A previously proposed standard providing for the showing of an "unmet demand" has been deleted, for the following three reasons: 1) The Division believes that an unintended consequence of that proposed standard would have been the preclusion of a new, non-county-contiguous hospice agency ever to develop a Service Area from those counties and receive a CON to serve them; 2) After review of hospice utilization data for the past three JARs, the Division has learned that, in counties that showed a positive need of less than 40 under the existing need formula, existing hospice agencies met substantially all (if not all) of the positive need of additional hospice service recipients, providing evidence that the orderly development of hospice services in such counties currently exists; and 3) the Division recognizes that the HSDA already has the inherent authority to determine, based on evidence provided, that there is a need for expansion of hospice services into adjacent counties beyond that shown by the need formula.



**Criteria #3. Proposed Charges**

Hospice Agency	Home County	State ID	2023 Total Patient Days	2023 Total Net Revenue	Net Charge (Net Revenue/Patient Days)
Avalon Hospice	Davidson	19694	546,515	\$88,701,381	\$162.30
Caris Healthcare	Fayette	24606	27,017	\$3,917,680	\$145.00
AccentCare Hospice and Palliative Care of Tennessee*	Shelby	79716	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	79646	23,027	\$2,224,532	\$96.61
Baptist Trinity Hospice	Shelby	79616	48,060	\$6,323,041	\$131.57
Compassus - Memphis	Shelby	79686	28,851	\$4,916,441	\$170.41
Crossroads Hospice of Tennessee, LLC	Shelby	79676	82,707	\$13,193,708	\$159.52
Hope Hospice & Palliative Care	Shelby	79726	16,668	\$2,146,331	\$128.77
Methodist Alliance Hospice	Shelby	79666	67,577	\$11,247,322	\$166.44
<b>TOTAL</b>	<b>N/A</b>	<b>N/A</b>	<b>840,422</b>	<b>\$132,670,436</b>	<b>\$157.86</b>

Source: 2023 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information

2023 Benefit Level Charges in the Service Area Medicare Per Diem Rates						
Hospice Agency	Home County	State ID	Routine Hospice Care	Continuous Hospice Care	General Inpatient	Respite Inpatient
Avalon Hospice	Davidson	19694	193	1,368	1,016	452
Caris Healthcare	Fayette	24606	187	1,325	989	440
AccentCare Hospice and Palliative Care of Tennessee	Shelby	79716	N/A	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	79646	160	500	642	430
Baptist Trinity Hospice	Shelby	79616	163	500	785	428
Compassus - Memphis	Shelby	79686	203	1,463	1,068	474
Crossroads Hospice of Tennessee, LLC	Shelby	79676	187	1,324	989	440
Hope Hospice & Palliative Care	Shelby	79726	203	1,463	1,068	474
Methodist Alliance Hospice	Shelby	79666	180	1,291	947	422

Source: 2023 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information

**Criteria #14 and Criteria #17. Need Formula**

County Name	Hospice Patients Served			Total Hospice Deaths*		
	2021	2022	Mean	2021	2022	Mean
Fayette	156	132	144	518	522	520
Shelby	4,419	4,367	4,393	9,618	8,312	8,965
Tipton	244	234	239	734	735	735
<b>TENNESSEE TOTAL</b>	<b>45,022</b>	<b>50,301</b>	<b>47,662</b>	<b>81,575</b>	<b>75,416</b>	<b>78,496</b>

Source: Tennessee Department of Health, Division of Policy, Planning and Assessment, Office of Health Statistics. Death Statistical System, 2018-2022. Nashville, Tennessee. 2021-2022 JAR H

**Criteria #14 and Criteria #17.1**

County Name	Hospice Penetration Rate	Hospice Penetration Rate and Patient	
	Mean Number of Patients/Mean Number of Deaths	(Median Rate)*80%	(Median Rate)*85%
		0.443	0.471
Fayette	0.277	86	101
Shelby	0.490	(421)	(173)
Tipton	0.325	86	107
<b>TENNESSEE TOTAL</b>	0.607	(12,884)	(10,711)

Source: Tennessee Department of Health, Hospice (not including Residential Hospice) data used for patient data.

**ORIGINAL**  
**APPLICATION**



**State of Tennessee  
Health Facilities Commission**

502 Deaderick Street, Andrew Jackson Building, 9<sup>th</sup> Floor, Nashville, TN 37243

[www.tn.gov/hsda](http://www.tn.gov/hsda)

Phone: 615-741-2364

[hsda.staff@tn.gov](mailto:hsda.staff@tn.gov)

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## CERTIFICATE OF NEED APPLICATION

### **1A. Name of Facility, Agency, or Institution**

Heart N Soul Hospice Memphis

**Name**

1255 Lynnfield Road, Suite 258

Shelby

**Street or Route**

**County**

Memphis

Tennessee

38119

**City**

**State**

**Zip**

[www.heartnsoulhospice.com](http://www.heartnsoulhospice.com)

**Website Address**

**Note:** The facility's name and address **must be** the name and address of the project and **must be** consistent with the Publication of Intent.

### **2A. Contact Person Available for Responses to Questions**

Kim Looney

Partner

**Name**

**Title**

K&L Gates LLP

[kim.looney@klgates.com](mailto:kim.looney@klgates.com)

**Company Name**

**Email Address**

501 Commerce Street, Suite 1500

**Street or Route**

Nashville

Tennessee

37203

**City**

**State**

**Zip**

Attorney

615-780-6727

**Association with Owner**

**Phone Number**

### **3A. Proof of Publication**

Attach the full page of newspaper in which the notice of intent appeared with the mast and dateline intact or submit a publication affidavit from the newspaper that includes a copy of the publication as proof of the publication of the letter of intent. (Attachment 3A)

**Date LOI was Submitted:** 03/15/24

**Date LOI was Published:** 03/15/24



**RESPONSE:** Please find attached the proof of publication in Attachment 3A.

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**4A. Purpose of Review** (*Check appropriate box(es) – more than one response may apply*)

- Establish New Health Care Institution
- Relocation
- Change in Bed Complement
- Addition of a Specialty to an Ambulatory Surgical Treatment Center (ASTC)
- Initiation of MRI Service
- MRI Unit Increase
- Satellite Emergency Department
- Addition of Therapeutic Catheterization
- Positron Emission Tomography (PET) Service
- Initiation of Health Care Service as Defined in §TCA 68-11-1607(3)

Please answer all questions on letter size, white paper, clearly typed and spaced, single sided, in order and sequentially numbered. In answering, please type the question and the response. All questions must be answered. If an item does not apply, please indicate “N/A” (not applicable). Attach appropriate documentation as an Appendix at the end of the application and reference the applicable item Number on the attachment, i.e. Attachment 1A, 2A, etc. The last page of the application should be a completed signed and notarized affidavit.

**5A. Type of Institution** (*Check all appropriate boxes – more than one response may apply*)

- Hospital
- Ambulatory Surgical Treatment Center (ASTC) – Multi-Specialty
- Ambulatory Surgical Treatment Center (ASTC) – Single Specialty
- Home Health
- Hospice
- Intellectual Disability Institutional Habilitation Facility (ICF/IID)
- Nursing Home
- Outpatient Diagnostic Center
- Rehabilitation Facility
- Residential Hospice
- Nonresidential Substitution Based Treatment Center of Opiate Addiction
- Other

Other -

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Hospital -

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**6A. Name of Owner of the Facility, Agency, or Institution**

Heart N Soul Hospice Memphis LLC

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**Name**

51 Century Blvd, Suite 110

678-333-7880

**Street or Route**

**Phone Number**

Nashville

Tennessee

37214

**City**

**State**

**Zip**

**7A. Type of Ownership of Control (Check One)**

- Sole Proprietorship
- Partnership
- Limited Partnership
- Corporation (For Profit)
- Corporation (Not-for-Profit)
- Government (State of TN or Political Subdivision)
- Joint Venture
- Limited Liability Company
- Other (Specify)

Attach a copy of the partnership agreement, or corporate charter and certificate of corporate existence. Please provide documentation of the active status of the entity from the Tennessee Secretary of State's website at <https://tnbear.tn.gov/ECommerce/FilingSearch.aspx>. If the proposed owner of the facility is government owned must attach the relevant enabling legislation that established the facility. (Attachment 7A)

Describe the existing or proposed ownership structure of the applicant, including an ownership structure organizational chart. Explain the corporate structure and the manner in which all entities of the ownership structure relate to the applicant. As applicable, identify the members of the ownership entity and each member's percentage of ownership, for those members with 5% ownership (direct or indirect) interest.

**RESPONSE:** The existing ownership structure of the applicant consists of four owners. Attached is an organizational chart illustrating the ownership structure: David Turner (45%), Tracy Wood (35%), Andre Lee (10%), and Sandy McClain (10%).

**8A. Name of Management/Operating Entity (If Applicable)**

**Name**

**Street or Route**

**County**

**City**

**State**

**Zip**

**Website Address**

For new facilities or existing facilities without a current management agreement, attach a copy of a draft management agreement that at least includes the anticipated scope of management services to be provided, the anticipated term of the agreement, and the anticipated management fee payment schedule. For facilities with existing management agreements, attach a copy of the fully executed final contract. (Attachment 8A)

**9A. Legal Interest in the Site**

Check the appropriate box and submit the following documentation. (Attachment 9A)

The legal interest described below must be valid on the date of the Agency consideration of the Certificate of Need application.

- Ownership (Applicant or applicant’s parent company/owner) – Attach a copy of the title/deed.
  - Lease (Applicant or applicant’s parent company/owner) – Attach a fully executed lease that includes the terms of the lease and the actual lease expense.
  - Option to Purchase - Attach a fully executed Option that includes the anticipated purchase price.
  - Option to Lease - Attach a fully executed Option that includes the anticipated terms of the Option and anticipated lease expense.
  - Letter of Intent, or other document showing a commitment to lease the property - attach reference document
  - Other (Specify)
- 

**RESPONSE:** Please find attached a copy of the fully executed lease in Attachment 9A. The Lease outlines the terms and lease expenses pending CON approval. This highlights Applicant's commitment to providing complete and comprehensive information for consideration.

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**10A. Floor Plan**

If the facility has multiple floors, submit one page per floor. If more than one page is needed, label each page. (Attachment 10A)

- Patient care rooms (Private or Semi-private)
- Ancillary areas
- Other (Specify)

**RESPONSE:** Hospice office floor plan included as Attachment 10A.

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**11A. Public Transportation Route**

Describe the relationship of the site to public transportation routes, if any, and to any highway or major road developments in the area. Describe the accessibility of the proposed site to patients/clients. (Attachment 11A)

**RESPONSE:** The hospice clinical staff will travel to the patients to provide services rather than the patients traveling to the office site to receive treatment. Therefore, the existence of convenient public transportation routes is not relevant for patients.

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**12A. Plot Plan**

Unless relating to home care organization, briefly describe the following and attach the requested documentation on a letter size sheet of white paper, legibly labeling all requested information. It **must** include:

- Size of site (in acres);
- Location of structure on the site;
- Location of the proposed construction/renovation; and
- Names of streets, roads, or highways that cross or border the site.

(Attachment 12A)

**RESPONSE:** N/A

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### **13A. Notification Requirements**

- TCA §68-11-1607(c)(9)(B) states that “... If an application involves a healthcare facility in which a county or municipality is the lessor of the facility or real property on which it sits, then within ten (10) days of filing the application, the applicant shall notify the chief executive officer of the county or municipality of the filing, by certified mail, return receipt requested.” Failure to provide the notifications described above within the required statutory timeframe will result in the voiding of the CON application.
  - Notification Attached (Provide signed USPS green-certified mail receipt card for each official notified.)
  - Notification in process, attached at a later date
  - Notification not in process, contact HFC Staff
  - Not Applicable
  
- TCA §68-11-1607(c)(9)(A) states that “... Within ten (10) days of the filing of an application for a nonresidential substitution based treatment center for opiate addiction with the agency, the applicant shall send a notice to the county mayor of the county in which the facility is proposed to be located, the state representative and senator representing the house district and senate district in which the facility is proposed to be located, and to the mayor of the municipality, if the facility is proposed to be located within the corporate boundaries of the municipality, by certified mail, return receipt requested, informing such officials that an application for a nonresidential substitution based treatment center for opiate addiction has been filed with the agency by the applicant.
  - Notification Attached (Provide signed USPS green-certified mail receipt card for each official notified.)
  - Notification in process, attached at a later date
  - Notification not in process, contact HFC Staff
  - Not Applicable

## **EXECUTIVE SUMMARY**

### **1E. Overview**

Please provide an overview not to exceed **ONE PAGE** (for 1E only) in total explaining each item point below.

- Description: Address the establishment of a health care institution, initiation of health services, and/or bed complement changes.

#### **RESPONSE:**

Heart N Soul Hospice Memphis LLC, a Tennessee limited liability company, is seeking to establish a home care/hospice institution and to initiate hospice care services in three counties in the West Tennessee area: Fayette, Tipton and Shelby.

---

- Ownership structure

**RESPONSE:** The existing ownership structure of the applicant consists of four owners. Attached is an organizational chart illustrating the ownership structure: David Turner (45%), Tracy Wood (35%), Andre' L. Lee (10%), Sandy McClain (10%). All principals are of African American descent. David Turner, a 45% owner of the Applicant, is also a minority owner of CNS Hospice, whose headquarters and business is located in Troy, Michigan. He has successfully operated hospice since 2010 throughout the Southeast Michigan area, focusing on the African American population Tracy Wood, a 35% owner of the Applicant, is a seasoned hospice professional with over 20 years of experience. Her most recent experience with Hospice of Chattanooga from 2016-2021 focusing on the underserved community in East Tennessee. Andre' L. Lee, DPA, a 10% owner of the Applicant, is a retired hospital Administrator, former hospice owner and currently an adjunct professor at Purdue Global University and Southern New Hampshire University, teaching healthcare focused classes in leadership, organization, human resources and economics. Reverend Sandy McClain, a 10% owner of the Applicant, is an active minister of Mt. Calvary Baptist Church in Madison. He is familiar with African American parishioners, as his congregation is predominantly African American. He understands their fears of hospice services and unwillingness to use such services. He is confident that with the proper education on the benefits of hospice services, more African Americans will avail themselves of this necessary service for their family members. David Turner, Andre' L. Lee , and Sandy McClain are also owners of Heart and Soul Hospice, LLC.

---

- Service Area

**RESPONSE:** Our service area is limited to three counties: Fayette, Shelby, and Tipton. Our administrative office location is central to all three and affords easy access for our staff to meet the needs of any patients, family or staff. The applicant believes it can be a significant asset to this service area by serving a minority and underserved population.

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- Existing similar service providers

**RESPONSE:** There are 9 hospice providers in our proposed service area but we believe we can enhance the service to African Americans, Hispanic and other minority and underinsured persons by forming a relationship of faith and trust focused on reducing the hesitancy of the African American community so often associated with the use of terminal care through a very robust educational program. Dr. McClain has already begun our effort in this regard by reaching out to many religious denominations.

---

- Project Cost

**RESPONSE:** The project costs are estimated at approximately \$182,500. The costs are reasonable. Initial funding will come from the cash reserves of Mr. David Turner, one of the principals of the Applicant.

---

- Staffing

**RESPONSE:** The Applicant is prepared to hire all necessary staff to meet State, Federal and National Association for Home Care and Hospice (NAHC) and Community Health Accreditation Partner (CHAP) requirements and guidelines. Owners have the necessary experience to train and supervise necessary personnel in the hospice area. The applicant believes it will have no difficulty in recruiting and retaining all of the qualified personnel from the proposed service area. Some of the requirements of the NAHC regarding personnel that the applicant intends to follow include: operating as an equal opportunity employer and complying with all applicable laws, rules and regulations; providing an ongoing evaluation process for employees; hiring employees who are qualified and using them at the level of their competency; providing supervision; providing continuing education and in-service training for employees; and hiring adequate staff to meet the needs of the patients they serve. A personalized plan of care will be developed for each patient with input from family and caregivers. The interdisciplinary team on the hospice side will include nurses, physician, aides, social workers, counselors, ministers and spiritual support counselors, as well as therapists and dieticians, all as necessary to meet the health care needs of a particular patient. The initial staffing will follow traditional patterns of hospice staffing necessary to meet patient volume and includes a CEO, DON, Medical Director, Pastor, Social Worker, home health aides, therapists, and nurses, among other necessary personnel. Patient Care Positions (Projected FTE - Year 1) Medical Director 0.25 RN 1.00 LPN 2.00 Nursing Aide 3.00 Social Worker 1.25 Chaplain 1.00 Total Direct Care 8.25.

---

## 2E. Rationale for Approval

A Certificate of Need can only be granted when a project is necessary to provide needed health care in the area to be served, will provide health care that meets appropriate quality standards, and the effects attributed to competition or duplication would be positive for consumers

Provide a brief description not to exceed ONE PAGE (for 2E only) of how the project meets the criteria necessary for granting a CON using the data and information points provided in criteria sections that follow.

- Need

**RESPONSE:** As shown in the tables on Attachment 5N, the African American population does not utilize hospice services at the same rate as its white counterparts. This population deserves the same access and focus as other populations. Applicant will focus on providing hospice services to the underserved and minority community irrespective of race. Because the principals are African American, Applicant feels it is in a better position to meet the needs of this community than other hospice agencies. Principals of Applicant have developed a relationship with many area providers and community agencies to ensure appropriate continuity of care. This is also manifested in Applicant's connection to key faith-based community entities. Applicant believes, as a minority owned entity, it will be successful because to serve the African American population requires a collaborative relationship with the religious community and other community providers and leaders in both an educational way and a service rendering, which it is uniquely positioned to provide.

---

- Quality Standards

**RESPONSE:** The applicant plans to be accredited by CHAP and will follow its quality standards. CHAP divides its Standards of Excellence into three key areas: Patient centered care, safe care delivery, and sustainable organizational structure. Each key performance area (KPA) has standards and evidence guidelines. Some of the standards are: ensuring there is a defined process to report alleged violations involving mistreatment, neglect, or abuse; having an interdisciplinary group to facilitate ongoing assessment of patient and family need and developing and implementing a care plan; ensuring that care and services such as nursing, medical social, and physician are provided in a manner consistent with accepted standards of practice; providing effective infection prevention and control processes; and ensuring that there is adequate staffing with personnel who have the knowledge, skills, and experience necessary to deliver safe, quality, patient-centered care to the patients. Heart and Soul Hospice, LLC in Nashville has reported limited quality measures on the Medicare Compare website at this time. The agency has reported the conditions that it treats, but otherwise has not provided meaningful patient care measures. At the next reporting period, more quality measures will be reported. Heart and Soul Hospice Memphis will contract with Healthcare First to monitor and analyze its quality assurance and performance improvement program just as Heart and Soul Hospice, LLC does.

---

- Consumer Advantage

- Choice

**RESPONSE:** Equitable access is another fundamental principle of hospice care. Applicant will serve all patients in its area without discrimination and has clearly outlined plans for caring for low-income patients, and marginalized patients allowing all consumers to benefit from hospice care regardless of financial status. Applicant focuses on outreach to underserved communities, such as minority populations, by educating these populations to improve awareness of hospice benefits and increase access for those who traditionally face barriers, empowering consumers to make informed choices about their end-of-life care.

---

- Improved access/availability to health care service(s)

**RESPONSE:** As shown in tables in Attachment 5N of the application, the African American population does not utilize hospice services at the same rate as its white counterparts. This population deserves the same access and focus as other populations. The Applicant will focus on providing hospice services to the underserved and minority community irrespective of race. Because the principals are African American, the applicant feels it is in a better

position to meet the needs of this community than other hospice agencies. Principals of the Applicant have developed a relationship with many area providers and community agencies to ensure appropriate continuity of care. This is also manifested in the applicant's connection to key faith-based community entities. The applicant believes, as a minority owned entity, it will be successful because to serve the underserved population it requires a collaborative relationship with the religious community and other community providers and leaders in both an educational way and a service rendering, which it is uniquely positioned to provide.

---

○ Affordability

**RESPONSE:** Applicant is committed to promoting economic efficiencies within the healthcare system. We understand that our proposed charges should align with those of other similar facilities. Additionally, we believe educating the healthcare community about hospice services can lead to more informed decision-making with regards to end-of-life care, potentially reducing unnecessary costs. This education component also supports our goal of recruiting, developing, and retaining a qualified healthcare workforce.

---

### **3E. Consent Calendar Justification**

- Letter to Executive Director Requesting Consent Calendar (Attach Rationale that includes addressing the 3 criteria)
- Consent Calendar NOT Requested

If Consent Calendar is requested, please attach the rationale for an expedited review in terms of Need, Quality Standards, and Consumer Advantage as a written communication to the Agency's Executive Director at the time the application is filed.



**4E. PROJECT COST CHART**

A. Construction and equipment acquired by purchase:		
1. Architectural and Engineering Fees		
2. Legal, Administrative (Excluding CON Filing Fee), Consultant Fees		\$40,000
3. Acquisition of Site		
4. Preparation of Site		
5. Total Construction Costs		\$2,000
6. Contingency Fund		
7. Fixed Equipment (Not included in Construction Contract)		
8. Moveable Equipment (List all equipment over \$50,000 as separate attachments)		\$2,500
9. Other (Specify): _____		
B. Acquisition by gift, donation, or lease:		
1. Facility (inclusive of building and land)		\$135,000
2. Building only		
3. Land only		
4. Equipment (Specify): _____		
5. Other (Specify): _____		
C. Financing Costs and Fees:		
1. Interim Financing		
2. Underwriting Costs		
3. Reserve for One Year's Debt Service		
4. Other (Specify): _____		
D. Estimated Project Cost (A+B+C)		\$179,500
E. CON Filing Fee		\$3,000
F. Total Estimated Project Cost (D+E)	<b>TOTAL</b>	\$182,500

## GENERAL CRITERIA FOR CERTIFICATE OF NEED

In accordance with TCA §68-11-1609(b), “no Certificate of Need shall be granted unless the action proposed in the application for such Certificate is necessary to provide needed health care in the area to be served, will provide health care that meets appropriate quality standards, and the effect attributed to completion or duplication would be positive for consumers.” In making determinations, the Agency uses as guidelines the goals, objectives, criteria, and standards adopted to guide the agency in issuing certificates of need. Until the agency adopts its own criteria and standards by rule, those in the state health plan apply.

Additional criteria for review are prescribed in Chapter 11 of the Agency Rules, Tennessee Rules and Regulations 01730-11.

The following questions are listed according to the three criteria: (1) Need, (2) the effects attributed to competition or duplication would be positive for consumers (Consumer Advantage), and (3) Quality Standards.

### **NEED**

The responses to this section of the application will help determine whether the project will provide needed health care facilities or services in the area to be served.

- 1N. Provide responses as an attachment to the applicable criteria and standards for the type of institution or service requested. A word version and pdf version for each reviewable type of institution or service are located at the following website. <https://www.tn.gov/hsda/hsda-criteria-and-standards.html> (Attachment 1N)

#### **RESPONSE:**

Please see Attachment 1N (Criteria and Standards Narrative) and Attachment 1N (Criteria and Standards Data).

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- 2N. Identify the proposed service area and provide justification for its reasonable ness. Submit a county level map for the Tennessee portion and counties boarding the state of the service area using the supplemental map, clearly marked, and shaded to reflect the service area as it relates to meeting the requirements for CON criteria and standards that may apply to the project. Please include a discussion of the inclusion of counties in the border states, if applicable. (Attachment 2N)

#### **RESPONSE:**

See county level map included Attachment 2N.

### **Proposed Service Area**

Our proposed service area encompasses Shelby, Fayette, and Tipton counties in Tennessee. These counties were carefully chosen based on several factors that demonstrate the reasonableness of this service area.

### **Justification for Reasonableness**

- **Unmet Need & Disparities:** Our research confirms a significant unmet need for hospice services across the region, with a critical need to address disparities that harm underserved populations. An analysis of hospice penetration by race/ethnicity in Shelby, Fayette, and Tipton counties reveals a lower hospice utilization rate compared to the overall population average. Our service model will prioritize targeted outreach, culturally sensitive care, and increased awareness of hospice benefits within these communities to combat this disparity.
- **Accessibility:** Our operational plan emphasizes accessibility, ensuring that all patients within these counties can access the hospice care they deserve. We will service all three counties by ensuring presence in all 3 areas. Our Shelby County office will be strategically located to began outreach.

- **Competition and Patient Choice**: While there are existing hospice providers in the area, our in-depth analysis indicates opportunities to offer more specialized or responsive services. We are committed to developing culturally responsive programs to increase patient choice, empower underserved communities, and address the disparities highlighted in the data for all three counties.
- **Capacity**: We have the staff, resources, and operational infrastructure to effectively serve Shelby, Fayette, and Tipton counties. Each patient will receive a personalized care plan developed collaboratively with their family and caregivers. Our hospice interdisciplinary team includes nurses, physicians, aides, social workers, counselors, spiritual support providers, therapists, and dietitians, ensuring comprehensive care that addresses all aspects of our patients' needs.
- **Staffing**: Our initial staffing structure aligns with established hospice best practices. Key roles include a CEO, DON, Medical Director, Spiritual Care Coordinator, Social Worker, home health aides, physical, occupation, and speech therapists, nurses, and additional personnel as patient volume dictates. This robust staffing model demonstrated our capacity, while maintaining our high standards for care within diverse communities.
- **Map and Border Counties**: The attached county-level map of Tennessee clearly highlights our proposed service area.

### **Commitment to Meeting CON Standards and Addressing Disparities**

We have thoroughly reviewed the applicable CON criteria and standards. Our proposal and justification are carefully designed to align with these requirements. We are especially focused on providing a hospice service that benefits all communities in our service region. Our commitment to actively reducing the disparities in hospice utilization underscores our dedication to equitable, compassionate end-of-life care.

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Complete the following utilization tables for each county in the service area, if applicable.

**PROJECTED UTILIZATION**

Unit Type: <input type="checkbox"/> Procedures <input type="checkbox"/> Cases <input type="checkbox"/> Patients <input checked="" type="checkbox"/> Other <u>Patient Days</u> _____		
Service Area Counties	Projected Utilization Recent Year 1 (Year = 2025)	% of Total
Fayette	2,225	26.99%
Shelby	4,534	55.00%
Tipton	1,484	18.00%
Total	8,243	100%

3N. A. Describe the demographics of the population to be served by the proposal.

**RESPONSE:**

The target population for hospice services is age 65+ although there are patients younger than 65 who receive hospice services. The median age of the service area population at 40.4 is slightly higher than that of the state at 39.2. Shelby County has the highest percentage of TennCare enrollees in the service area, at 28.4%, which is higher than the state’s percentage of TennCare enrollees of 21.9%.

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**B.** Provide the following data for each county in the service area:

- Using current and projected population data from the Department of Health. ([www.tn.gov/health/health-program-areas/statistics/health-data/population.html](http://www.tn.gov/health/health-program-areas/statistics/health-data/population.html));
- the most recent enrollee data from the Division of TennCare (<https://www.tn.gov/tenncare/information-statistics/enrollment-data.html>),
- and US Census Bureau demographic information (<https://www.census.gov/quickfacts/fact/table/US/PST045219>).

**RESPONSE:**

See included Attachment 3N.B.

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- 4N. Describe the special needs of the service area population, including health disparities, the accessibility to consumers, particularly those who are uninsured or underinsured, the elderly, women, racial and ethnic minorities, TennCare or Medicaid recipients, and low income groups. Document how the business plans of the facility will take into consideration the special needs of the service area population.

**RESPONSE:**

The African American population does not utilize hospice services at the same rate as its white counterparts. This population deserves the same access and focus as other populations. The Applicant will focus on educating the community and providing hospice services to the underserved and minority community irrespective of race. Because the principals are African American, the applicant feels it is in a better position to meet the needs of this community than other hospice agencies.

Principals of the Applicant have developed a relationship with many area providers and community agencies to ensure appropriate continuity of care. This is also manifested in the applicant's connection to key faith-based community entities. The applicant believes, as a minority owned entity, it will be successful because to serve the African American population requires a collaborative relationship with the religious community and other community providers and leaders in both an educational way and a service rendering, which it is uniquely positioned to provide.

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- 5N. Describe the existing and approved but unimplemented services of similar healthcare providers in the service area. Include utilization and/or occupancy trends for each of the most recent three years of data available for this type of project. List each provider and its utilization and/or occupancy individually. Inpatient bed projects must include the following data: Admissions or discharges, patient days. Average length of stay, and occupancy. Other projects should use the most appropriate measures, e.g. cases, procedures, visits, admissions, etc. This does not apply to projects that are solely relocating a service.

**RESPONSE:**

Please see Attachment 5N. Although the number of patients served by hospice agency varies from year to year, the number of patients served has grown slightly from 2021 to 2023 overall. One of the tables identifies the utilization by hospice agency by county for 2021 to 2023. The number of patients served by race is also shown by agency by county for each year from 2021 to 2023.

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- 6N. Provide applicable utilization and/or occupancy statistics for your institution services for each of the past three years and the project annual utilization for each of the two years following completion of the project. Additionally, provide the details regarding the methodology used to project utilization. The methodology must include detailed calculations or documentation from referral sources, and identification of all assumptions.

**RESPONSE:**

Please see Attachment 6N (Projected Utilization) for project annual utilization for each of the two years following completion of the project.

Projected Utilization: As a new hospice program, Applicant lacks historical utilization statistics. However, we have formulated careful projections based on strategic plans and realistic assumptions. Over the first two years of operation, we anticipate serving a steadily increasing number of patients. We expect to serve the five patients required for CHAP accreditation within the first two months of operation. Following accreditation, we project an incremental growth of 2-3 patients per month.

Methodology: Our projections are based on the following key assumptions:

- Incremental growth at a rate of 2-3 patients per month, driven by targeted outreach efforts.
- A requirement of serving a minimum of five patients for CHAP accreditation- census starts at 5.
- An average hospice length of stay of 75 days.

We believe these projections are achievable due to our focus on several key strategies:

- **Underserved Populations:** We will actively engage with underserved communities through community events, partnerships with churches, and collaborations with referral sources. This outreach will address disparities in hospice access, opening up a significant potential patient pool.
  - **Specialty Care Programs:** We will offer specialized programs focusing on cardiac care, pulmonary care, and Alzheimer's care (among others) to attract patients with specific needs and demonstrate our expertise.
  - **Referral Relationships:** We will build relationships in community, churches, and with hospitals, long-term care facilities, and physician groups to establish a strong referral base.
-

7N. Complete the chart below by entering information for each applicable outstanding CON by applicant or share common ownership; and describe the current progress and status of each applicable outstanding CON and how the project relates to the applicant, and the percentage of ownership that is shared with the applicant's owners.

**RESPONSE:**

Not applicable.

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**CONSUMER ADVANTAGE ATTRIBUTED TO COMPETITION**

The responses to this section of the application helps determine whether the effects attributed to competition or duplication would be positive for consumers within the service area.

1C. List all transfer agreements relevant to the proposed project.

**RESPONSE:** Not applicable.

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2C. List all commercial private insurance plans contracted or plan to be contracted by the applicant.

- Aetna Health Insurance Company
- Ambetter of Tennessee Ambetter
- Blue Cross Blue Shield of Tennessee
- Blue Cross Blue Shield of Tennessee Network S
- Blue Cross Blue Shiled of Tennessee Network P
- BlueAdvantage
- Bright HealthCare
- Cigna PPO
- Cigna Local Plus
- Cigna HMO - Nashville Network
- Cigna HMO - Tennessee Select
- Cigna HMO - Nashville HMO
- Cigna HMO - Tennessee POS
- Cigna HMO - Tennessee Network
- Golden Rule Insurance Company
- HealthSpring Life and Health Insurance Company, Inc.
- Humana Health Plan, Inc.
- Humana Insurance Company
- John Hancock Life & Health Insurance Company
- Omaha Health Insurance Company
- Omaha Supplemental Insurance Company
- State Farm Health Insurance Company
- United Healthcare UHC
- UnitedHealthcare Community Plan East Tennessee
- UnitedHealthcare Community Plan Middle Tennessee
- UnitedHealthcare Community Plan West Tennessee



WellCare Health Insurance of Tennessee, Inc.

Others

3C. Describe the effects of competition and/or duplication of the proposal on the health care system, including the impact upon consumer charges and consumer choice of services.

**RESPONSE:**

Increased Consumer Choice:

- The presence of Applicant's hospice service will offer patients and their families more options when considering end-of-life care. This empowers them to choose a provider that best aligns with their cultural preferences and care needs.

Potential Cost Reduction:

- Competition can incentivize all hospice providers, including existing ones, to become more efficient in their operation, which could lead to a reduction in overall costs, potentially benefiting both patients and payers.

Focus on Underserved Populations:

- Applicant emphasis on educating minority communities, particularly African Americans, can address a gap in awareness and access to hospice services. This can improve health equity by ensuring these populations have the information they need to make informed choices about end-of-life care.

Impact on Overall Costs:

- It's important to acknowledge that duplication of services may not significantly reduce overall healthcare costs. While patients might forgo unnecessary aggressive treatments, hospice care itself typically represents a smaller portion of overall healthcare spending in the final stages of life.

Duplication Concerns:

- Applicant has a unique approach to culturally appropriate care and community education. Applicant's services will complement existing providers by filling a specific gap. Applicant is committed to collaboration and forging partnerships with other healthcare providers to ensure our services complement one another instead of duplicating resources.

Consumer Charges:

- The impact on consumer charges is difficult to predict. Competition may lead to some price variation, but this should be weighed against the value proposition of culturally competent care and improved access for underserved populations. Applicant is committed to contribute to a more robust and equitable healthcare system in Fayette, Shelby, and Tipton counties.

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4C. Discuss the availability of and accessibility to human resources required by the proposal, including clinical leadership and adequate professional staff, as per the State of Tennessee licensing requirements, CMS, and/or accrediting agencies requirements, such as the Joint Commission and Commission on Accreditation of Rehabilitation Facilities.

**RESPONSE:**

Applicant is committed to meeting all state licensing, CMS, and CHAP staffing requirements. We will maintain a registered nurse to patient ratio within recommended guidelines. Our registered nurses are highly experienced in hospice and palliative care, ensuring the highest quality of clinical oversight. Furthermore, we have secured commitments from two exceptional medical directors with extensive end-of-life care expertise. While recognizing national staffing challenges, we are confident in our recruiting strategies, which include competitive compensation packages and a focus on professional development.

- Compliance: Applicant's staffing model is robust and adheres to all Tennessee state licensing, CMS, and relevant accreditation standards (like CHAP and the Joint Commission).

- Addressing Staffing Shortages: Applicant acknowledges the potential challenge of healthcare staffing shortages, particularly registered nurses. Applicant has had great success in recruiting and retaining outstanding hospice professionals, by providing competitive pay and benefits, a positive work environment, flexible schedules and opportunities for professional development. Owners of the applicant are also owners of a hospice in Middle Tennessee, which has been successful in recruiting professionals.
- Initially our core team may be small, we are committed to care coordination and collaborating with community physicians, specialists, and hospitals to provide comprehensive, well-coordinated care.

Clinical Leadership:

- Applicant aims to recruit a registered nurse who will oversee clinical operations. He or she will have over 2 years of leadership experience and extensive clinical experience.
- Medical Directors: Will harness a great understanding in hospice and end-of-life care.

Support Services:

- Applicant will staff according to the attached staffing model to ensure effective care for patients.
- Cultural Competence: All team members will participate in a robust 6 week training that will provide culturally sensitive care aligned with Applicant's mission of health equity.

- 5C. Document the category of license/certification that is applicable to the project and why. These include, without limitation, regulations concerning clinical leadership, physician supervision, quality assurance policies and programs, utilization review policies and programs, record keeping, clinical staffing requirements, and staff education.

**RESPONSE:**

Applicant will obtain the mandatory Hospice Agency License issued by the State of Tennessee. This license, along with associated CMS regulations, establishes strict guidelines for clinical leadership, physician supervision, quality assurance, utilization review, record-keeping, and clinical staffing. These regulations ensure we provide safe and compassionate end-of-life care. Applicant will also pursue accreditation from CHAP. This demonstrates our commitment to exceeding baseline standards and providing the highest quality hospice care within our community.

Key Regulations and Requirements

The Tennessee Hospice Agency licensure and relevant regulations dictate the following critical areas:

- Clinical Leadership:
  - Applicant will contract with a qualified physician must be designated as the Medical Director. This individual assumes responsibility for the medical component of the hospice program.
  - Applicant will hire registered nurse that is designated as the Clinical Supervisor or Director of Nursing, overseeing patient and clinical staff.
- Physician Supervision:
  - Applicant will ensure all care is provided under the direction of a physician, who maintains an active role in developing and managing patient care plans in collaboration with the hospice interdisciplinary team.
- Quality Assurance Policies and Programs:
  - Applicant has established a formal, documented quality assurance program to monitor, evaluate, and continuously improve quality of patient care and services.
- Utilization Review Policies and Programs:
  - Applicant has established a documented utilization review plan is required to ensure services are medically necessary, appropriate for the patient's diagnosis, and provided effectively and efficiently.
- Record Keeping:
  - Applicant will implement an EMR- (Homecare Homebase) a comprehensive medical records system that will maintain records for each patient, documenting the plan of care, services provided, and clinical assessments. Records will meet all privacy security standards (such as HIPAA).
- Clinical Staffing Requirements and Education:
  - All clinical staff will attend a comprehensive orientation process including core disciplines, including nurses, social workers, chaplains, and aides.

- All staff will have the necessary licenses, certifications, and qualifications for their roles.
  - Applicant will provide ongoing education and training for its staff to maintain competency and knowledge of hospice practices.
  - Accrediting Agencies: Applicant will obtain accreditation from CHAP to demonstrate a commitment to the highest standard of hospice care.
-

**PROJECTED DATA CHART**

- Project Only
- Total Facility

Give information for the *two (2)* years following the completion of this proposal.

	<b>Year 1</b>	<b>Year 2</b>
	<u>2025</u>	<u>2026</u>
A. Utilization Data		
Specify Unit of Measure <u>Other : Patient Days</u>	<u>8243</u>	<u>18627</u>
B. Revenue from Services to Patients		
1. Inpatient Services	<u>\$0.00</u>	<u>\$0.00</u>
2. Outpatient Services	<u>\$1,481,102.00</u>	<u>\$3,440,593.00</u>
3. Emergency Services	<u>\$0.00</u>	<u>\$0.00</u>
4. Other Operating Revenue (Specify) _____	<u>\$0.00</u>	<u>\$0.00</u>
<b>Gross Operating Revenue</b>	<u>\$1,481,102.00</u>	<u>\$3,440,593.00</u>
C. Deductions from Gross Operating Revenue		
1. Contractual Adjustments	<u>\$0.00</u>	<u>\$0.00</u>
2. Provision for Charity Care	<u>\$22,500.00</u>	<u>\$67,500.00</u>
3. Provisions for Bad Debt	<u>\$21,442.00</u>	<u>\$48,168.00</u>
<b>Total Deductions</b>	<u>\$43,942.00</u>	<u>\$115,668.00</u>
<b>NET OPERATING REVENUE</b>	<u>\$1,437,160.00</u>	<u>\$3,324,925.00</u>

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7C. Please identify the project’s average gross charge, average deduction from operating revenue, and average net charge using information from the Historical and Projected Data Charts of the proposed project.

**Project Only Chart**

	Previous Year to Most Recent Year	Most Recent Year	Year One	Year Two	% Change (Current Year to Year 2)
<b>Gross Charge</b> ( <i>Gross Operating Revenue/Utilization Data</i> )	\$0.00	\$0.00	\$179.68	\$184.71	0.00
<b>Deduction from Revenue</b> ( <i>Total Deductions/Utilization Data</i> )	\$0.00	\$0.00	\$5.33	\$6.21	0.00
<b>Average Net Charge</b> ( <i>Net Operating Revenue/Utilization Data</i> )	\$0.00	\$0.00	\$174.35	\$178.50	0.00

8C. Provide the proposed charges for the project and discuss any adjustment to current charges that will result from the implementation of the proposal. Additionally, describe the anticipated revenue from the project and the impact on existing patient charges.

**RESPONSE:**

Our proposed per diem rates directly align with the 2024 Medicare final rule reimbursement rates:

- Routine Home Care: \$192.39
- Continuous Care: \$1,356.56
- Inpatient Respite: \$451.96
- General Inpatient: \$1,014.40

This ensures transparency and financial responsibility while adhering to established Medicare guidelines. Since all hospices receive standardized reimbursement for Medicare and Medicaid patients, these rates are consistent across providers.

9C. Compare the proposed project charges to those of similar facilities/services in the service area/adjoining services areas, or to proposed charges of recently approved Certificates of Need.

If applicable, compare the proposed charges of the project to the current Medicare allowable fee schedule by common procedure terminology (CPT) code(s).

**RESPONSE:**

Please see Attachment 9C for a list of net charges for the hospice facilities in the applicant's service area.

- **Similar to Existing Hospices:** Our rates align with existing hospices in the region, promoting fair competition and ensuring patients have access to quality care within a predictable reimbursement structure.
- **Unique Services:** Applicant focuses on educating underserved populations and providing culturally appropriate care. We provide disease specific services and education. In addition to grief services to the entire family including friends and in and around the community. We also provide additional services like music therapy.
- **New to the Market:** Our rates reflect the established Medicare value for comprehensive hospice care. We are committed to providing high-quality services at competitive rates when private pay is needed.

We anticipate serving an average of 23 patients per day in Year One, with an average length of stay of 65 days for routine home care. This translates to a projected monthly revenue of \$132,155.90 based on established Medicare reimbursement rates.

We do not anticipate any additional changes or adjustments to charges specifically resulting from implementing this project. Our charges are aligned with the established standard reimbursement rates, and this project will focus on expanding access to these services within our community. We prioritize affordable care with a sliding scale fee program and partnerships with community organizations to reach patients regardless of their ability to pay. Our commitment to accessibility aligns with Medicare and Medicaid's focus on equitable access to hospice services.

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**10C.** Report the estimated gross operating revenue dollar amount and percentage of project gross operating revenue anticipated by payor classification for the first and second year of the project by completing the table below.

If applicable, compare the proposed charges of the project to the current Medicare allowable fee schedule by common procedure terminology (CPT) code(s).

**Applicant’s Projected Payor Mix  
Project Only Chart**

Payor Source	Year-2025		Year-2026	
	Gross Operating Revenue	% of Total	Gross Operating Revenue	% of Total
Medicare/Medicare Managed Care	\$1,332,991.80	90.0	\$3,096,533.70	90.0
TennCare/Medicaid	\$148,110.20	10.0	\$344,059.30	10.0
Commercial/Other Managed Care	\$0.00	0	\$0.00	0
Self-Pay	\$0.00	0	\$0.00	0
Other(Specify)	\$0.00	0	\$0.00	0
<b>Total</b>	\$1,481,102.00	100%	\$3,440,593.00	100%
Charity Care	\$22,500.00		\$67,500.00	

*\*Needs to match Gross Operating Revenue Year One and Year Two on Projected Data Chart*

Discuss the project’s participation in state and federal revenue programs, including a description of the extent to which Medicare, TennCare/Medicaid, and medically indigent patients will be served by the project.

**RESPONSE:** The project anticipates significant participation in federal and state programs. Medicare/Medicare Managed Care is projected to be the primary revenue source, representing 90% of gross operating revenue in both years one and two. TennCare/Medicaid is also expected to contribute, accounting for 10% of gross operating revenue each year.

The project is committed to serving medically indigent patients. Charity care provisions are in place with an allocation of \$22,500 in year one and \$67,500 in year two. These funds will be used to offset costs for patients unable to pay for essential care. Additionally, the project has a strategic partnership with a local community clinic to identify and refer medically indigent patients, ensuring they have access to necessary services.

**QUALITY STANDARDS**

**1Q.** Per PC 1043, Acts of 2016, any receiving a CON after July 1, 2016, must report annually using forms prescribed by the Agency concerning appropriate quality measures. Please attest that the applicant will submit an annual Quality Measure report when due.

- Yes
- No

**2Q.** The proposal shall provide health care that meets appropriate quality standards. Please address each of the following questions.

- Does the applicant commit to maintaining the staffing comparable to the staffing chart presented in its CON application?

- Yes

No

- Does the applicant commit to obtaining and maintaining all applicable state licenses in good standing?

Yes

No

- Does the applicant commit to obtaining and maintaining TennCare and Medicare certification(s), if participation in such programs are indicated in the application?

Yes

No



3Q. Please complete the chart below on accreditation, certification, and licensure plans. Note: if the applicant does not plan to participate in these type of assessments, explain why since quality healthcare must be demonstrated.

Credential	Agency	Status (Active or Will Apply)	Provider Number or Certification Type
Licensure	<input checked="" type="checkbox"/> Health Facilities Commission/Licensure Division <input type="checkbox"/> Intellectual & Developmental Disabilities <input type="checkbox"/> Mental Health & Substance Abuse Services	Will Apply	
Certification	<input checked="" type="checkbox"/> Medicare <input checked="" type="checkbox"/> TennCare/Medicaid <input type="checkbox"/> Other _____	Will Apply Will Apply	
Accreditation(s)	CHAP – Community Health Accreditation Partner	Will Apply	

4Q. If checked “TennCare/Medicaid” box, please list all Managed Care Organization’s currently or will be contracted.

- AMERIGROUP COMMUNITY CARE- East Tennessee
- AMERIGROUP COMMUNITY CARE - Middle Tennessee
- AMERIGROUP COMMUNITY CARE - West Tennessee
- BLUECARE - East Tennessee
- BLUECARE - Middle Tennessee
- BLUECARE - West Tennessee
- UnitedHealthcare Community Plan - East Tennessee
- UnitedHealthcare Community Plan - Middle Tennessee
- UnitedHealthcare Community Plan - West Tennessee
- TENNCARE SELECT HIGH - All
- TENNCARE SELECT LOW - All
- PACE
- KBB under DIDD waiver
- Others

5Q. Do you attest that you will submit a Quality Measure Report annually to verify the license, certification, and/or accreditation status of the applicant, if approved?

- Yes
- No

6Q. For an existing healthcare institution applying for a CON:

- Has it maintained substantial compliance with applicable federal and state regulation for the three years prior to the CON application. In the event of non-compliance, the nature of non-compliance and corrective action should be discussed to include any of the following: suspension of admissions, civil monetary penalties, notice of 23-day or 90-day termination proceedings from Medicare/Medicaid/TennCare, revocation/denial of accreditation, or other similar actions and what measures the applicant has or will put into place to avoid similar findings in the future.

- Yes
- No
-

N/A

- Has the entity been decertified within the prior three years? If yes, please explain in detail. (This provision shall not apply if a new, unrelated owner applies for a CON related to a previously decertified facility.)

- Yes
- No
- N/A

**7Q.** Respond to all of the following and for such occurrences, identify, explain, and provide documentation if occurred in last five (5) years.

**Has any of the following:**

- Any person(s) or entity with more than 5% ownership (direct or indirect) in the applicant (to include any entity in the chain of ownership for applicant);
- Any entity in which any person(s) or entity with more than 5% ownership (direct or indirect) in the applicant (to include any entity in the chain of ownership for applicant) has an ownership interest of more than 5%; and/or.

**Been subject to any of the following:**

- Final Order or Judgement in a state licensure action;

- Yes
- No

- Criminal fines in cases involving a Federal or State health care offense;

- Yes
- No

- Civil monetary penalties in cases involving a Federal or State health care offense;

- Yes
- No

- Administrative monetary penalties in cases involving a Federal or State health care offense;

- Yes
- No

- Agreement to pay civil or administrative monetary penalties to the federal government or any state in cases involving claims related to the provision of health care items and services;

- Yes
- No

- Suspension or termination of participation in Medicare or TennCare/Medicaid programs; and/or

- Yes
- No

- Is presently subject of/to an investigation, or party in any regulatory or criminal action of which you are aware.

- Yes
- No

8Q. Provide the project staffing for the project in Year 1 and compare to the current staffing for the most recent 12-month period, as appropriate. This can be reported using full-time equivalent (FTEs) positions for these positions.

Existing FTE not applicable (Enter year)

Position Classification	Existing FTEs(enter year)	Projected FTEs Year 1
<b>A. Direct Patient Care Positions</b>		
Hospice Aide/Homemaker	0.00	3.30
Nurse, RN Case Manager	0.00	2.10
Nurse, Oncall	0.00	0.90
Nurse, LVN/LPN (incl in Nurse RNCM #)	0.00	0.00
Coordinator, Volunteer	0.00	0.20
Nurse, Oncall Triage	0.00	0.00
Admission Nurse	0.00	0.30
Bereavement Coordinator	0.00	0.20
Social Worker	0.00	0.70
Chaplain	0.00	0.50
<b>Total Direct Patient Care Positions</b>	N/A	8.2

<b>B. Non-Patient Care Positions</b>		
Manager, Office	0.00	1.00
Coordinator, Volunteer	0.00	0.20
Director, Executive	0.00	1.00
Chaplain	0.00	0.50
Site Billing Coordinator	0.00	0.00
Patient Care Manager	0.00	1.00
Coordinator, Admissions	0.00	0.50
Patient Care Secretary	0.00	1.00
Office Support (Recp/other)	0.00	0.40
<b>Total Non-Patient Care Positions</b>	N/A	5.6
<b>Total Employees (A+B)</b>	0	13.8

<b>C. Contractual Staff</b>		
Contractual Staff Position	0.00	1.20
<b>Total Staff (A+B+C)</b>	0	15

## **DEVELOPMENT SCHEDULE**

TCA §68-11-1609(c) provides that activity authorized by a Certificate of Need is valid for a period not to exceed three (3) years (for hospital and nursing home projects) or two (2) years (for all other projects) from the date of its issuance and after such time authorization expires; provided, that the Agency may, in granting the Certificate of Need, allow longer periods of validity for Certificate of Need for good cause shown. Subsequent to granting the Certificate of Need, the Agency may extend a Certificate of Need for a period upon application and good cause shown, accompanied by a non-refundable reasonable filing fee, as prescribed by rule. A Certificate of Need authorization which has been extended shall expire at the end of the extended time period. The decision whether to grant an extension is within the sole discretion of the Commission, and is not subject to review, reconsideration, or appeal.

- Complete the Project Completion Forecast Chart below. If the project will be completed in multiple phases, please identify the anticipated completion date for each phase.
- If the CON is granted and the project cannot be completed within the standard completion time period (3 years for hospital and nursing home projects and 2 years for all others), please document why an extended period should be approved and document the “good cause” for such an extension.

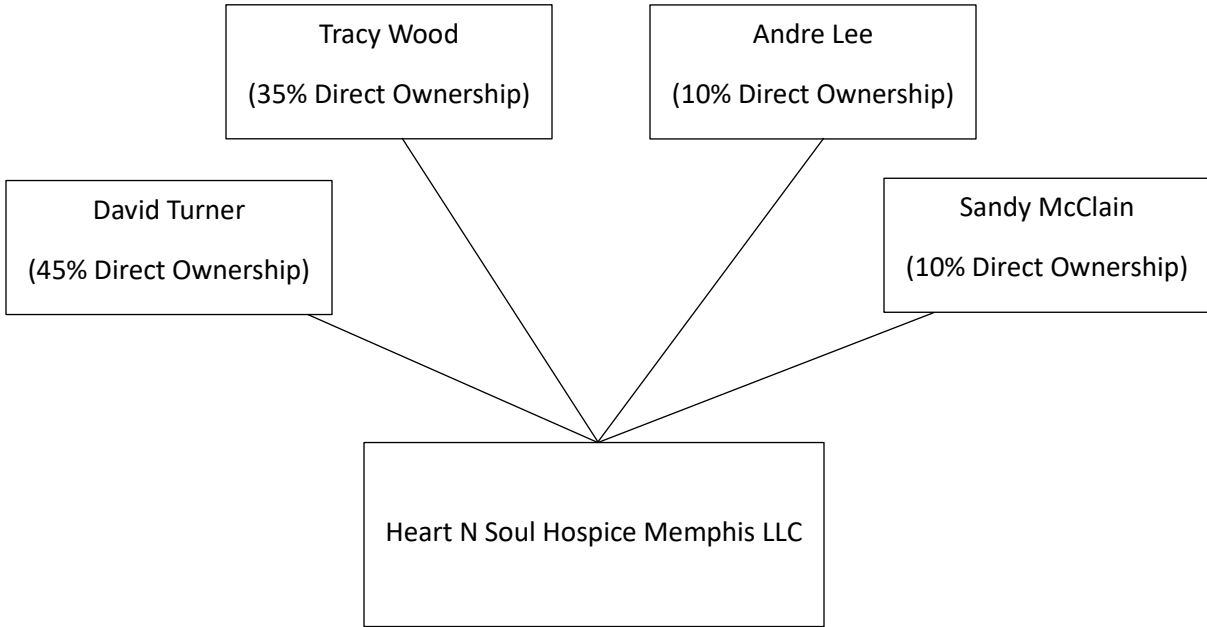
## **PROJECT COMPLETION FORECAST CHART**

Assuming the Certificate of Need (CON) approval becomes the final HFC action on the date listed in Item 1 below, indicate the number of days from the HFC decision date to each phase of the completion forecast.

<b>Phase</b>	<b>Days Required</b>	<b>Anticipated Date (Month/Year)</b>
1. Initial HFC Decision Date		05/22/24
2. Building Construction Commenced	0	05/21/24
3. Construction 100% Complete (Approval for Occupancy)	0	05/21/24
4. Issuance of License	30	06/20/24
5. Issuance of Service	60	07/20/24
6. Final Project Report Form Submitted (Form HR0055)	61	07/21/24

Note: If litigation occurs, the completion forecast will be adjusted at the time of the final determination to reflect the actual issue date.

**Attachment 7A – Organization Chart**





**Tre Hargett**  
Secretary of State

**Division of Business Services**  
**Department of State**  
State of Tennessee  
312 Rosa L. Parks AVE, 6th FL  
Nashville, TN 37243-1102

## Filing Information

Name: **Heart N Soul Hospice Memphis LLC**

### General Information

<b>SOS Control #</b>	<b>001515979</b>	Formation Locale: TENNESSEE
Filing Type:	Limited Liability Company - Domestic	Date Formed: 02/28/2024
	02/28/2024 7:40 AM	Fiscal Year Close 12
Status:	Active	Member Count: 2
Duration Term:	Perpetual	
Managed By:	Member Managed	
Series LLC:	Yes	

### Registered Agent Address

DAVID TURNER  
DAVID TURNER  
110  
51 CENTURY BLVD  
NASHVILLE, TN 37214

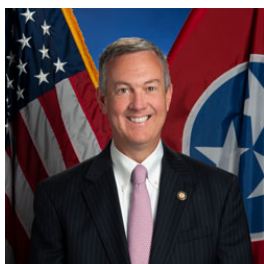
### Principal Address

DAVID TURNER  
110  
51 CENTURY BLVD  
NASHVILLE, TN 37214

The following document(s) was/were filed in this office on the date(s) indicated below:

<u>Date Filed</u>	<u>Filing Description</u>	<u>Image #</u>
02/28/2024	Initial Filing	B1513-8844

<u>Active Assumed Names (if any)</u>	<u>Date</u>	<u>Expires</u>
--------------------------------------	-------------	----------------



Tennessee  
Secretary of State  
Tre Hargett

Business Services Online > Find and Update a Business Record > Business Entity Detail

# Business Entity Detail

<b>Available Entity Actions</b>	<a href="#">File Annual Report (after 12/01/2024)</a>
	<a href="#">Certificate of Existence</a>
	<a href="#">More</a>

Entity details cannot be edited. This detail reflects the current state of the filing in the system.

Return to the [Business Information Search](#).

001515979: Limited Liability Company - Domestic Printer Friendly Version

<b>Name:</b> Heart N Soul Hospice Memphis LLC	
<b>Status:</b> Active	<b>Initial Filing Date:</b> 02/28/2024
<b>Formed in:</b> TENNESSEE	<b>Delayed Effective Date:</b>
<b>Fiscal Year Close:</b> December	<b>AR Due Date:</b> 04/01/2025
<b>Term of Duration:</b> Perpetual	<b>Inactive Date:</b>
<b>Principal Office:</b> DAVID TURNER 51 CENTURY BLVD 110 NASHVILLE, TN 37214 USA	
<b>Mailing Address:</b> DAVID TURNER 51 CENTURY BLVD 110 NASHVILLE, TN 37214 USA	
<b>AR Exempt:</b> No	<b>Obligated Member Entity:</b> No
	<b>Series LLC:</b> Yes
<b>Managed By:</b> Member Managed	<b>Number of Members:</b> 2

[Assumed Names](#) | [History](#) | [Registered Agent](#)

Name	Status	Expires
No Assumed Names Found...		



## Secretary of State Tre Hargett

Tre Hargett was elected by the Tennessee General Assembly to serve as Tennessee’s 37th secretary of state in 2009 and re-elected in 2013, 2017, and 2021. Secretary Hargett is the chief executive officer of the Department of State with oversight of more than 300 employees. He also serves on 16 boards and commissions, on two of which he is the presiding member. The services and oversight found in the Secretary of State's office reach every department and agency in state government.



## About the Office

The Tennessee Secretary of State has oversight of the Department of State. The Secretary of State is one of three Constitutional Officers elected by the General Assembly, in joint session. The Secretary of State is elected to a four-year term. The constitution mandates that it is the secretary's duty to keep a register of the official acts and proceedings of the governor, and, when required, to "lay same, all papers, minutes and vouchers relative thereto, before the General Assembly."

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**Attachment 8A – Management Agreement**

Not applicable to Applicant.

Attachment 1E

Please see table below for existing service area providers. There are 9 providers: (i) 8 are licensed in all 3 counties, and (ii) 1 is licensed in only 1 of the 3 counties.

Agency	Home County	State ID	Fayette	Shelby	Tipton
Avalon Hospice	Davidson	19694	X	X	X
Caris Healthcare	Fayette	24606	X	X	X
AccentCare Hospice and Palliative Care of Tennessee	Shelby	79716	X	X	X
Amedisys Hospice Care	Shelby	79646	X	X	X
Baptist Trinity Home Care & Hospice	Shelby	79616	X	X	X
Compassus - Memphis	Shelby	79686	X	X	X
Crossroads Hospice of Tennessee, L.L.C.	Shelby	79676	X	X	X
Hope Hospice & Palliative Care	Shelby	79726		X	
Methodist Alliance Hospice	Shelby	79666	X	X	X

**PROOF OF PUBLICATION**

Kim Looney  
K&L Gates LLP  
501 Commerce ST  
Nashville TN 37203-6039

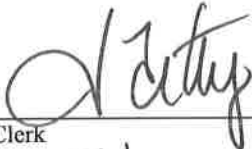
STATE OF WISCONSIN, COUNTY OF BROWN

The Commercial Appeal, a newspaper published in the city of Memphis, Shelby County, State of Tennessee, and personal knowledge of the facts herein state and that the notice hereto annexed was Published in said newspapers in the issue:

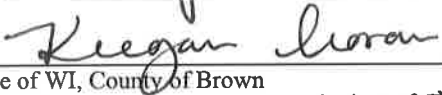
03/15/2024

and that the fees charged are legal.  
Sworn to and subscribed before on 03/15/2024

**NOTIFICATION OF INTENT TO APPLY FOR A CERTIFICATE OF NEED**  
This is to provide official notice to the Health Facilities Commission and all interested parties, in accordance with T.C.A. §68-11-1601 et seq., and the Rules of the Health Facilities Commission, that Heart N Soul Hospice Memphis, a new hospice agency owned by Heart N Soul Hospice Memphis LLC with an ownership type of limited liability company and to be managed by itself intends to file an application for a Certificate of Need for the establishment of a hospice agency and the initiation of hospice services in the following counties: Fayette, Shelby, and Tipton. The address of the project will be 1255 Lynnfield Road, Suite 258, Memphis, TN 38119. The estimated project cost will be approximately \$300,000.00. The anticipated date of filing the application is April 1, 2024. The contact person for this project is Kim H. Looney, Attorney, who may be reached at 501 Commerce Street, Suite 1500, Nashville, TN 37203, (615) 780-6727. The published Letter of Intent must contain the following statement pursuant to T.C.A. §68-11-1607 (c)(1). (A) Any healthcare institution wishing to oppose a Certificate of Need application must file a written notice with the Health Facilities Commission no later than fifteen (15) days before the regularly scheduled Health Facilities Commission meeting at which the application is originally scheduled; and (B) Any other person wishing to oppose the application may file a written objection with the Health Facilities Commission at or prior to the consideration of the application by the Commission, or may appear in person to express opposition. Written notice of opposition may be sent to: Health Facilities Commission, Andrew Jackson Building, 9th Floor, 503 Deaderick Street, Nashville, TN 37243 or email at hsda.staff@tn.gov.



Legal Clerk



Notary, State of WI, County of Brown

2.14.28

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State of Wisconsin

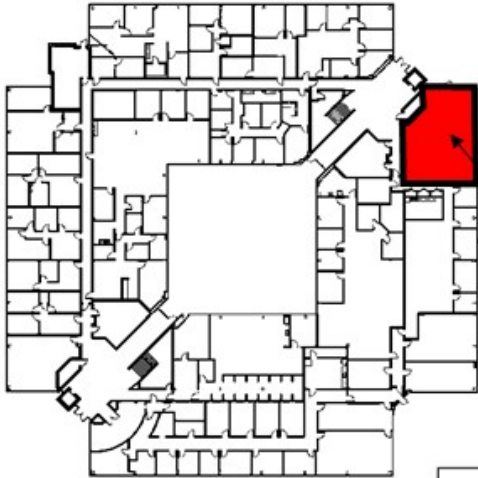


**EXHIBIT A**




**PREMISES**

This floor plan is diagrammatic only, is intended only to be a general description of the Premises as of the date of this Lease, and is not intended to show the exact dimensions or configuration of the Premises.

**Building A – 1255 Lynnfield Rd  
2<sup>nd</sup> Floor**



**1 FLOOR PLAN SUITE 258**  
SCALE: 1/8" = 1'-0"  
OFFICE AREA: 1,800 RSF

<b>LYNNFIELD OFFICE PARK A</b> 		 <small>85-85-1741 Fax: 914-639-5812 COPYRIGHT 2018 THE CRUMP FIRM, INC.</small>	PROJECT # CLARK
			DATE: 6/15/18
			DRAWN BY: KD
			<b>BD</b>



Attachment 3N.BR – Service Area Demographic Chart

**Population 65+**

Demographic Variable/ Geographic Area	Department of Health/Health Statistics							Census Bureau				TennCare	
	Total Population- Current Year <b>2024</b>	Total Population- Projected Year <b>2028</b>	Total Population-% Change	*Target Population- <b>65+</b> Current Year <b>2024</b>	Target Population- <b>65+</b> Project Year <b>2028</b>	Target Population- % Change	Target Population Projected Year as % of Total	Median Age	Median Household Income	Person Below Poverty Level	Person Below Poverty Level as % of Total	TennCare Enrollees	TennCare Enrollees as % of Total
Fayette	43,558	45,222	3.8%	10,951	12,212	11.5%	27.0%	46.8	\$81,074	4,530	10.4%	7,283	16.7%
Shelby	943,252	948,770	0.6%	149,228	158,419	6.2%	16.7%	36.1	\$59,621	156,580	16.6%	267,693	28.4%
Tipton	63,206	64,229	1.6%	10,910	11,977	9.8%	18.6%	38.4	\$70,674	8,786	13.9%	13,409	21.2%
Service Area Total	1,050,016	1,058,221	0.8%	171,089	182,608	6.7%	17.3%	40.4	\$70,456	169,896	16.2%	288,385	27.5%
State of TN Total	7,125,908	7,331,859	2.9%	1,324,362	1,438,845	8.6%	19.6%	39.2	\$64,035	947,746	13.3%	1,574,879	22.1%

Source:

1. TN Department of Health Population Projections 2024-2028
2. Census Bureau QuickFacts
3. TennCare 2024 Enrollment Data (February)



**Population 65+ (African American Only)**

Demographic Variable/ Geographic Area	Department of Health/Health Statistics						
	Total Population- Current Year <b>2024</b>	Total Population- Projected Year <b>2028</b>	Total Population-% Change	*Target Population- <b>65+ (African American)</b> Current Year <b>2024</b>	Target Population- <b>65+ (African American)</b> Project Year <b>2028</b>	Target Population- % Change	Target Population Projected Year as % of Total
Fayette	43,558	45,222	3.8%	2,337	2,611	11.7%	5.8%
Shelby	943,252	948,770	0.6%	69,493	76,930	10.7%	8.1%
Tipton	63,206	64,229	1.6%	1,627	1,855	14.0%	2.9%
Service Area Total	1,050,016	1,058,221	0.8%	73,457	81,396	10.8%	7.7%
State of TN Total	7,125,908	7,331,859	2.9%	159,113	178,258	12.0%	2.4%

Source:

1. TN Department of Health Population Projections 2020-2034

**Item 5NR - Service Area Historical Utilization**

<i>Fayette, Shelby, and Tipton Counties All Patients Served from 2021-2023</i>										
Hospice Agency	Home County	State ID	2021				2022			
			Fayette	Shelby	Tipton	Service Area Total	Fayette	Shelby	Tipton	Service Area Total
Avalon Hospice	Davidson	19694	17	413	29	459	16	331	27	374
Caris Healthcare	Fayette	24606	46	39	12	97	30	51	9	90
AccentCare Hospice and Palliative Care of Tennessee	Shelby	79716	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	79646	18	357	61	436	21	414	61	496
Baptist Trinity Hospice	Shelby	79616	14	457	46	517	21	475	55	551
Compassus - Memphis	Shelby	79686	8	222	6	236	18	321	17	356
Crossroads Hospice of Tennessee, LLC	Shelby	79676	8	1,566	14	1,588	3	1,225	8	1,236
Hope Hospice & Palliative Care	Shelby	79726	N/A	N/A	N/A	N/A	0	101	0	101
Methodist Alliance Hospice	Shelby	79666	43	1,365	76	1,484	21	1,445	56	1,522
<b>TOTAL</b>	<b>N/A</b>	<b>N/A</b>	<b>154</b>	<b>4,419</b>	<b>244</b>	<b>4,817</b>	<b>130</b>	<b>4,363</b>	<b>233</b>	<b>4,726</b>

Source: 2021-2023 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information

2023				% Change
Fayette	Shelby	Tipton	Service Area Total	Service Area Total 2021-2023
13	236	28	277	-39.7%
38	37	13	88	-9.3%
N/A	N/A	N/A	N/A	N/A
10	242	81	333	-23.6%
22	543	74	639	23.6%
12	371	27	410	73.7%
3	1,180	6	1,189	-25.1%
0	177	0	177	N/A
20	1,571	58	1,649	11.1%
<b>118</b>	<b>4,357</b>	<b>287</b>	<b>4,762</b>	<b>-1.1%</b>

**Item 5NR - Service Area Historical Utilization**

Fayette, Shelby, and Tipton Counties Patients Served by Race 2023								
Hospice Agency	Home County	State ID	Fayette			Shelby		
			White	Black	Other	White	Black	Other
Avalon Hospice	Davidson	19694	10	0	3	97	78	61
Caris Healthcare	Fayette	24606	35	2	1	29	6	2
AccentCare Hospice and Palliative Care of Tennessee	Shelby	79716	N/A	N/A	N/A	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	79646	9	1	0	130	91	21
Baptist Trinity Hospice	Shelby	79616	19	3	0	324	202	17
Compassus - Memphis	Shelby	79686	5	4	3	145	128	98
Crossroads Hospice of Tennessee, LLC	Shelby	79676	2	1	0	737	423	20
Hope Hospice & Palliative Care	Shelby	79726	0	0	0	144	31	2
Methodist Alliance Hospice	Shelby	79666	19	1	0	759	777	35
<b>TOTAL</b>	<b>N/A</b>	<b>N/A</b>	<b>99</b>	<b>12</b>	<b>7</b>	<b>2,365</b>	<b>1,736</b>	<b>256</b>

Source: 2023 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information

**Item 5NR - Service Area Historical Utilizatio**

Hospice Agency	Home County	Tipton			Service Area Total	% Black	Total Age 65+ (Not Race Specific)
		White	Black	Other			
Avalon Hospice	Davidson	19	6	3	277	30.3%	Fayette - 10 Shelby - 196 Tipton - 23
Caris Healthcare	Fayette	12	1	0	88	10.2%	Fayette - 37 Shelby - 35 Tipton - 12
AccentCare Hospice and Palliative Care of Tennessee	Shelby	N/A	N/A	N/A	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	58	17	6	333	32.7%	Fayette - 9 Shelby - 193 Tipton - 73
Baptist Trinity Hospice	Shelby	65	8	1	639	33.3%	Fayette - 18 Shelby - 465 Tipton - 67
Compassus - Memphis	Shelby	17	1	9	410	32.4%	Fayette - 9 Shelby - 320 Tipton - 22
Crossroads Hospice of Tennessee, LLC	Shelby	3	2	1	1,189	35.8%	Fayette - 3 Shelby - 1,080 Tipton - 5
Hope Hospice & Palliative Care	Shelby	0	0	0	177	17.5%	Fayette - 0 Shelby - 173 Tipton - 0
Methodist Alliance Hospice	Shelby	50	8	0	1,649	47.7%	Fayette - 13 Shelby - 1,161 Tipton - 45
<b>TOTAL</b>	<b>N/A</b>	<b>224</b>	<b>43</b>	<b>20</b>	<b>4,762</b>	<b>37.6%</b>	Fayette - 99 Shelby - 3,623 Tipton - 247

Source: 2023 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information

**Item 5NR - Service Area Historical Utilization**

Fayette, Shelby, and Tipton Counties Patients Served by Race 2022								
Hospice Agency	Home County	State ID	Fayette			Shelby		
			White	Black	Other	White	Black	Other
Avalon Hospice	Davidson	19694	14	2	0	196	87	48
Caris Healthcare	Fayette	24606	25	3	2	33	12	6
AccentCare Hospice and Palliative Care of Tennessee	Shelby	79716	N/A	N/A	N/A	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	79646	16	0	5	202	180	32
Baptist Trinity Hospice	Shelby	79616	18	3	0	277	176	22
Compassus - Memphis	Shelby	79686	5	3	10	109	72	140
Crossroads Hospice of Tennessee, LLC	Shelby	79676	2	1	0	727	477	21
Hope Hospice & Palliative Care	Shelby	79726	0	0	0	62	37	3
Methodist Alliance Hospice	Shelby	79666	13	8	0	610	808	27
<b>TOTAL</b>	<b>N/A</b>	<b>N/A</b>	<b>93</b>	<b>20</b>	<b>17</b>	<b>2,216</b>	<b>1,849</b>	<b>299</b>

Source: 2022 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information

**Item 5NR - Service Area Historical Utilization**

Hospice Agency	Home County	Tipton			Service Area Total	% Black	Age 65+ (Not Race Specific)
		White	Black	Other			
Avalon Hospice	Davidson	23	4	0	374	24.9%	Fayette - 16 Shelby - 294 Tipton - 25
Caris Healthcare	Fayette	9	0	0	90	16.7%	Fayette - 28 Shelby - 41 Tipton - 7
AccentCare Hospice and Palliative Care of Tennessee	Shelby	N/A	N/A	N/A	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	42	5	14	496	37.3%	Fayette - 21 Shelby - 315 Tipton - 55
Baptist Trinity Hospice	Shelby	51	3	1	551	33.0%	Fayette - 20 Shelby - 407 Tipton - 47
Compassus - Memphis	Shelby	4	0	13	356	21.1%	Fayette - 16 Shelby - 289 Tipton - 14
Crossroads Hospice of Tennessee, LLC	Shelby	3	4	1	1,236	39.0%	Fayette - 2 Shelby - 1,073 Tipton - 7
Hope Hospice & Palliative Care	Shelby	0	0	0	102	36.3%	Fayette - 0 Shelby - 93 Tipton - 0
Methodist Alliance Hospice	Shelby	47	9	0	1,522	54.2%	Fayette - 15 Shelby - 1,057 Tipton - 42
<b>TOTAL</b>	<b>N/A</b>	<b>179</b>	<b>25</b>	<b>29</b>	<b>4,727</b>	<b>40.1%</b>	Fayette - 118 Shelby - 3,569 Tipton - 197

Source: 2022 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information

**Item 5NR - Service Area Historical Utilization**

Fayette, Shelby, and Tipton Counties Patients Served by Race 2021								
Hospice Agency	Home County	State ID	Fayette			Shelby		
			White	Black	Other	White	Black	Other
Avalon Hospice	Davidson	19694	14	3	0	237	159	17
Caris Healthcare	Fayette	24606	38	7	1	23	15	1
AccentCare Hospice and Palliative Care of Tennessee	Shelby	79716	N/A	N/A	N/A	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	79646	13	3	2	176	131	50
Baptist Trinity Hospice	Shelby	79616	9	4	1	261	175	21
Compassus - Memphis	Shelby	79686	5	0	3	86	54	82
Crossroads Hospice of Tennessee, LLC	Shelby	79676	3	4	1	601	941	24
Hope Hospice & Palliative Care	Shelby	79726	N/A	N/A	N/A	N/A	N/A	N/A
Methodist Alliance Hospice	Shelby	79666	34	9	0	566	754	45
<b>TOTAL</b>	<b>N/A</b>	<b>N/A</b>	<b>116</b>	<b>30</b>	<b>8</b>	<b>1,950</b>	<b>2,229</b>	<b>240</b>

Source: 2021 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information



**Item 5NR - Service Area Historical Utilization**

Hospice Agency	Home County	Tipton			Service Area Total	% Black	Age 65+ (Not Race Specific)
		White	Black	Other			
Avalon Hospice	Davidson	25	0	4	459	35.3%	Fayette - 17 Shelby - 359 Tipton - 23
Caris Healthcare	Fayette	12	0	0	97	22.7%	Fayette - 44 Shelby - 34 Tipton - 7
AccentCare Hospice and Palliative Care of Tennessee	Shelby	N/A	N/A	N/A	N/A	N/A	N/A
Amedisys Hospice Care	Shelby	50	1	10	436	31.0%	Fayette - 30 Shelby - 294 Tipton - 54
Baptist Trinity Hospice	Shelby	37	8	1	517	36.2%	Fayette - 24 Shelby - 393 Tipton - 41
Compassus - Memphis	Shelby	4	0	2	236	22.9%	Fayette - 15 Shelby - 202 Tipton - 5
Crossroads Hospice of Tennessee, LLC	Shelby	5	8	1	1,588	22.7%	Fayette - 13 Shelby - 1,369 Tipton - 12
Hope Hospice & Palliative Care	Shelby	N/A	N/A	N/A	N/A	N/A	N/A
Methodist Alliance Hospice	Shelby	65	11	0	1,484	52.2%	Fayette - 34 Shelby - 980 Tipton - 63
<b>TOTAL</b>	<b>N/A</b>	<b>198</b>	<b>28</b>	<b>18</b>	<b>4,817</b>	<b>47.5%</b>	Fayette - 177 Shelby - 3,631 Tipton - 205

Source: 2021 Joint Annual Report - Hospice Agencies

N/A: JAR Data Insufficient to Complete Required Information

	<b>Jan-24</b>	<b>Feb-24</b>	<b>Mar-24</b>	<b>Apr-24</b>	<b>May-24</b>	<b>Jun-24</b>	<b>Jul-24</b>
<b>Days in Month</b>	<b>31</b>	<b>29</b>	<b>31</b>	<b>30</b>	<b>31</b>	<b>30</b>	<b>31</b>
<b>Heart N Soul Hospice Memphis</b>							
ADC	0	0	0	0	0	0	0
Patient Days	0	0	0	0	0	0	0

	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	Apr-25
<b>Days in Month</b>	<b>31</b>	<b>30</b>	<b>31</b>	<b>30</b>	<b>31</b>	<b>31</b>	<b>28</b>	<b>31</b>	<b>30</b>
<b>Heart N Soul Hospice Memphis</b>									
ADC	0	0	0	0	0	5	8	11	15
Patient Days	0	0	0	0	0	155	229	352	436

	May-25	Jun-25	Jul-25	Aug-25	Sep-25	Oct-25	Nov-25	Dec-25	Jan-26	Feb-26	Mar-26
<b>Days in Month</b>	<b>31</b>	<b>30</b>	<b>31</b>	<b>31</b>	<b>30</b>	<b>31</b>	<b>30</b>	<b>31</b>	<b>31</b>	<b>28</b>	<b>31</b>
<b>Heart N Soul Hospice Memphis</b>											
ADC	18	21	24	27	30	34	37	40	42	43	45
Patient Days	550	627	747	845	914	1,043	1,105	1,240	1,296	1,218	1,400

	<b>Apr-26</b>	<b>May-26</b>	<b>Jun-26</b>	<b>Jul-26</b>	<b>Aug-26</b>	<b>Sep-26</b>	<b>Oct-26</b>	<b>Nov-26</b>	<b>Dec-26</b>
<b>Days in Month</b>	<b>30</b>	<b>31</b>	<b>30</b>	<b>31</b>	<b>31</b>	<b>30</b>	<b>31</b>	<b>30</b>	<b>31</b>
<b>Heart N Soul Hospice Memphis</b>									
ADC	47	48	50	52	53	55	57	58	60
Patient Days	1,405	1,503	1,505	1,606	1,658	1,655	1,761	1,755	1,860

## Attachment 9C – Service Area Hospice Agency Charges

### Net Charge/Patient Day Service Area Hospice Agencies - 2023

Hospice	2023 Net Revenue	2023 Patient Days	Net Charge (Net Revenue/Patient Days)
Avalon Hospice (Davidson) (State ID No. 19694)	\$88,701,381	546,515	\$162.30
*AccentCare Hospice & Palliative Care of TN, LLC (Shelby) (State ID No. 79716)	N/A	N/A	N/A
Amedisys Hospice Care (Shelby) (State ID No. 79646)	\$2,224,532	23,027	\$96.61
Baptist Trinity Home Care & Hospice (Shelby) (State ID No. 79616)	\$6,323,041	48,060	\$131.57
Caris Healthcare (Fayette) (State ID No. 24606)	\$3,917,680	27,017	\$145.01
Compassus – Memphis (Shelby) (State ID No. 79686)	\$4,916,441	28,851	\$170.41
Crossroads Hospice of Tennessee, LLC (Shelby) (State ID No. 79676)	\$13,193,708	82,707	\$159.52
Hope Hospice & Palliative Care (Shelby) (State ID No. 79726)	\$2,146,331	16,668	\$128.77
Methodist Alliance Hospice (Shelby) (State ID No. 79666)	\$11,247,322	67,577	\$166.44

**Source: 2023 Joint Annual Reports**

\*2023 JAR Data provides insufficient information to complete.

OFFICE LEASE AGREEMENT

This Office Lease Agreement (hereinafter, the "Lease") entered into this 27 day of March, 2024, by and between LYNNFIELD OFFICE PROJECT, LLC, a Tennessee limited liability company (hereinafter, the "Landlord"), c/o In-Rel Properties North, LLC (hereinafter, the "Manager"), and HEART AND SOUL HOSPICE MEMPHIS, LLC, a Tennessee limited liability company (hereinafter, the "Tenant").

WITNESSETH

In consideration of the covenants, conditions, agreements and stipulations herein contained, on the part of the Tenant to be kept and performed, the Landlord does hereby lease to the Tenant that certain space described herein. To Have and to Hold the same on the following terms and conditions:

SECTION 1.1 GENERAL PROVISION Term shall be for a period of thirty-seven (37) month(s) from the Commencement Date (as hereinafter defined) (hereinafter, the "Initial Term").

1.2 Property: A certain property located on the 1st floor at 1255 Lynnfield Road and commonly known as Building A within Lynnfield Office Park (hereinafter, the "Property" or "Building") consisting of approximately 279,621 square feet (hereinafter, the "Property Size" or "Building Size").

1.3 Premises: A certain space commonly known as Suite 258 (hereinafter, the "Premises"). The Premises are set forth on Exhibit A attached hereto and made a part hereof.

1.4 Square Footage: Landlord and Tenant deem the Premises to consist of 1,600 rentable square feet (hereinafter, the "Square Footage").

1.5 Base Rent: As set forth in the schedule below (hereinafter, the "Base Rent").

Table with 3 columns: Period, Base Rent, Period Total. Rows include 5/1/24 - 4/30/25, 5/1/25 - 4/30/26, and 5/1/26 - 5/31/27.

1.6 Base Rent Increase: As set forth in Section 1.5.

1.7 Base Rent Abatement: Provided that no Default (as hereinafter defined) has existed prior to the month of any abatements provided herein, the Base Rent shall be abated as follows: first month of the Initial Term, subject to the terms of Section 2 (hereinafter, the "Base Rent Abatement").

1.8 Common Area Maintenance: Common Area Maintenance (as hereinafter defined) is included in the Base Rent, subject to the terms set forth in Section 6.

1.9 Real Estate Taxes: Real Estate Taxes (as hereinafter defined) are included in the Base Rent, subject to the terms set forth in Section 8.

1.10 Property Insurance: Property Insurance (as hereinafter defined) is included in the Base Rent, subject to the terms set forth in Section 9.

1.11 Sales Tax: Intentionally Deleted.

1.12 Security Deposit: \$2,687.61 (hereinafter, the "Security Deposit") and as further described in Section 24.

1.13 Tenant's Use(s): The use (the "Use"), as further described in Section 12, shall mean general office use for hospice care services.

1.14 Intentionally deleted

1.15 Commencement Date: Shall mean May 1, 2024 (hereinafter, the "Commencement Date"). Should the Commencement Date differ from the Commencement Date defined above, a modified Commencement Date will be confirmed by way of a Landlord's Notice of Possession and Commencement, the form of which is attached hereto as Exhibit E and made a part hereof for all purposes.

1.16 Expiration Date: Shall mean May 31, 2027, subject to the terms of Section 5.3 (hereinafter, the "Expiration Date").

1.17 Landlord's Notice Address: Lynnfield Office Project, LLC, c/o In-Rel Properties North, LLC, 200 Lake Avenue, 2nd Floor, Lake Worth Beach, FL 33460

1.18 Tenant's Notice Address: Heart and Soul Hospice Memphis, LLC, 51 Century Blvd., Suite 110, Nashville, TN 37214, Attn: David Turner

1.19 Real Estate Broker(s): Colliers Management Services - Memphis, LLC on behalf of the Landlord and Commercial Advisors, LLC on behalf of the Tenant (hereinafter, the "Real Estate Broker(s)") and as further described in Section 37. If no Real Estate Broker(s) are named herein, it shall be understood that there are none.

1.20 Due at Execution Items: Upon execution of this Lease by Tenant, Tenant shall remit to Landlord \$5,220.94, which shall include the following: Base Rent for first month of Initial Term, Security Deposit, and prior to Possession (as hereinafter defined), Tenant shall submit to Landlord Tenant's certificate of insurance as required in Section 15 (hereinafter, the "Due at Execution Items"). If the Due at Execution Items are not delivered in full, then Landlord, at its option, shall have the right to deem this Lease null and void.

1.21 Payments: All rental checks should be made payable to Lynnfield Office Project, LLC and submitted to the following unless otherwise advised by Landlord:

Standard / Overnight Mailing Address: c/o In-Rel Properties, Inc., 200 Lake Avenue, 2nd Floor, Lake Worth Beach, FL 33460

or by wire transfer to:

**Wire/ACH Instructions:**  
Bank Name: Truist Bank  
ABA #: 263 191 387  
Acct #: 1100009945812  
Acct Name: In-Rel Properties, Inc.  
Must include reference: **Lynnfield Office Park**

**1.22 Condition of Premises:** Landlord shall provide Tenant with turnkey improvements to the Premises based on the improvement plan and scope of work described on Exhibit D (collectively, the "**Landlord's Work**"). Any changes made by Tenant to Landlord's Work and resulting cost shall be the sole responsibility of Tenant and shall be paid prior to the commencement of the work, and in no event later than five (5) days following request of payment from Landlord. Landlord and Tenant agree that all alterations, improvements and additions made to the Premises according to Exhibit D, whether paid for by Landlord or Tenant, will, without compensation to Tenant, become Landlord's property upon installation and will remain Landlord's property at the expiration or earlier termination of the Lease. Except for the above-referenced Landlord's Work, Tenant shall accept the Premises in its current AS-IS Condition.

**1.23** Intentionally Deleted.

**1.24 Base Year:** Calendar Year 2024 (hereinafter, the "**Base Year**").

**SECTION 2 – RENT.** All (a) Base Rent, (b) Tenant's Proportionate Share (as hereinafter defined) of (i) Common Area Maintenance, (ii) Real Estate Taxes and (iii) Property Insurance, and (c) Additional Rent (as hereinafter defined) (hereinafter, the "**Rent**"), shall be due and payable at Landlord's Notice Address in advance without demand, on the first (1st) day of each month. In the event Landlord has not received the full Rent by the first (1st) day of each month, Tenant shall pay the greater of \$200.00 or fifteen percent (15%) of unpaid portion of the Rent as a late fee (hereinafter, the "**Late Fee**") for each month that the amount remains unpaid. In addition to Rent, any other tax, charge or fee that Tenant assumes or agrees to pay hereunder (hereinafter, the "**Additional Rent**"), shall be due and payable as set forth in this Lease and in the event of non-payment, Landlord shall have all rights and remedies as herein provided for failure to pay Rent. If any check given to Landlord by Tenant shall not be honored by the bank upon which it is drawn, Landlord, at its option, may require all future payments made by Tenant to Landlord to be made by cash, certified check, cashier's check, money order or wire transfer. If, at any time during the Term, Tenant is in Default, beyond any applicable cure period, the Base Rent Abatement shall become immediately due and payable to Landlord.

**SECTION 3 – TERM.** The term of this Lease shall be for the Initial Term (plus the partial month, if the Commencement Date is other than the first day of a month), together with any extension, renewal or option term(s) (hereinafter, the "**Term**"), unless sooner terminated as hereinafter provided. The term "**Lease Year**" shall be defined as the first twelve (12) months following the Commencement Date. If the Commencement Date falls on a day other than the first day of the month, the Lease Year shall be deemed to begin the first day of the following month. The term "**Calendar Year**" shall be the period commencing January 1 and ending December 31 of any given year.

**SECTION 4 - PREMISES; COMMON AREAS.** Tenant is given the right to the non-exclusive use of all such facilities designed for common use, and Landlord shall have the right from time to time to change such facilities, to do such things as in the Landlord's sole discretion may be necessary regarding such facilities. The Square Footage includes the area contained within the Premises together with a common area percentage factor of the Premises proportionate to the total Building Size.

A common area conference room (the "**Common Conference Room**") for tenants of Property is i) located on east side 2nd floor of Building B known as 1355 Lynnfield Road; ii) available on-a first-come-first-serve basis; and iii) at no rent to Tenant. Notwithstanding the above, Landlord has the option to charge Tenant a janitorial service fee at its option should Landlord determine the Common Conference Room requires such service after Tenant's use.

**SECTION 5 - POSSESSION; PREPARATION OF PREMISES**

**5.1** All work in renovating and preparing the Premises for Tenant's use, other than Landlord's Work, if applicable, (hereinafter, the "**Tenant's Work**"), shall be accomplished by Tenant at Tenant's sole expense, but only in accordance with plans and specifications approved in writing by Landlord. Tenant's Work shall be in conformity with all laws, ordinances, building codes, and fire regulations applicable to the Premises and the Property (hereinafter, the "**Law**" or "**Laws**"), and Tenant shall hold Landlord harmless from any penalty, damage, injury, loss, or expense of whatever kind arising out of Tenant's Work.

**5.2** At the sooner to occur of the Commencement Date or the date that Landlord delivers the Premises to Tenant (hereinafter, the "**Possession**"), Tenant shall accept the Premises and the Property in their existing condition and state of repair. By taking Possession of the Premises, Tenant shall be deemed to establish conclusively that all improvements have been completed in accordance with the Work Letter, if applicable, and are suitable for the purposes for which the Premises are let. Tenant further agrees that, if requested by Landlord, Tenant will furnish Landlord with a written statement that Tenant has accepted the Premises and that Landlord has fully complied with Landlord's covenants and obligations hereunder (an example of which is included in this Lease, if applicable). If Tenant shall fail to execute within five (5) days after such request, it shall be understood that the contents of such document are correct.

**5.3** If Landlord shall be unable to give Possession of the Premises on the Commencement Date by any reason, except Tenant's failure to commence or complete the plans or construction of Tenant's Work, then Tenant's obligation to pay Rent shall not commence until Possession of the Premises is given or is available, whereby the Commencement Date shall become the date Tenant takes Possession and the Expiration Date shall be extended by the same amount of time that the Commencement Date was delayed. If pursuant to the previous sentence, the Expiration Date becomes a day other than the last day of a month, the Expiration Date, in that event, shall become the last day of the month in which it falls. Tenant agrees to accept such abatement of Rent as liquidated damages in full satisfaction of the failure of Landlord to give Possession of the Premises on said date, including, without limitation, the ability to terminate the Lease. Should a delay result pursuant to this Section 5.3, Landlord shall send a document for Tenant to exercise to clearly define the adjustment in such dates. If Tenant fails to execute within five (5) days of such request, it shall be understood that the contents of such document are correct.

**5.4** If Tenant shall occupy the Premises prior to the Commencement Date with Landlord's prior written consent, but not open for business, such occupancy by Tenant shall be deemed to be that of a Tenant under all of the terms, covenants and conditions of this Lease, except that the obligation to pay Rent shall not be due and payable until the Commencement Date.



#### **SECTION 6 - COMMON AREA MAINTENANCE**

**6.1** If in any Calendar Year during the Term after the Base Year, as defined in Section 1, the costs and expenses necessary to operate the Property in Landlord's discretion (hereinafter, the "**Common Area Maintenance**") exceeds the amount of Common Area Maintenance in the Base Year, then Tenant shall pay, as Additional Rent to Landlord, an amount which is the product of (i) the amount of such increase in Common Area Maintenance, and (ii) Tenant's Proportionate Share. Additionally, Tenant shall pay any Partial Year Proportionate Share of Common Area Maintenance as defined in Section 6. If Tenant's Common Area Maintenance estimate payments result in an underpayment to Landlord, Tenant shall, within ten (10) days after the receipt of the statement, pay to Landlord an amount equal to such underpayment as Additional Rent.

**6.2** "**Tenant's Proportionate Share**" shall be a fraction, the numerator of which is the Square Footage and the denominator of which is the Building Size. Tenant's "**Partial Year Proportionate Share**" shall be calculated by multiplying the amount of Tenant's Proportionate Share for the full Calendar Year by a fraction, the numerator of which is the number of days during such Calendar Year falling within the Term and the denominator of which is three hundred and sixty-five (365).

**6.3** If at any time during the Base Year, or during any subsequent Calendar Year (hereinafter, the "**Subsequent Year**"), less than ninety-five percent (95%) of the total rentable square feet of office space in the Building is occupied by tenants, the amount of Common Area Maintenance for the Base Year, or for any such Subsequent Year, as the case may be, shall be deemed to be the amount of Common Area Maintenance as reasonably estimated by Landlord that would have been incurred if the percentage of occupancy of the Building during the Base Year or any such Subsequent Year was ninety-five percent (95%). "**Operating Expenses**" shall mean Common Area Maintenance, Public Utilities, Real Estate Taxes and Property Insurance.

**SECTION 7 - PUBLIC UTILITIES.** If in any Calendar Year during the Term after the Base Year the amount of all charges for utilities at and relating to the Property, which shall include, but not limited to, electricity, water, sewer, gas and trash removal (hereinafter, the "**Public Utilities**") exceeds the amount of Public Utilities in the Base Year, then Tenant shall pay, as Additional Rent to Landlord, an amount which is the product of (i) the amount of such increase in Public Utilities, and (ii) Tenant's Proportionate Share. Additionally, Tenant shall pay any Partial Year Proportionate Share of Public Utilities. If Tenant's Public Utilities estimate payments result in an underpayment to Landlord, Tenant shall, within ten (10) days after the receipt of the statement, pay to Landlord an amount equal to such underpayment as Additional Rent. Tenant shall pay to Landlord on demand such charges as Landlord may reasonably prescribe for any electric service required by Tenant for computers and other electrical equipment or other electric service deemed by Landlord to be excessive or non-standard.

**SECTION 8 - TAXES.** If in any Calendar Year during the Term after the Base Year the amount of all real estate taxes, assessments and other charges at and relating to the Property (hereinafter, the "**Real Estate Taxes**") exceed the amount of Real Estate Taxes in the Base Year, then Tenant shall pay, as Additional Rent to Landlord, an amount which is the product of (i) the amount of such increase in Real Estate Taxes, and (ii) Tenant's Proportionate Share. Tenant shall pay any Partial Year Proportionate Share of Real Estate Taxes. If Tenant's Real Estate Taxes estimate payments result in an underpayment to Landlord, Tenant shall, within ten (10) days after the receipt of the statement, pay to Landlord an amount equal to such underpayment as Additional Rent. Tenant shall pay, without contribution from Landlord, all taxes on Tenant's personal property and trade fixtures that are assessed and payable as they become due, and shall hold Landlord harmless with respect thereto.

**SECTION 9 - PROPERTY INSURANCE.** If in any Calendar Year during the Term after the Base Year the amount of all policies of insurance carried by Landlord in connection with Landlord's ownership and operation of the Property (hereinafter, the "**Property Insurance**") exceed the amount of Property Insurance in the Base Year, then Tenant shall pay, as Additional Rent to Landlord, an amount which is the product of (i) the amount of such increase in Property Insurance, and (ii) Tenant's Proportionate Share. Additionally, Tenant shall pay any Partial Year Proportionate Share of Property Insurance. If Tenant's Property Insurance Estimate payments result in an underpayment to Landlord, Tenant shall, within ten (10) days after the receipt of the statement, pay to Landlord an amount equal to such underpayment as Additional Rent.

#### **SECTION 10 - MAINTENANCE AND REPAIR OF PREMISES**

**10.1** Tenant shall keep the Premises in good working order, repair and condition. Tenant's obligations hereunder shall include, but not be limited to, Tenant's trade fixtures and equipment, ceilings, walls, entrances, signs, interior decorations, window coverings, burglar alarm systems, card access or tele-entry systems, floor-coverings, wall-coverings, entry and interior doors, interior glass, plumbing fixtures, light fixtures and bulbs, keys and locks, fire extinguishers and fire protection systems, and equipment and lines for water, sewer (including free flow up to the common sewer line), restroom and/or breakroom supplies within the Premises, HVAC systems and equipment, (as further described in Section 10.2), if any, electrical, gas, steam, sprinkler and mechanical facilities from the point of connection to and within the Premises, and other systems or equipment within or which serve the Premises exclusively (whether located within or outside the Premises), and all alterations and improvements to the Premises whether installed by Landlord or Tenant. Without limiting the generality of the foregoing, at all times during the Term of this Lease, Tenant shall maintain the appearance of the Premises as a first-class business establishment.

**10.2** Intentionally Deleted.

**10.3** Landlord shall keep the roof above, the foundation, exterior walls, and the structural portions of the Premises in working order and repair (provided that Tenant shall give Landlord reasonable prior notice of the necessity for such repairs, and further provided that any damage thereto shall not have been caused by any act or omission of, or violation of this Lease by Tenant or any other occupant of the Premises, or any of their employees, agents, invitees or contractors, in which event Landlord may perform at Tenant's expense or require that Tenant perform such repairs as provided above without limiting Landlord's other remedies therefor).

**10.4** Landlord agrees to furnish Tenant while occupying the Premises the following: (i) water at those points of supply provided for general use of tenants of the Building, (ii) heated and refrigerated air-conditioning in season, at such temperatures and in such amounts as are considered by Landlord to be standard on Monday through Friday between the hours of 7:00 A.M. and 6:00 P.M., such services on Saturday, Sunday and holidays excepted), (iii) elevator service, if applicable, and (iv) electrical service in the manner and to the extent deemed by Landlord to be standard; but failure to any extent to furnish or any stoppage of these defined services shall not render Landlord liable in any respect for damages to person, property or business, nor be construed as an eviction of Tenant or as an abatement of Rent, or relieve Tenant from fulfillment of any covenant or agreement hereof.

**10.5** Charges for any services for which Tenant is required to pay from time to time hereunder, shall be due and payable within fifteen (15) business days after such billing as Additional Rent.

**10.6** Landlord shall provide Building standard janitorial services to the Premises on a schedule to be provided by Landlord.

#### **SECTION 11 - TRADE FIXTURES, ALTERATIONS AND LIENS**

**11.1** Tenant shall not perform any Tenant's Work or repairs on or to the Premises, the Property or the Systems and Equipment therein or servicing the Premises without the prior written consent of Landlord. "**Systems and Equipment**", as used herein, shall mean any plant, machinery, HVAC equipment, transformers, ducts, cables, wires and other equipment, facilities and systems designed to supply light, heat, ventilation, air conditioning and humidity and other services or utilities, or comprising or serving as any other component or portion of any electrical, gas, steam, plumbing, water, sewer, sprinkler, communications, alarm, security, or fire/life/safety systems or equipment, or any other electrical, mechanical, electronic, computer or other systems or equipment for the Property, except to the extent the same serves any tenant exclusively. Tenant shall pay Landlord a reasonable fee to reimburse Landlord's out-of-pocket costs, including but not limited to, the cost of any outside engineer, architect or consultant, in reviewing Tenant's plans and specifications and performing any supervision of Tenant's Work or repairs. All fixtures, including light fixtures, air-conditioning, heating and plumbing, and trade fixtures, installed and paid for by Tenant or Landlord in the Premises shall remain the property of Landlord at the expiration or earlier termination as allowed in this Lease or any renewal or extension thereof.

**11.2** For any Tenant's Work that Landlord approves pursuant to Section 5.1 or 11.1, Tenant shall do the following prior to commencement of the Tenant's Work: (i) provide the names, addresses and background information concerning all contractors, subcontractors and suppliers, (ii) post permits and bonds in amounts designated by Landlord, (iii) submit a certificate of insurance from any contractor(s) or subcontractor(s) naming Landlord and Manager as additional insureds, (iv) submit contractor(s), subcontractor(s) and supplier(s) lien waivers in form satisfactory to Landlord, and (v) submit a signed and notarized statement from any contractor(s), subcontractor(s) and supplier(s) that such business or individual agrees to not file any lien against the Landlord or the Property and will seek payment from Tenant solely.

**11.3** All Tenant's Work shall be performed: (i) in a thoroughly first class and professional manner, (ii) only with materials that are high quality and free of defects, (iii) strictly in accordance with plans and specifications approved by Landlord in advance in writing, and (iv) diligently to completion and so as to cause the least possible interference with other tenants and the operation of the Property. If Tenant fails to perform the Tenant's Work as required herein, and such failure continues for forty-eight (48) hours or more, Landlord shall have the right to stop the Tenant's Work until such failure is cured (and doing so shall in no way limit Landlord's other remedies and shall not serve to abate the Rent or abrogate or affect any of Tenant's other obligations under this Lease).

**11.4** Tenant shall keep the Property, the Premises and this Lease free from any mechanics, materialmans or similar liens or encumbrances, and any claims thereof. Tenant shall give Landlord written notice at least ten (10) days prior to the commencement of any Tenant's Work to afford Landlord the opportunity to post and record appropriate notices of non-responsibility. If, however, any lien or encumbrance is filed against the Property or any portion thereof, Tenant shall remove any such lien or encumbrance by bond or otherwise within fifteen (15) days after filing thereof. If Tenant fails to do so, Landlord may pay the amount or take such other action, as Landlord deems necessary to remove such lien or encumbrance, without being responsible for investigating the validity thereof. The amount so paid and costs incurred by Landlord shall be deemed Additional Rent under this Lease payable upon demand, without limitation as to other remedies available to Landlord. Any claim to a lien or encumbrance upon the Property or the Premises arising in connection with any work shall be null and void, or at Landlord's option shall attach only against Tenant's interest in the Premises and shall in all respects be subordinate to Landlord's title to the Property and the Premises.

**SECTION 12 - USE AND OPERATING REQUIREMENTS.** Tenant shall use the Premises for the purposes specified in Section 1, and for no other purpose whatsoever. Landlord makes no representation that the Premises are suitable for the purposes specified in Section 1. Tenant shall, throughout the Term of this Lease, operate the business located at the Premises in a dignified, first-rate manner. Tenant shall not allow any activity to be conducted on the Premises that will produce any Hazardous Materials (as hereinafter defined), and will not permit any Hazardous Materials to be brought into or stored in the Premises. As used herein, the term "**Hazardous Materials**" shall mean pollutants, contaminants, toxic or hazardous wastes, or any other substances, the use and/or the removal of which is required or the use of which is restricted, prohibited or penalized by any present or future federal, state or local laws, ordinances or other statutes of a governmental or quasi-governmental authority, relating to pollution or protection of the environment.

**SECTION 13 - RIGHTS OF LANDLORD.** Landlord reserves, in addition to any rights reserved herein, the following rights with respect to the Premises: (a) At all reasonable times, by itself or its duly authorized agents, to go upon and inspect the Premises, and at its option to make repairs, alterations, and additions thereto or to the Property of which the Premises are a part. If Tenant shall not be personally present, to open and permit an entry by Landlord into the Premises, and if an entry therein shall be necessary in the case of an emergency, Landlord or Landlord's agents may make forcible entry without rendering Landlord or such agent liable therefor and without in any manner affecting the obligations and covenants of this Lease. Tenant hereby grants Landlord the necessary licenses to carry out the terms of this provision, (b) At any time within six (6) months prior to the expiration of the Lease, to display "For Lease" signs and such signs shall be placed upon such part of the Premises designated by Landlord. Furthermore, Landlord shall be permitted to enter the Premises at any time during normal business hours for the purposes of showing the Premises to new prospective tenants, (c) Landlord shall at all times have the option to retain a key with which to unlock all the doors in, upon and about the Premises. Tenant shall not change Landlord's lock system or in any manner prohibit Landlord from entering the Premises without Landlord's prior written consent. Landlord shall have the right to use any and all means which Landlord may deem proper to open any door in an emergency without liability therefor, (d) To change the Building's name or street address, (e) To establish controls for the purpose of regulating all property and packages (both personal and otherwise) to be moved into or out of the Building and Premises, (f) To regulate delivery and service of supplies in order to insure the cleanliness and security of the Building and Premises, (g) Within ten (10) days after written request, Landlord may require Tenant to furnish to Landlord reasonably requested financial information of Tenant, and (h) At any time hereafter, Landlord may (upon thirty (30) days prior written notice) substitute for the Premises other premises in the Property (herein referred to as the "**New Premises**"), provided that the New Premises shall be similar to the Premises in area and usable for Tenant's purposes; and if Tenant is already in occupancy of the Premises, Landlord shall pay the expenses of Tenant's moving from the Premises to the New Premises. Such move shall be made during evening, weekends, or otherwise so as to incur the least inconvenience to the Tenant. If Landlord moves Tenant to such New Premises, this Lease and each and all of its terms, covenants, conditions shall remain in full force and effect and be deemed applicable to such New Premises as though Landlord and Tenant had entered into an express written amendment of this Lease with respect thereto.

**SECTION 14 - DAMAGE TO PREMISES.** In the event of a partial destruction of the Premises during the Term from any cause, Landlord shall have the option to forthwith repair the same, provided that such repairs can be made within two hundred and seventy (270) days under the Laws and Tenant shall be entitled to a proportionate reduction of Rent while such repairs shall interfere with the business of Tenant at the Premises. If such repairs cannot be made within said two hundred and seventy (270) days, Landlord, upon agreement with Tenant, which shall not be unreasonably withheld, conditioned or delayed, may make the same within a reasonable time, with this Lease continuing in effect with the Rent proportionately reduced as aforesaid. In the event that Landlord shall not elect to make such repairs, or such repairs cannot be made within two hundred and seventy (270) days or an agreed upon extended period of time, or there is more than a partial destruction of the Premises, Landlord may elect to terminate this Lease. If Landlord is required to repair the Premises pursuant to this Section 14, its obligations shall be limited to the basic building, excluding, however, all work, alterations, fixtures, or signs installed by or for Tenant and all floor coverings, furniture, equipment and decorations; and Tenant shall, at Tenant's sole cost and expense,

promptly perform all repairs and restoration to the Premises not required to be done by Landlord and shall promptly re-enter the Premises and commence its business in all parts thereof upon its repair and restoration. Any damage caused by any intentional or negligent act of Tenant, its employees, agents or invitees shall be Tenant's responsibility and shall result in no Rent reduction.

#### **SECTION 15 - INDEMNIFICATION, TENANT INSURANCE SUBROGATION AND WAIVER OF CLAIMS**

**15.1** Tenant agrees to indemnify and hold harmless Landlord and Manager and their respective shareholders, members, partners, officers, directors, employees and agents from any claims arising from Tenant, Tenant's employees, agents, invitees, customers, visitors, contractors, sub-contractors, licensees or any other person or entity. Tenant hereby agrees to pay all costs, expenses, and attorney fees incurred by Landlord in connection with this Section 15. All of Tenant's personal property in the Premises shall be and remain at Tenant's sole risk. The agreements and indemnifications of Tenant set forth herein shall survive the termination or expiration of this Lease.

**15.2** Tenant covenants and agrees that from and after Possession, Tenant will carry and maintain, at its sole cost and expense, the following types of insurance, in no less than the amounts specified and in the form hereinafter provided for (Landlord shall have the right to reasonably increase the amount or expand the scope of insurance to be maintained by Tenant hereunder): (a) Commercial general liability insurance which (i) is written on an ISO CG 00 01 policy form or equivalent, (ii) insures without exclusion damage or injury arising from heat, smoke or fumes from a hostile fire, (iii) has limits of not less than: (A) \$1,000,000 per occurrence, (B) \$2,000,000 general aggregate per location, (C) \$2,000,000 products and completed operations aggregate, (D) \$1,000,000 for personal and advertising injury liability, (iv) includes coverage for "insured contracts", and (v) contains a standard separation of insured's provision, (b) Worker's compensation in statutory limits and with employer's liability insurance with limits of not less than \$100,000 for each accident, \$100,000 for each employee for bodily injury by disease, and \$500,000 policy limit for bodily injury by disease, (c) Excess liability/umbrella insurance, in addition to and in excess of the commercial general liability, business auto liability, worker's compensation and employer's liability insurance described herein, which insures against claims for bodily injury, personal injury, advertising injury and property damage and having limits of not less than \$5,000,000, (d) "Special Form" property insurance covering all of Tenant's personal property, inventory, equipment, fixtures, alterations and improvements at the Premises up to the replacement cost of such property, (e) Business income and extra expense insurance with limits of at least twenty-five percent (25%) of Tenant's gross revenue for a twelve (12) month period, (f) Business auto liability insurance which insures against bodily injury and property damage claims arising out of ownership, use or maintenance of any auto with a combined single limit per accident of not less than \$1,000,000, and (g) Errors and omissions insurance with limits of not less than \$1,000,000 per occurrence and \$2,000,000 general aggregate per location.

**15.3** All policies of insurance provided for in this Lease shall be issued in a form acceptable to Landlord by insurance companies having and maintaining an AM Best Rating of A- VII or better and qualified to do business in the state in which the Property is located. Each and every such policy: (a) shall name Landlord and Manager, as well as any mortgagee requested by Landlord, and any other party reasonably designated by Landlord, as an additional insured, (b) shall be delivered to Landlord prior to Possession, and thereafter within thirty (30) days prior to the expiration of each such policy, and, as often as any such policy shall expire or terminate (renewal or additional policies shall be procured and maintained by Tenant in like manner and to like extent), (c) shall contain a provision that the insurer will give to Landlord and such other parties in interest at least thirty (30) days' notice in writing in advance of any cancellation, termination or lapse, or the effective date of any reduction in the amounts of insurance, and (d) shall be written as a primary policy which does not contribute to and is not in excess of coverage which Landlord may carry.

**15.4** In the event that Tenant shall fail to carry and maintain the insurance coverages set forth in this Lease, Landlord may procure such policies and Tenant shall promptly reimburse Landlord for the premium costs thereof, plus a twenty percent (20%) convenience fee, plus interest at the maximum rate allowed by Law, compounded monthly from the date of payment by Landlord until repaid by Tenant.

**15.5** Tenant will not do anything on the Premises or permit the Premises to be used for any purpose or in any manner that would (i) void the insurance thereon, (ii) increase the insurance risk, (iii) cause the disallowance of any sprinkler credits, or (iv) cause the insurance to be cancelled. Tenant shall pay any increase in the cost of any insurance on the Premises, which is caused by Tenant's Use of the Premises, or because Tenant vacates the Premises.

**15.6** Tenant hereby waives any rights of subrogation against Landlord on account of any loss or damage occasioned to Tenant, Tenant's property, the Premises, its contents or to the other portions of the Property, arising from any risk covered by insurance policy or policies carried on the Premises. Tenant agrees to cause its insurance companies insuring the property of Tenant against any such loss, to waive any right of subrogation that such insurers may have against Landlord.

#### **SECTION 16 - ASSIGNING, MORTGAGING, SUBLETTING**

**16.1** Tenant shall not, without the prior written consent of Landlord in each instance, which consent shall be granted or withheld by Landlord in its sole discretion: (i) assign, mortgage, pledge, hypothecate, encumber, permit any lien to attach to, or otherwise transfer, this Lease or any interest hereunder, by operation of Law or otherwise, (ii) sublet the Premises or any part thereof, or extend, renew or modify any sublease, or (iii) permit the use of the Premises by any parties other than Tenant and its employees, whether as licensee, franchisee or otherwise (all of the foregoing are hereinafter referred to collectively as a "Transfer" and any party to whom any Transfer is made or sought to be made is hereinafter referred to as a "Transferee"). For purposes of this Lease, a Transfer shall also include the following, whether accomplished directly or indirectly: (i) if Tenant is a partnership or limited liability company, the withdrawal or change, voluntary, involuntary or by operation of Law, of a majority of the partners or members, as applicable, or a transfer of a majority of interests, in the aggregate on a cumulative basis, or the dissolution of the partnership or limited liability company, as applicable, and (ii) if Tenant is a corporation (other than a corporation whose stock is listed and traded on a nationally recognized stock exchange): (a) the dissolution, merger, consolidation or other corporate reorganization of Tenant, or (b) the sale or other transfer of more than a cumulative aggregate of fifty percent (50%) of the voting shares of Tenant, and (iii) the sale, mortgage, hypothecation or pledge of more than a cumulative aggregate of fifty percent (50%) of Tenant's net assets. Any Transfer made without complying with this Section 16 shall, at Landlord's option, be null, void and of no effect (which shall not be in limitation of Landlord's other remedies). Whether or not Landlord grants consent, Tenant shall pay an application fee of \$300.00 towards Landlord's review. If assignment is approved by Landlord, then Tenant shall pay a transfer fee equal to one month rent at the then current rate, as well as any reasonable legal fees, if any, incurred by Landlord in connection therewith.

**16.2** If Landlord consents to a Transfer: (i) Tenant and Guarantor(s) (as hereinafter defined) shall remain fully liable for all obligations under this Lease, including without limitation, those obligations such as Rent arising before and after the Transfer, and any Transferee shall expressly assume all of Tenant's obligations, (ii) such consent shall not be deemed consent to any further Transfer by either Tenant or a Transferee, (iii) Tenant shall deliver to Landlord promptly after execution, an original executed copy of all documentation pertaining to the Transfer in form reasonably acceptable to Landlord, and (iv) Landlord shall not be liable for any brokerage commission or other charge or expense in connection with such Transfer.

**16.3** When Tenant submits a Transfer application, it shall be deemed an offer from Tenant to Landlord whereby Landlord (or Landlord's designee) may, at its option and for any reason whatsoever, terminate this Lease (hereinafter, the "Landlord's Transfer Termination Option"). Said option may be exercised by Landlord by giving notice to Tenant given within sixty (60) days after such notice has been given by Tenant to Landlord; and during such sixty (60) day period Tenant shall not effectuate any Transfer.



**SECTION 17 - SUBORDINATION; ATTORNMENT.** This Lease is subject and subordinate to any and all mortgages now or hereafter placed by the Landlord on the Property of which the Premises are a part. Tenant agrees to execute any forms or agreements that may reasonably be requested by Landlord or any mortgagee within five (5) days of such request. If Tenant shall fail at any time to execute, acknowledge, and deliver any such form within the time required herein, Landlord, in addition to any other remedies available in consequence thereof, may execute, acknowledge, and deliver the same as Tenant's attorney-in-fact and in Tenant's name. Tenant hereby irrevocably makes, constitutes, and appoints Landlord, its successors, and assigns, its attorney-in-fact for the purpose.

**SECTION 18 - CUSTOM AND USAGE.** Any Law, usage, or custom to the contrary notwithstanding, Landlord shall have the right at all times to enforce the covenants and conditions of the Lease in strict accordance with the terms hereof, notwithstanding any conduct or custom on the part of Landlord in refraining from so doing at any time. The failure of Landlord at any time to enforce its rights under such covenants and conditions strictly in accordance with the same shall not be construed as having created a custom or estoppel in any way contrary to the specific covenants and conditions of the Lease or having in any way or manner modified the same.

**SECTION 19 - SURRENDER AND HOLDING OVER.** The Term of this Lease shall end on the final day thereof without the requirement of notice from either party to the other. Tenant, upon expiration or termination of the Lease shall peaceably surrender to Landlord the Premises in broom clean condition and in good repair as required in the Rules and Regulations. If Tenant remains in possession of the Premises with Landlord's consent but without a new Lease in writing and duly executed, Tenant shall be deemed to occupying the Premises as a Tenant from month to month. Rent shall be double (200%) the then current monthly Rent (hereinafter, the "**Holdover Rent**"), but otherwise subject to all the covenants and conditions of the Lease. Should Tenant remain in possession of the Premises without Landlord's prior written consent, such holding over shall be deemed to be that of a tenancy-at-will and in no event from month-to-month, and shall be subject to Holdover Rent. Should Landlord suffer harm from Tenant holding over without Landlord's consent, Tenant shall be liable to Landlord for such damages that Landlord incurs.

**SECTION 20 - CONDEMNATION.** If the whole of the Premises shall be taken or condemned by any competent authority, this Lease shall cease and terminate as of the date on which title shall vest thereby in that authority and the Rent reserved hereunder shall be apportioned and paid up to date. If only a portion of the Premises shall be taken or condemned, this Lease and the Term hereof, shall not cease or terminate, but the rent payable after the date on which Tenant shall be required to surrender possession of such portion shall be reduced in proportion to the decreased use suffered by Tenant as the parties may agree or as shall be determined by arbitration. In the event of any taking or condemnation in whole or in part, the entire resulting award of consequential damages shall belong to Landlord without any deduction therefrom for the value of the unexpired Term of this Lease or for any other estate or interest in the Premises now or later vested in Tenant. Tenant assigns to Landlord all its right, title, and interest in any and all such awards. However, Tenant shall not be prohibited from pursuing its own action for damages against the condemning authority.

**SECTION 21 - FORCE MAJEURE.** In the event that Landlord or Tenant shall be delayed or hindered in or prevented from doing or performing any act or thing required hereunder by reason of any matters beyond the reasonable control of either party, then that party shall not be liable or responsible for any such delays and the doing or performing of such act or thing shall be excused for the period of delay and the period for the performance of any such act shall be extended for a period equivalent to the period of such delay and this Lease. Notwithstanding anything herein, the obligations of Tenant to pay Rent hereunder and perform and comply with all of the terms and provisions of this Lease shall in no way be affected, impaired, or excused.

**SECTION 22 - ESTOPPEL STATEMENT.** Tenant and Guarantor(s) shall from time to time, within five (5) business days after written request from Landlord, execute, acknowledge and deliver a statement on Landlord's form: (a) certifying that this Lease is unmodified and in full force and effect or, if modified, stating the nature of such modification and certifying that this Lease as so modified, is in full force and effect (or if this Lease is claimed not to be in force and effect, specifying the grounds thereof) and the dates to which the Rent and all other charges hereunder have been paid, and the amount of any Security Deposit, (b) acknowledging that there are not, to Tenant's or Guarantor(s) knowledge, any uncured defaults on the part of Landlord hereunder, or specifying such defaults, if any are claimed, and (c) certifying such other matters as Landlord may reasonably request, or as may be requested by Landlord's current or prospective lenders, insurance carriers, auditors and prospective purchasers. Any such statement may be relied upon by any such parties. If Tenant or Guarantor(s) shall fail to execute and return such statement within the time required herein, Tenant and Guarantor(s) shall be deemed to have agreed with the matters set forth therein, and Landlord acting in good faith shall be authorized as Tenant's and/or Guarantor(s) attorney-in-fact to execute such statement on behalf of Tenant and/or Guarantor (which shall not be in limitation of Landlord's other remedies thereof).

### **SECTION 23 - DEFAULT AND LANDLORD'S REMEDIES**

**23.1** Any one or more of the following events at any time prior to or during the Term shall be considered a "**Default**": (a) failure by Tenant to pay when due any Rent; (b) failure by Tenant to observe or perform any term or condition of this Lease, other than the payment of Rent; (c) if Tenant shall fail to use and/or occupy the Premises in accordance with the terms hereof; or (d) (i) making by Tenant or Guarantor of any general assignment for the benefit of creditors, (ii) filing by or against Tenant or any Guarantor of a petition to have Tenant or such Guarantor adjudged bankrupt or a petition for reorganization or arrangement under any Law relating to bankruptcy or insolvency, (iii) appointment of a trustee or receiver to take possession of substantially all of Tenant's assets located in the Premises or of Tenant's interest in this Lease, (iv) attachment, execution or other judicial seizure of substantially all of Tenant's assets located on the Premises or of Tenant's interest in this Lease, (v) Tenant's or any Guarantor's convening of a meeting of its creditors or any class thereof for the purpose of effecting a moratorium upon or composition of its debt, or (vi) Tenant's or any Guarantor's insolvency or admission of an inability to pay its debts as they mature. Except as may be expressly provided by law, nothing contained in this **Section 23** or otherwise shall be deemed to require Landlord to give the notices herein provided for prior to the commencement of a summary proceeding for non-payment of Rent or for recovery of Rent on account of any Default in the payment of the same, it being intended that such notices are for the sole purposes of creating a conditional limitation hereunder pursuant to which this Lease shall terminate and if Tenant thereafter remains in possession after such termination, Tenant shall do so as a tenant holding over without the consent of Landlord as further described in **Section 19**. If Tenant fails more than twice within any twelve (12) month period to observe or perform any covenant, condition, or agreement of this Lease (including without limitation the payment of Rent), regardless of whether such Defaults shall have been cured by Tenant, the third (3<sup>rd</sup>) Default shall, at the election of Landlord, in its sole and absolute discretion, be deemed a non-curable Default.

**23.2** Upon a Default, as provided for in **Section 23.1**, or upon the termination of this Lease for any other reason whatsoever, or if Tenant is in Default under this Lease, Landlord shall have the rights and remedies hereinafter set forth to the extent permitted by Law, which shall be distinct, separate and cumulative with and in addition to any other rights and remedies allowed under any Law or other provisions of this Lease: (a) Landlord may immediately, or at any time after such Default or after the date upon which this Lease and the Term shall expire and come to an end, re-enter the Premises or any part

thereof, either (i) by force or otherwise, (ii) by summary proceedings or other applicable action or proceeding, (b) Landlord, at Landlord's option, may relet the whole or any part or parts of the Premises from time to time to such tenant or tenants, for such term or terms that Landlord elects, in its sole judgment (Landlord shall have no obligation to relet the Premises or any part thereof), and (c) Tenant, on its own behalf and on behalf of all persons claiming through or under Tenant, including all creditors, does further hereby waive any and all rights which Tenant and all such persons might otherwise have under any present or future Law to redeem, repossess, or reinstate the Premises or Lease, after (i) Tenant shall have been dispossessed by a judgment of possession or by warrant of eviction issued by any court, (ii) any entry by Landlord, or (iii) any expiration or termination of this Lease and the Term, whether such dispossession, re-entry, expiration or termination shall be by operation of Law or pursuant to the provisions of this Lease. The words "re-enter", "re-entry" and "re-entered" as used in this Lease shall not be deemed to be restricted to their technical legal meanings.

**23.3** If this Lease and the Term shall expire and come to an end for any reason whatsoever, or if Landlord shall re-enter the Premises, then, in any of said events: (a) Tenant shall pay to Landlord all Rent and other charges payable under this Lease by Tenant to Landlord to the date upon which this Lease and the Term shall have expired and come to an end or to the date of re-entry upon the Premises by Landlord, as the case may be; (b) Tenant also shall be liable for and shall pay to Landlord, as damages, any deficiency between the Rent reserved in this Lease for the period which otherwise would have constituted the unexpired portion of the Term and the net amount, if any, of rents collected under any reletting by Landlord affected pursuant to this Lease for any part of such period (first deducting from the rents collected under any such reletting all of Landlord's expenses in connection with the termination of this Lease, or Landlord's re-entry upon the Premises and with such reletting, including, but not limited to, all repossession costs, brokerage commissions, advertising, legal expenses, attorneys' fees and disbursements, expenses incurred by Landlord for any repairs, maintenance, changes, alterations and improvements to the Premises (whether to prevent damage or to prepare the Premises for reletting), any economic incentives given to enter leases with replacement tenants, costs of collecting rent from replacement tenants, and other expenses of preparing the Premises for such reletting (hereinafter, the "**Costs of Reletting**") (altogether hereinafter, the "**Deficiency**"). Any such Deficiency shall be paid in monthly installments by Tenant on the days specified in this Lease for payment of installments of Rent, Landlord shall be entitled to recover from Tenant monthly, the Deficiency as the same shall arise, and no suit to collect the amount of the Deficiency for any month shall prejudice Landlord's right to collect the Deficiency for any subsequent month by a similar proceeding. Landlord shall at all times have the right without prior demand or notice except as required by applicable Law to seek any declaratory or other equitable relief and sue for and collect any unpaid Rent which has accrued; or (c) Whether or not Landlord shall have collected any monthly Deficiency as aforesaid, Landlord shall be entitled to recover from Tenant, and Tenant shall pay to Landlord, on demand, in lieu of any further Deficiency and for liquidated and agreed final damages, a sum equal to the amount by which the Rent reserved in this Lease for the period which otherwise would have constituted the unexpired portion of the Term exceeds the then fair and reasonable rental value of the Premises for the same period, taking into account among other things, the condition of the Premises, market conditions and the period of time the Premises may reasonably remain vacant before Landlord is able to re-lease the same to a suitable replacement tenant, and Costs of Reletting that Landlord may incur in order to enter such replacement lease, less the aggregate amount of Deficiency theretofore collected by Landlord pursuant to the provisions of Section 23.3(b) for the same period. If, before presentation of proof of such liquidated damages to any court, commission or tribunal, the Premises, or any part thereof, shall have been relet by Landlord for the period which otherwise would have constituted the unexpired portion of the Term, or any part thereof, the amount of rent reserved upon such reletting shall be deemed, prima facie, to be the fair and reasonable rental value for the part or the whole of the Premises so relet during the term of the reletting. For purposes of computing the amount of Rent herein that would have accrued after the Expiration Date, Tenant's obligation for taxes, expenses and all other charges hereunder shall be projected, based upon the average rate of increase, if any, in such items from the Commencement Date through the Expiration Date.

**23.4** If this Lease or Tenant's right to possession is terminated, or Tenant vacates or abandons the Premises, Landlord may enter and secure the Premises, remove any property of Tenant therein, perform any alterations as Landlord shall determine in Landlord's sole discretion to prevent damage or deterioration to the Premises or prepare the same for reletting.

**23.5** Landlord shall be under no obligation to observe or perform any provision of this Lease on its part to be observed or performed which accrues after the date of any Default by Tenant.

**SECTION 24 - SECURITY DEPOSIT.** Tenant shall deposit with Landlord the amount set forth in Section 1 as the Security Deposit upon Tenant's execution and submission of this Lease by means reasonably acceptable to Landlord. The Security Deposit shall serve as security for the prompt, full and faithful performance by Tenant of the terms and provisions of this Lease. If Tenant shall Default hereunder, or owes any amount to Landlord upon the expiration of this Lease, Landlord shall have the right to draw down the entire Security Deposit and apply the proceeds or any part thereof for the payment or performance of Tenant's obligations hereunder. The use or application of the Security Deposit shall not prevent Landlord from exercising any other right or remedy available to Landlord and shall not be construed as liquidated damages. If Landlord shall have drawn down the Security Deposit and applied all or a portion thereof in accordance with the terms of this Section 24, then Tenant shall deposit with Landlord, within three (3) business days after notice from Landlord, a sufficient amount to bring the balance of the Security Deposit held by Landlord under this Section 24 to the amount of the Security Deposit as set forth in Section 1. Provided Tenant shall not be in Default, any remaining portion of the Security Deposit shall be returned to Tenant within sixty (60) days after the later of: (i) the Expiration Date, as may be amended, or (ii) the date that Tenant has vacated the Premises.

**SECTION 25** - Intentionally Deleted

**SECTION 26 - LIABILITY OF LANDLORD.** Tenant shall look solely to Landlord's interest in the Property for the satisfaction of any judgment or decree requiring the payment of money by Landlord, based upon any default hereunder, and no other property or asset of Landlord shall be subject to levy, execution, or enforcement procedure for the satisfaction of such judgment or decree.

**SECTION 27 - LEGAL EXPENSES.** In the event that it shall become necessary for Landlord or Tenant to employ the services of an attorney to enforce any of its rights under the Lease or to collect any sums due to it under the Lease or to remedy the breach of any covenant of the Lease on the part of either party to be kept or performed, the prevailing party shall be entitled to such reasonable fees and costs for such services be reimbursed by the other party. Should suit be brought for the recovery of possession of the Premises, or for Rent or any other sum due Landlord under the Lease, or because of the breach of any of Tenant's covenants under the Lease, Landlord shall be entitled to recover its reasonable attorney's fees and costs, including such fees and costs on appeal. Any such legal fees are considered Additional Rent for the purpose of this Lease.

**SECTION 28 - EASEMENTS, AGREEMENTS, OR ENCUMBRANCES.** The parties shall be bound by all existing and future easements, agreements, and encumbrances of record relating to the Premises including, but not limited to any deed or plat restrictions, and Rules and Regulations (as hereinafter defined) governing the Premises and the Property or any part thereof, as same may be amended.

**SECTION 29 - TIME OF THE ESSENCE.** Time is of the essence with respect to all provisions of this Lease.

**SECTION 30 - QUIET ENJOYMENT.** Landlord warrants that Tenant shall be granted peaceable and quiet enjoyment of the Premises free from any eviction or interference by Landlord if Tenant pays the Rent and other charges provided herein and otherwise fully and punctually performs and complies with the terms, conditions and provisions of this Lease.

**SECTION 31 - SIGNS.** Landlord shall install a Building standard sign by the entrance door for the Tenant to the Premises in a location and design to be specified by the Landlord. In addition, Tenant's name and suite number shall be included in Building's two (2) lobby directories, located on the north and south entrances, at no cost to Tenant. Any future signage changes or modifications shall be at Tenant's sole cost and expense. Within fifteen (15) days from the date of execution of the Lease, Tenant shall provide to Landlord its signage plans for the subject Premises for Landlord's review and approval. Tenant shall have five (5) days after receipt of Landlord's comments on such plans to make all necessary revisions and obtain Landlord's approval.

**SECTION 32 - SCOPE AND INTERPRETATION OF AGREEMENT.** The Lease and all Exhibits attached hereto set forth all of the covenants, promises, agreements, conditions, and understandings between Landlord and Tenant concerning the Premises and there are no covenants, promises, conditions, or understandings either oral or written between them other than herein set forth. Upon execution of the Lease, any and all proposals and/or letters of intent shall be superseded by the Lease. Except as otherwise provided, no subsequent alteration, change or addition to the Lease shall be binding upon the Landlord or Tenant unless reduced to writing and signed by both parties. Tenant also acknowledges and agrees that any subsequent renewal, extension, modification, or exercise of option period, if any option included, of this Lease of any type shall be conducted directly between the Tenant and Landlord without participation of any third-party or in-house real estate brokers which would require payment of a commission thereon. Should either Landlord or Tenant utilize any third-party or in-house real estate brokers which would require payment of a commission or fees of any type, the party requesting and utilizing the services of the particular broker shall be responsible for any and all fees or commissions incurred for the services of the broker related to the transaction. The law of the State of Tennessee shall govern the validity, interpretation, performance and enforcement of the Lease. The Lease shall not be more strictly enforced against either party regardless of who was more responsible for its preparation. Except at Landlord's option, no part of this Lease may be recorded in any public records of any municipality or county records.

**SECTION 33 - INVALID PROVISIONS.** If any provision of the Lease shall be determined to be void by any court of competent jurisdiction or any law enacted subsequent to the date hereof, then such determination shall not affect any other provision hereof, all of which other provisions shall remain in full force and effect.

**SECTION 34 - CAPTIONS.** Any headings preceding the text of the provisions and sub-paragraphs hereof are inserted solely for convenience of reference and shall not constitute a part of the Lease, nor shall they affect its meaning, construction, or effect.

**SECTION 35 - SUCCESSORS AND ASSIGNS.** All rights, obligations and liabilities given to, or imposed upon, the parties hereto shall extend to and bind the respective heirs, executors, administrators, successors, subtenants, licensees, concessionaires and assigns of such parties, subject to the terms of Section 35 hereof. No rights, however, shall inure to the benefit of any Transferee unless the Transfer to such Transferee has been approved by Landlord in writing as set forth in Section 16. Nothing contained in the Lease shall in any manner restrict Landlord's right to assign or encumber the Lease, or to modify the Manager listed herein, and in the event Landlord sells its interest in the Property and the purchaser assumed Landlord's obligations and covenants, Landlord (and Manager, if applicable) shall thereupon be relieved of all obligations hereunder.

**SECTION 36 - NOTICES.** Wherever in the Lease it shall be required or permitted that notice or demand be given or served by either party to or on the other, such notice or demand shall not be deemed to have been duly given or served unless in writing and (i) personally delivered, (ii) sent by registered or certified mail postage prepaid or equivalent of such, or (iii) sent by a nationally recognized overnight courier such as UPS or FedEx, in each case to the notice addresses set forth in Section 1 of this Lease. Such notice addresses may be changed from time to time by either party by serving notice, as above provided. If service of any notice is effected by registered or certified mail, delivery shall be deemed to have occurred two (2) business days after mailing, and by personally delivered or by a nationally recognized overnight courier, on the date of delivery.

**SECTION 37 - REAL ESTATE BROKER(S).** Landlord and Tenant warrant and represent to each other that, except for the Real Estate Broker(s) described in Section 1, no broker was involved on its behalf in negotiating or consummating this Lease, and each party agrees to indemnify, and hold the other harmless from and against any and all claims for brokerage commissions, arising out of any communications or negotiations conducted by such party with any broker, regarding the Premises, or any other premises in the Property, and/or the consummation of this Lease. Landlord shall be responsible for any compensation payable to the Real Estate Broker(s) pursuant to a separate agreement between Landlord and the Real Estate Broker(s).

**SECTION 38 - RULES AND REGULATIONS.** Tenant covenants and agrees to obey the Rules and Regulations as set forth and made a part hereof as Exhibit B.

**SECTION 39 - CONFIDENTIALITY.** Tenant hereby agrees to keep all of the terms and conditions of this Lease, as well as any other subsequent agreements, whether or not they are in writing, confidential and shall not share any of the terms or conditions of this Lease with anyone. The agreements of Tenant set forth in this Section 39 shall survive the termination or expiration of this Lease.

**SECTION 40 - TELECOMMUNICATIONS**

**40.1** Tenant acknowledges and agrees that all telephone, telecommunications, computer networking and other related services desired by Tenant shall be ordered and utilized at the sole expense of Tenant. Except as may be specified elsewhere in this Lease, unless Landlord otherwise requests or consents in writing, all of Tenant's telecommunications equipment shall be and remain solely in the Premises and, in accordance with rules and regulations adopted by Landlord from time to time, the telephone closets on the floors on which the Premises is located. Landlord shall have no responsibility for the maintenance of Tenant's telecommunications equipment, including wiring, nor for any wiring or other infrastructure to which Tenant's telecommunications equipment may be connected. Tenant agrees that to the extent any such service is interrupted, curtailed or discontinued, Landlord shall have no obligation or liability with respect thereto and it shall be the sole obligation of Tenant at its expense to obtain substitute service.

**40.2** Any and all telecommunications equipment installed in the Premises or elsewhere in the Building by or on behalf of Tenant, including wiring, or other facilities for telecommunications transmittal, shall be removed prior to the expiration or earlier termination of the Term, by Tenant at its sole cost, or at Landlord's election, by Landlord at Tenant's sole cost, with the cost thereof to be paid as Additional Rent. Landlord shall have the right, however,

upon written notice to Tenant given no later than thirty (30) days prior to the expiration or earlier termination of the Term, to require Tenant to abandon and leave in place, without additional payment to Tenant or credit against Rent, any and all telecommunications wiring and related infrastructure, or selected components thereof, whether located in the Premises or elsewhere in the Building.

**40.3** Except as may be specified elsewhere in this Lease, Tenant shall not utilize any wireless communications equipment (other than usual and customary cellular telephones and wireless internet), including antenna and satellite receiver dishes, within the Premises or the Building, without Landlord's prior written consent. Without limiting the foregoing, Landlord reserves the right to condition its consent upon Tenant's agreement to pay to Landlord a reasonable charge for the right to utilize any communications equipment as described in this Section 40.3.

**40.4** In the event telecommunications equipment, wiring and facilities installed by or at the request of Tenant within the Tenant's Premises, or elsewhere within or on the Building causes interference to equipment used by another party, Tenant shall assume all liability related to such interference. Tenant shall use reasonable efforts, and shall cooperate with Landlord and other parties, to promptly eliminate such interference. In the event that Tenant is unable to do so, Tenant will substitute alternative equipment which remedies the situation. If such interference persists, Tenant shall discontinue the use of such equipment, and, at Landlord's discretion, remove such equipment according to the foregoing specifications.

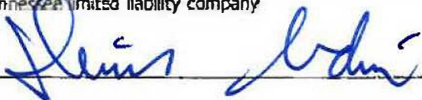
**SECTION 41 – WAIVER OF TRIAL BY JURY.** To the extent permitted by Law, Landlord and Tenant hereby mutually waive any right to trial by jury in any action, proceeding or counterclaim brought by either party on any matters whatsoever arising out of or in any way connected with this Lease, the relationship of Landlord and Tenant, the Premises, and/or the Property.

**SECTION 42 – CONTINGENCY.** This lease is contingent upon Tenant providing to Landlord the Certificate of Need (the "CON") presented by the Health Services and Development Agency for the State of Tennessee to Tenant for the Licensure of Hospice Services. Such CON is to be delivered to Landlord no later than April 30, 2024. Should the CON not be delivered to Landlord by such date, then this Lease will become null and void.

*Signatures on following page*

This Lease may be executed in two or more counterparts, each of which shall be deemed an original, but all of which taken together shall constitute one in the same instrument. Tenant expressly agrees that if the signature of Landlord and/or Tenant on this Lease is not an original, but is a digital, mechanical, or electronic reproduction (such as, but not limited to, a photocopy, fax, or email), then such signature shall be as enforceable, valid, and binding as, and the legal equivalent to, an authentic and traditional ink-on-paper original wet signature penned manually by its signatory. The parties hereto further agree to be bound by all terms and provisions of this Lease, including, without limitation, all exhibits and amendments, which are made a part hereof. The following Exhibits, if any, have been made a part of this Lease before the parties' execution hereof: Exhibit A, Exhibit B, Exhibit C, Exhibit D, and Exhibit E.

Landlord:  
Lynnfield Office Project, LLC,  
a Tennessee limited liability company

By: 

Print Name: Dennis Udwin

Print Title: President

Tenant:  
Heart and Soul Hospice  
Memphis, LLC,  
a Tennessee limited liability company

By: 

Print Name: Sandy McClain

Print Title: \_\_\_\_\_

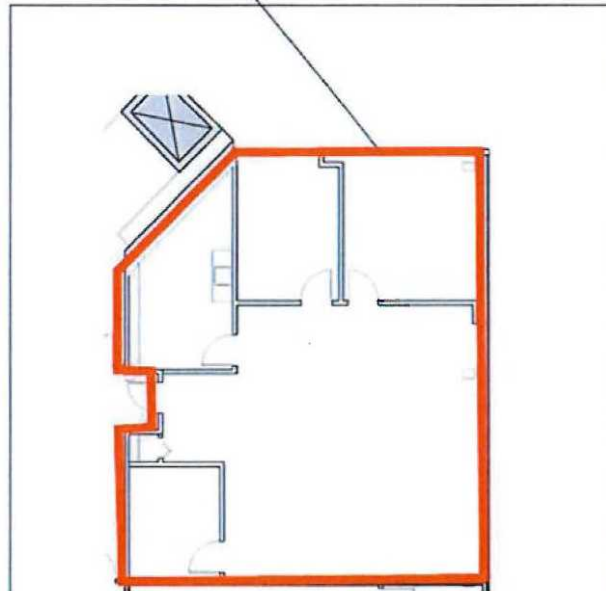
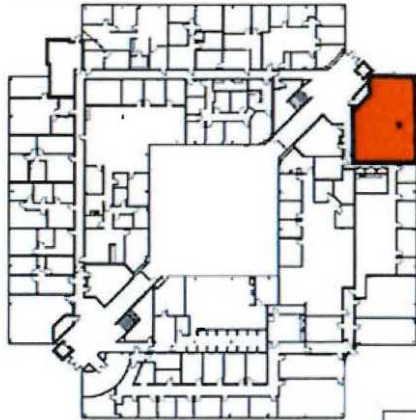


**EXHIBIT A**

**PREMISES**

This floor plan is diagrammatic only, is intended only to be a general description of the Premises as of the date of this Lease, and is not intended to show the exact dimensions or configuration of the Premises.

**Building A – 1255 Lynnfield Rd**  
**2<sup>nd</sup> Floor**



**1 FLOOR PLAN SUITE 258**  
SCALE: 1/8" = 1'-0"  
OFFICE AREA: 1,800 RSF

LYNNFIELD OFFICE PARK A



PROJECT # CLARK  
DATE 6/15/13  
DRAWN BY KD

**BD**

## EXHIBIT B

### RULES AND REGULATIONS

Tenant covenants and agrees with Landlord to obey the following Rules and Regulations (hereinafter, the "Rules"):

1. **Common Areas.** Tenant shall not use the common areas of the Property, including areas adjacent to the Premises, for any purpose other than ingress and egress, and any such use thereof shall be subject to the other provisions of this Lease, including these Rules.
2. **Deliveries.** Fixtures, furniture, inventory and all other deliveries may be brought into the Property only at times, in the location and manner designated by Landlord, in compliance with all Laws, at Tenant's sole risk.
3. **Processing.** Whenever Tenant shall submit to Landlord any plan, agreement or other document for the consent or approval of Landlord, Tenant shall pay to Landlord, on demand, and as an Additional Rent hereunder, a processing fee in the amount of the reasonable fees for review and negotiation thereof, including the services of any architect, engineer, attorney or other consultant or professional employed by Landlord to review such plan, agreement or document.
4. Intentionally Deleted.
5. Intentionally Deleted.
6. **Signs and Display Windows.** Tenant shall not place, erect or maintain or permit to be placed, erected or maintained any sign or other thing of any kind outside the Premises (including without limitation, exterior walls and roof, or the Property signage), or on the interior or exterior surfaces of glass panes or doors, except such single sign as Landlord shall expressly approve in writing for or in connection with Tenant's entryway (collectively, "Tenant's Signage"). Tenant's Signage shall comply with the sign criteria adopted from time to time by Landlord and shall comply with other requirements relating to Tenant's Signage (collectively, the "Sign Criteria") which Landlord may impose with respect thereto. Tenant acknowledges and agrees that all aspects of Tenant's Signage are subject to Landlord's advance written approval. All Tenant's signs shall be professionally designed, prepared and installed, in good taste and first class in all respects so as not to detract from the appearance of the Premises as a first class business or the Property and shall comply with the Sign Criteria adopted by Landlord from time to time. Blinds, shades, drapes, window tint or other such items shall not be placed in or about the windows in the Premises except to the extent, if any, that the character, shape, design, color, material and make thereof is first approved by Landlord in writing. Any approval by Landlord pursuant to this Rule 6 may be granted or withheld by Landlord in its sole and absolute discretion. If Tenant places, erects or maintains or permits to be placed, erected or maintained, any sign in violation of the foregoing terms of this Rule 6, such sign may be removed by or on behalf of Landlord without notice and without such removal constituting a breach of this Lease or entitling Tenant to claim damages on account thereof. Landlord's approval sought by Tenant pursuant to this Rule 6 may be granted or withheld in Landlord's sole discretion.
7. **Plumbing Equipment.** The toilet rooms, urinals, wash bowls, sinks (including mop sinks, if applicable), drains and sewers and other plumbing fixtures, equipment and lines, whether in the Premises or common areas, shall not be misused or used for any purpose other than that for which they were constructed and no foreign substance of any kind whatsoever shall be thrown therein.
8. **Roof, Awnings and Projections.** Tenant shall not install any antennae, satellite dish or any other device on the roof, exterior walls or common areas of the Property without Landlord's prior written approval, which approval Landlord may grant or withhold in its sole discretion.
9. **Overloading Floors.** Tenant shall not place or allow a load on any floor in the Property which exceeds the floor load per square foot which such floor was designed and is permitted to carry including any public corridors or elevators therein, and Landlord may direct and control the location of safes, vaults and all other heavy articles and require supplementary supports of such material and dimensions as Landlord may, in its sole discretion deem necessary to properly distribute the weight at Tenant's expense (including expenses for structural review and engineering).
10. **Locks and Keys.** Landlord will provide Tenant with one (1) key to the Premises and one (1) access card (if applicable). Any additional keys and/or access cards shall be at Landlord's current rate at the time of such request. Upon termination of the Lease or Tenant's right to possession, Tenant shall: (a) return to Landlord all keys or access cards, and in the event of loss of any such items shall pay Landlord therefor, and (b) advise Landlord as to the combination of any vaults or locks that Landlord permits to remain in the Premises.
11. **Unattended Premises.** Before leaving the Premises unattended, Tenant shall close and securely lock all doors or other means of entry to the Premises and shut off all lights, water faucets and other controllable utilities in the Premises (except heat to the extent necessary to prevent the freezing or bursting of pipes). This provision shall not imply that Tenant may leave the Premises unattended in violation of the operating requirements set forth elsewhere in this Lease.
12. **Energy Conservation.** Tenant shall not waste electricity, water, heat or air conditioning, or other utilities or services, and agrees to cooperate fully with Landlord and comply with any Laws to assure the most effective and energy efficient operation of the Property.
13. **Labor Relations.** Tenant shall not, at any time prior to or during the Term, directly or indirectly employ, or permit the employment of, any contractor, mechanic or laborer in or with respect to the Premises, whether in connection with any work or otherwise, if in Landlord's sole judgment, such employment will (or is likely to) interfere or cause any conflict with other contractors, mechanics or laborers engaged in the construction, maintenance or operation thereof by Landlord, Tenant or others. In the event of any such interference or conflict, Tenant, upon demand of Landlord, shall cause all contractors, mechanics or laborers causing such interference or conflict to leave the Property immediately. If Tenant fails to cease such interference or conflict, Landlord, in addition to any other rights available under this Lease and pursuant to Law, shall have the right to seek an injunction with or without notice in accordance with applicable Laws. Tenant shall be required to submit a valid certificate of insurance for any vendors/contractors employed by tenant, scope of work should also be submitted to Landlord for approval to ensure they are in compliance with the Laws and the Rules.
14. **Landlord's Tradename and Trademarks.** No symbol, design, name, mark or insignia adopted by Landlord for the Property or picture or likeness of the Property shall be used by Tenant without the prior written consent of Landlord, which consent may be granted or withheld in Landlord's sole discretion.
15. **Parking.** In addition to Landlord's rights relating to parking of Tenant's and its employee's vehicles set forth in the Lease, no parking shall be permitted overnight, except with Landlord's prior written consent. Landlord does not provide safekeeping, nor shall it be deemed an insurer for any vehicles or their contents that are parked at any time on the Property. Landlord shall not be responsible for fire, theft, damage or losses of any kind to any vehicle.
16. **Prohibited Activities.** Tenant shall not: (i) operate any loudspeaker, television set, phonograph, radio or other musical or sound producing instrument or device which is audible outside the Premises, (ii) operate any electrical or other device which interferes with or impairs radio, television, microwave or other broadcasting or reception from or in the Property or elsewhere, (iii) bring or permit any bicycle, moped, scooter or other vehicle, or dog (except in the company of a blind party) or other animal, fish or bird in the Property, (iv) make or permit objectionable noise, vibration or odor to emanate from the Premises or any equipment serving the same, (v) do or permit anything in or about the Property that is unlawful, immoral, obscene or pornographic, or any sort of massage parlor or which, in Landlord's sole judgment, is likely to create or maintain a nuisance, or do or permit anything in

or about the Property that is likely to injure the reputation of the Property, (vi) use or permit upon the Premises anything that violates the certificates of occupancy issued for the Premises or the Property, and Tenant shall comply with all requirements of Landlord's insurance carriers, the American Insurance Association, and any board of fire underwriters, (vii) use the Premises for any purpose, or permit upon the Premises anything, that may be dangerous to parties or property (including but not limited to flammable oils, fluids, paints, chemicals, firearms or any explosive articles or materials), (viii) do or permit anything to be done upon the Premises in any way tending to disturb, bother or annoy any other tenant or occupant of the Property or the tenants or occupants of any neighboring property or Landlord, and (ix) clean or require, permit, suffer or allow any window in the Premises to be cleaned from the outside in violation of any other applicable Law or of any other board or body having or asserting jurisdiction.

**17. Responsibility for Compliance.** Tenant shall be responsible for ensuring compliance with the Rules by Tenant's employees and as applicable, by Tenant's agents, invitees, contractors, subcontractors and suppliers.

**18.** Tenant must inform Landlord of the actual date of Tenant's move (both into the Premises and out of the Premises), and such date must be mutually agreed to by Tenant and Landlord. All elevators, if applicable, must be padded and protected. The move will not take place during normal business hours, unless otherwise agreed. Additionally, Tenant must provide their moving company's certificate of insurance prior to the commencement of the move.

**19.** Prior to vacating the Premises, Tenant shall: (i) be certain all Rent is paid in full, (ii) discharge any liens placed on the Premises due to Tenant's action, (iii) clean the entire Premises, including any shelves or cabinets, and remove all debris and trash, (iv) vacuum and professionally clean all carpet(s) and submit receipt to Landlord, (v) patch and spackle all walls so they are ready for painting, (vi) submit keys and access cards to the Premises to Landlord, (vii) replace all burned out or missing light bulbs, (viii) clean all mini-blinds, verticals and other window treatments, including their tracks and repair and/or replace any verticals or slats as necessary, (ix) wash all windows and glass doors, (x) remove any decals or signage, and (xi) clean bathroom(s), if applicable.

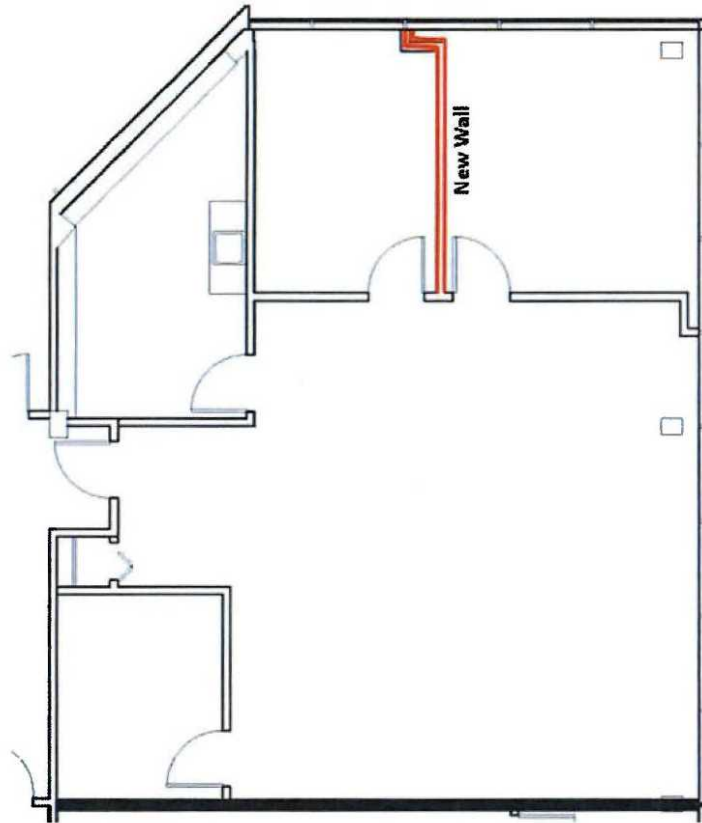
**20. Rules.** Landlord reserves the right to rescind, alter, waive or add, as to one or more or all tenants, any rule or regulation at any time prescribed for the Property when, in the reasonable judgment of Landlord, Landlord deems it necessary or desirable for the reputation, safety, character security, care, appearance or interests of the Property or any portion thereof, or the preservation of good order therein or the operation or maintenance of the Property or any portion thereof, or the equipment thereof, or the comfort of the tenants or others therein. No rescission, alteration, waiver or addition of any rule or regulation in respect of one tenant shall operate as a rescission, alteration or waiver in respect of any other tenant.

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**EXHIBIT C**  
**INTENTIONALLY DELETED**

**EXHIBIT D**

**LANDLORD'S WORK: SCOPE OF WORK**



Landlord shall perform the following scope of work to the Premises, utilizing building-standard finishes:

- 1) Construct new wall to split the existing large room into 2 private offices; location as shown above in red
- 2) Apply paint to new wall, color to match existing
- 3) Install new cove base to match existing
- 4) Clean existing carpet and existing LVT flooring throughout the Premises

Please note that except for the above-referenced Landlord's Work, Tenant shall accept Premises in its current **AS-IS Condition**.

**EXHIBIT E**

**LANDLORD'S NOTICE OF COMPLETION AND COMMENCEMENT – EXAMPLE ONLY**

Dear {NAME},

Referring to the Lease dated [LEASE DATE] between [LANDLORD] and [TENANT] for the Premises located at the [BUILDING NAME], [SUITE ADDRESS] (the "Lease"), all stipulations have been met for the Term and Rent to commence as set forth in the Lease. All capitalized terms used herein shall have the meanings attributed to them in the Lease, unless otherwise expressly stated herein, or unless the context hereof requires otherwise.

The following dates/terms shall now apply:

- The Commencement Date shall now mean [DATE];
- The Expiration Date shall now mean [DATE];
- The Base Rent shall be as set forth in the following schedule:

[RENT SCHEDULE]

Please acknowledge your agreement to the dates set forth above by signing below. If you fail to execute this agreement within five (5) days of receipt, it shall be understood that the contents of this agreement are correct.

Kind Regards,  
{LANDLORD}

Content Agreed To:

By: \_\_\_\_\_

Print Name: \_\_\_\_\_

Print Title: \_\_\_\_\_

Date: \_\_\_\_\_

## List of Licensed Hospice Agencies in Proposed Service Area by County

### **Fayette County**

Number of Agencies Licensed for County: 8

1. Avalon Hospice (Davidson) (State ID No. 19694)
2. AccentCare Hospice & Palliative Care of TN, LLC (Shelby) (State ID No. 79716)
3. Amedisys Hospice Care (Shelby) (State ID No. 79646)
4. Baptist Trinity Home Care & Hospice (Shelby) (State ID No. 79616)
5. Caris Healthcare (Shelby) (State ID No. 24606)
6. Compassus – Memphis (Shelby) (State ID No. 79686)
7. Crossroads Hospice of Tennessee, LLC (Shelby) (State ID No. 79676)
8. Methodist Alliance Hospice (Shelby) (State ID No. 79666)

### **Shelby County**

Number of Agencies Licensed for County: 9

1. Avalon Hospice (Davidson) (State ID No. 19694)
2. AccentCare Hospice & Palliative Care of TN, LLC (Shelby) (State ID No. 79716)
3. Amedisys Hospice Care (Shelby) (State ID No. 79646)
4. Baptist Trinity Home Care & Hospice (Shelby) (State ID No. 79616)
5. Caris Healthcare (Shelby) (State ID No. 24606)
6. Compassus – Memphis (Shelby) (State ID No. 79686)
7. Crossroads Hospice of Tennessee, LLC (Shelby) (State ID No. 79676)
8. Hope Hospice & Palliative Care (Shelby) (State ID No. 79726)
9. Methodist Alliance Hospice (Shelby) (State ID No. 79666)

### **Tipton County**

Number of Agencies Licensed for County: 8

1. Avalon Hospice (Davidson) (State ID No. 19694)
2. AccentCare Hospice & Palliative Care of TN, LLC (Shelby) (State ID No. 79716)
3. Amedisys Hospice Care (Shelby) (State ID No. 79646)
4. Baptist Trinity Home Care & Hospice (Shelby) (State ID No. 79616)
5. Caris Healthcare (Shelby) (State ID No. 24606)
6. Compassus – Memphis (Shelby) (State ID No. 79686)
7. Crossroads Hospice of Tennessee, LLC (Shelby) (State ID No. 79676)
8. Methodist Alliance Hospice (Shelby) (State ID No. 79666)





Heart'n Soul  
Hospice

## Cardiac Journey<sup>®</sup>

### Health Providers Tip Sheet

#### WHEN IS IT TIME TO CONSIDER HOSPICE?

Like many other chronic and debilitating diseases, CHF, CAD, and heart disease are terminal illnesses. Many family members and physicians agree the primary focus for these individuals should be disease and symptom management at home where they are most comfortable. Primary symptoms to look for in making a referral are:

#### NYHA CLASS 4

##### 1. Maybe you have seen a cycle of increasing symptoms including:

- Increased weight gain/edema/ascites
- Increased pulmonary congestion
- Increased shortness of breath
- Decreased activities
- Fatigue
- Anxiety
- Poor appetite
- Increased weakness
- Weight loss
- Supine for 50% of the day
- Increase sleeping
- Oxygen use

##### 2. High volume of phone calls to your office and family overwhelmed by management of care regime at home.

##### 3. Is your patient not able to carry on any physical activity without discomfort?

##### 4. Does your patient have significant symptoms at rest?

##### 5. Does your patient have other co-existing illnesses such as pulmonary disease, diabetes, hypertension, renal disease, or other complicating factors contributing to the life limiting condition?

To make a referral, please call (615) 835-3822

Our goal is to admit all eligible patients within 2 hours of assessment.







**NYHA CLASS 4 (CONTINUED)**

- 6. Multiple hospitalizations or ER visits.**
- 7. Multiple office visits.**
- 8. Optimally treated with ACE inhibitors, Beta Blockers, diuretics, and vasodilators.**
- 9. History of cardiac arrest or resuscitation in any setting.**
- 10. History of unexplained syncope of any cause.**

**HOW CAN THE CARDIAC JOURNEY® PROGRAM BENEFIT  
MY END-STAGE CARDIAC DISEASE PATIENT?**

- **Primary goal is to maximize your patient's quality of life.**
- **A team approach to address medical, psychosocial, and spiritual needs of patients and their families.**
- **Frequent visits and phone calls.**
- **Specific protocols in place for symptom management of dyspnea, pain, anxiety, and edema.**
- **Education and support for the patient and families.**
- **Cardiac medications specific to the cardiac patient's needs for symptom control.**
- **Hospice nurse available 24-hours a day, 7 days a week.**
- **Support for patients as well as caregivers and families**

**To make a referral, please call (615) 835-3822**  
Our goal is to admit all eligible patients within 2 hours of assessment.





# COPD Journey<sup>®</sup>

## Health Providers Tip Sheet



### WHEN IS IT TIME TO CONSIDER HOSPICE?

- Patients with end-stage pulmonary disease (prognosis of 6 months or less to live if the disease runs its normal course) with the following can be admitted into the COPD Journey<sup>®</sup> Program:
- Severe chronic lung disease as documented by both a and b:
  - a. Disabling dyspnea at rest, poorly or unresponsive to bronchodilators, resulting in decreased functional capacity, e.g., bed to chair existence, fatigue, and cough.
  - b. Progression of end stage pulmonary disease, shown through increasing visits to the emergency department, declining lung function, or hospitalizations for pulmonary infections with respiratory failure or increasing physician home visits prior to initial certification.

### OTHER KEY CRITICAL FACTORS MAY INCLUDE:

- Recent hospitalizations or ER visits
- Tachypnea
- Hypoxemia despite oxygen therapy
- O<sub>2</sub> saturation level at 88% or below on room air
- Spending most of the time in bed or chair; difficulty breathing
- Steroid dependent
- FEV-1  $\leq$  30%

To make a referral, please call (615) 835-3822

Our goal is to admit all eligible patients within 2 hours of assessment.







# COPD Journey<sup>®</sup>

## Health Providers Tip Sheet



- Right heart failure (RHF) secondary to pulmonary disease (cor pulmonale) (e.g., not secondary to left heart disease or valvulopathy)
- Unintentional progressive weight loss of > 10% of body weight over the preceding six months
- Resting tachycardia >100/min.
- Progressive decline of activities of daily living (ADLs) as measured by:
  - Increasing daily medical management requirements for patient as well as family support at home being overwhelmed by management of care
  - Patient is not able to carry on any physical activity without discomfort
  - Patient has significant symptoms at rest

### **HOW CAN HEART'N SOUL HOSPICE'S COPD JOURNEY<sup>®</sup> PROGRAM BENEFIT MY END-STAGE COPD PATIENT?**

- Dedicated hospice team trained in COPD symptoms and therapies to maximize quality of life
- Symptom management for dyspnea, air hunger or pain
- Daily calls and/or visits from the hospice team
- Medication and equipment management
- 24/7 medical, emotional and spiritual support
- Dedicated on call professionals for COPD Journey<sup>®</sup> patients
- Symptom management guides, allowing patients and caregivers to maintain control of symptoms at home
- Patient and caregiver education
- Specialized emergency kit for acute situations to ensure symptom management

To make a referral, please call (615) 835-3822

Our goal is to admit all eligible patients within 2 hours of assessment.







# **UNITY** *in* **THE COMMUNITY**

**CONCERT & BENEFIT**

**SUNDAY, APRIL 21 • 4PM**

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**SHOWCASING THE RICH MUSICAL TALENTS IN OUR COMMUNITY  
& RAISING FUNDS FOR THE HEART 'N SOUL FOUNDATION  
FEATURING 5 LOCAL GOSPEL CHOIRS**

---

**MT. CALVARY MADISON**  
1238 BRIARVILLE RD. MADISON, TN 37115





# Bartlett "Bart" Chesterfield Durham



**View  
memory  
board**



**Share  
obituary**



**Listen to  
this story**



**Send  
flowers**



**Plant a tree**

Bartlett "Bart" Chesterfield Durham of Nashville, Tennessee, passed away on Tuesday, April 9, 2024, at the age of 89. Known to the public as the founder and face of Nashville-based personal injury firm Bart Durham Injury Law, Bart was best known as a beloved husband, father, and grandfather, as well as a caring lawyer and employer. Bart also was a member of Nashville Korean Presbyterian Church along with his wife, Cindy (Sin Young Kang).

Bart was born on March 5, 1935, and raised in Ripley, Tenn., by his parents B.C. and Nelle (Pierson) Durham. He was a small-town boy with humble beginnings who attributed his life's successes to hard work, others' investments in him and luck.

Before his career in law began, Bart first served in the U.S. Army for two years and spent time in Germany. He attended the University of Tennessee in Knoxville but finished his degree at Southern Law University in Memphis. Bart's appreciation for his education inspired him to be a life-long learner and, later, to financially support numerous individuals – inside and outside of his family, including team members at his firm – in their pursuits of higher education.

Upon graduation, Bart passed the Tennessee Bar Exam in 1963 and began practicing law in his hometown alongside his father. Soon after, Bart served with the U.S. Department of Justice in Memphis, a career experience Bart called “the opportunity of a lifetime,” where he and his colleagues prosecuted and defended all cases in the 33 counties of West Tennessee.

Bart's modest self-esteem as “a nobody” and “night law school graduate” – compared to his “smarter, more experienced, and certainly more sophisticated” colleagues – fueled his work ethic to arrive at the office early and leave late. It also instilled a habit he kept throughout his life: to reflect and remember how lucky he was.

Bart moved to Nashville in 1969 for a job as a prosecuting attorney in the State Attorney General's Office. In charge of federal civil rights cases throughout the state, Bart appeared regularly in every U.S. District Court from Memphis to East Tennessee and argued more than 100 cases before the U.S. Court of Appeals in Cincinnati, Ohio. Arguing three cases before the U.S. Supreme Court was also among Bart's proudest accomplishments.

Then, in 1975, with “no clients, just a little bit of money saved, the optimism of youth and high hopes,” Bart went into private practice with his peer, Henry Haile. Before long, Bart was the first lawyer in Tennessee to advertise his services in print, on the radio and TV, and thousands of Tennesseans grew up seeing his face on their home television sets. In his faithful pursuit of justice for victims of personal tragedies, Bart became known as a voice for the underserved.

Bart went on to represent thousands of personal injury cases, and he was named a Senior Counselor by the Tennessee Bar Association. He employed many fine lawyers and team members, including his youngest son, Blair, whom he thoroughly enjoyed working with. Unwilling to retire because of his love for work, and for fear of getting bored, Bart continued assisting with work at his firm until his passing.

Relatives, friends, and acquaintances alike knew Bart to be both a character and a generous man committed to his family, his community and his clients. He not only liked to be in on a good joke, he also was down to earth, easy to talk to and quick to offer compliments.

In his personal life, Bart had a fondness for flair. His hobbies included flying, entering the ring as a wrestling ringside manager alongside Regina Hale and attending Ferrari racing meets. He acquired a few Ferraris of his own, founded the Tennessee Chapter of the Ferrari Club of America in 1997 and served as the Tennessee president and regional director of the Southeast Region.

Bart is survived by his wife, Cindy; his children, Colin and Michele (Falletta) Durham, Blair and Kelley (Bean) Durham; and his grandchildren, Ethan and Adelynn.

Visitation with the Durham family will be on Tuesday, April 16, 2024, from 10AM until 11AM, at Woodmont Christian Church located at 3601 Hillsboro Road. The Celebration of Life will follow at 12PM. A private burial service is planned for the family.


In lieu of flowers, cards, and gifts, Bart and the family have requested donations of time and resources be shared with Heart'n Soul Hospice. (615) 835 3822.

([www.heartnsoulhospice.com/get-involved/](http://www.heartnsoulhospice.com/get-involved/)).

Arrangements in the care of Compassion Funeral & Cremation Services, Nashville, TN. (615) 857-9955. We proudly remain locally owned & operated.

Posted online on April 10, 2024

Published in The Tennessean

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**TURNER • FEILD**

S T A N D I N G F I R M

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April 1, 2024

Commissioner Ralph Alvarado  
710 James Robertson Parkway  
Nashville, Tennessee 37243

**RE: CERTIFICATE OF NEED**

Dear Members of the Certificate of Need Board:

I am writing to provide my perspective regarding the Certificate of Need (CON) application submitted by Heart n Soul Memphis to operate within our community. As the Former President of the National Association for the Advancement of Colored People (NAACP) Memphis Branch and former Chairman of the Board of Commissioners for Shelby County, Tennessee, I want to express my full support for the establishment of a new hospice agency in our area. I would like to shed light on the existing healthcare needs of our community, specifically among underserved Black and Brown populations.

The NAACP has long been a pillar in the local community and along with the County Commission have long supported providing comprehensive, high-quality care to all individuals within Memphis and Shelby County. We understand the importance of ensuring equitable access to healthcare services, especially within underserved communities. It is the NAACP's mission to ensure the political, educational, social, and economic equality of rights of all persons and to eliminate racial hatred and racial discrimination, especially in healthcare. Further, the NAACP works to bolster an environment where every individual in our community can receive the care they require and deserve.

CERTIFICATE OF NEED

Page 2

Considering the needs of our community, particularly those of underserved populations, I am aware that there is still much work to be done to meet the demand for hospice services. I believe the NAACP and Commission would support the CON application submitted by Heart n Soul because it is crucial to recognize the importance of addressing the existing gaps in healthcare through collaboration and coordination amongst various organizations operating in the same geographic area.

I believe that the introduction of Heart n Soul can potentially increase the availability of hospice care options for those underserved members of our community, ensuring that they receive the high-quality care they need during their most vulnerable moments. By working in tandem with them, we are confident that we can collectively strive to bridge the existing gaps in healthcare and make a profound impact on the lives of the individuals we serve.

I kindly request the Certificate of Need Board to consider the broader perspective of this situation, acknowledging the necessity of enhanced hospice services for underserved populations within our community. By understanding the importance of collaboration between existing healthcare providers and Heart N Soul, we can better serve the needs of our community while avoiding unnecessary duplication of services.

Thank you for your time and consideration. Should you require additional information or further discussion on this matter, please do not hesitate to contact me. I appreciate the opportunity to provide my insight and support for the development of a comprehensive, accessible, and inclusive healthcare service for all members of our community.

Sincerely,

**TURNER FEILD, PLLC**

By: /s/ Van D. Turner, Jr.

Van D. Turner, Jr.



SCHOOL OF MEDICINE  
*Department of Family and Community Medicine*

March 21, 2024

To Whom It May Concern:

I am a Family Physician located in Nashville, TN.

I want to share with you that I have referred many patients to Heart n Soul Hospice in Nashville, TN. What I want you to know is that they provide the BEST care to my patients at the end of life. They do it right, always consistent follow through and best of all, the patient's and families love them.

While I don't live in Memphis, I wanted you to know my thoughts. Dave Turner, CEO of Heart n Soul Hospice shared with me that Heart n Soul is applying for a CON to provide care to Shelby and its surrounding counties.

We all know that physicians have a choice when selecting hospice services for their patients. My choice is Heart n Soul Hospice. Why? Attentiveness, collaboration, kindness, going above and beyond for my patients and a dedicated and trained staff. I mention a dedicated and trained staff as Mr. Turner has told me if selected for the CON, they will provide the same training and support as they do here in Nashville.

Please accept this Letter of Support for Heart and Soul Hospice's application for the CON in Shelby and the surrounding counties.

Sincerely

A handwritten signature in blue ink, appearing to read "MD Collins".

Millard D. Collins, MD, FAAFP



April 12, 2024

To Whom It May Concern:

My name is Joel Parker, MD and I am a primary care physician located in Brentwood, TN.

I want to share with you that I have referred many patients to Heart n Soul Hospice in Nashville, TN. What I want you to know is that they provide the BEST care to my patients at the end of life. They do it right, always consistent follow through and best of all, the patient's and families love them.

While I don't live in Memphis, I wanted you to know my thoughts. Dave Turner, CEO of Heart n Soul Hospice, shared with me that Heart n Soul is applying for a CON to provide care to Shelby and its surrounding counties.

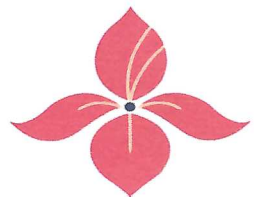
We all know that physicians have a choice when selecting hospice services for their patients. My choice is Heart n Soul Hospice. Why? Attentiveness, collaboration, kindness, going above and beyond for my patients and a dedicated and trained staff. I mention a dedicated and trained staff as Mr. Turner has told me if selected for the CON, they will provide the same training and support as they do here in Nashville.

Please accept this Letter of Support for Heart and Soul Hospice's application for the CON in Shelby and the surrounding counties..

Sincerely,

A handwritten signature in blue ink, appearing to be "JP", with a long horizontal flourish extending to the right.

Joel Parker, MD  
Iris Medical Group  
9019 Overlook Blvd, Ste C1  
Brentwood, TN 37027



April 29, 2024

My name is Stacy Hardy, CEO of Hardy House Health in Memphis, TN. Hardy House is a Family Practice clinic that provides valuable healthcare to all families in the Shelby County Area of Tennessee. We provide services to clients of all ages with the aim of reducing morbidity and mortality caused by preventive illnesses in our community by ensuring compliance with preventive and routine healthcare screenings.

I have learned that Heart n Soul Hospice is applying for a hospice Certificate of Need in Shelby County.

Heart n Soul Hospice believes in equality and outcomes, regardless of who you are. Through their many specialty programs, one in particular is Senior Journey, they work at bridging any gaps that exist in healthcare access and ensure equal availability of quality end-of-life care for people of all backgrounds and especially for our seniors.

Heart n Soul Hospice is a group poised to help in the expansion of these desperately needed programs to our seniors. And to also provide culturally appropriate education to our seniors.

I fully support Heart and Soul Hospice application for the CON.

Sincerely,



Stacy Hardy, CEO

Hardy House Your Family Healthcare Provider, PLLC  
2747 Bartlett Blvd | Bartlett, TN 3834  
Office: (901) 748-5308  
Fax: (901) 529-7716  
[www.hardyhousehealth.com](http://www.hardyhousehealth.com)

# Regional One Physicians

A Regional One Health and UT Health Science Center Partnership

April 24, 2024

Heart'n Soul Hospice  
51 Century Blvd., Suite #110  
Nashville, Tennessee 37214

Re: Palliative Care Partnership

My name is Randy Sites, CEO at University of Tennessee Regional One Physicians (UTROP) in Memphis, TN. UT Regional One Physicians is a collaborative effort between Regional One Health and The University of Tennessee Health Science Center. Together, they lead the largest academic physician group in the mid-south.

At Regional One Physicians, our providers have dedicated their careers to a variety of specialties – but they share a commitment to providing exceptional, compassionate patient care. Heart'n Soul Hospice has the same dedication to their patients.

Today, I met with Tracy Wood, COO of Heart'n Soul Hospice and learned Heart'n Soul Hospice is applying for a hospice Certificate of Need in Shelby, Tipton and Fayette counties. Their focus and leadership is poised to reach the underserved in our communities.

Together, we can ensure the patient receives the right care at the right time. Our ONE Health program is a national model for complex care, offering a new way to support vulnerable patients by addressing both their medical needs and social determinants of health. The Senior Journey program through Heart'n Soul Hospice bridges any gaps that exist in healthcare access and ensure equal availability of quality end-of-life care for people of all backgrounds and especially for our seniors and addresses the social determinants of health. Together, we will work to reach the underserved in our markets for quality end of life services.

Heart'n Soul Hospice will also partner with UTROP's Palliative Care program to reach out to the underserved for palliative services across Shelby, Tipton and Fayette counties. It's all about providing the right service at the right time. By partnership with us, Heart'n Soul Hospice patients will receive the best care from our many palliative and hospice trained physicians.



# **UT** Regional One Physicians

A Regional One Health and UT Health Science Center Partnership

Heart'n Soul Hospice is a group poised to help in the expansion of these desperately needed programs to our seniors. And as a minority owned hospice, they have the necessary tools to provide culturally appropriate education to our seniors. Heart'n Soul Hospice is Memphis!

Once approved for the CON, Heart'n Soul Hospice will contract with our system for inpatient and respite beds when needed for hospice patients.

I fully support Heart'n Soul Hospice's application for the CON.

Sincerely,



**Randy Sites**  
Chief Executive Officer  
UT Regional One Physicians





“What’s unique about our study is that we show this disparity is persistent — not decreasing over time — and appears to be fairly general because it is not specific to a few diseases such as cancer,” says [David L. Roth, Ph.D.](https://www.hopkinsmedicine.org/profiles/results/directory/profile/2653005/david-roth), (<https://www.hopkinsmedicine.org/profiles/results/directory/profile/2653005/david-roth>) director of the Johns Hopkins Center on Aging and Health (COAH) and a co-author of the study. These persistent disparities may impact the quality of end-of-life experiences differently for Black and white Americans and underline the importance of advance care planning and advance directives — things that [other studies](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2654372/) (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2654372/>) have shown are less likely to be in place for Black Americans.

In a report on the study published online Aug. 24 in the *Journal of the American Medical Association Network Open* (<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2769692>), the investigators note that the increasing use of hospice services in the last six months of life is seen as a positive trend — reducing emergency department visits, repeated hospital stays, and intensive, invasive life-preserving procedures such as intubation/mechanical ventilation, tracheostomies and feeding tubes. For the study, researchers analyzed data from the ongoing, population-based REasons for Geographical and Racial Differences in Stroke (REGARDS) study coordinated by the University of Alabama at Birmingham and funded by the National Institutes of Health. Between 2003 and 2007, REGARDS enrolled more than 30,000 participants in the United States, ages 45 or older, to better understand why Southerners and Black Americans have higher rates of stroke, and related diseases that affect brain health, than other Americans. By design, REGARDS has an oversampling of Black Americans and residents of the “stroke belt” in the Southeastern United States (including Alabama, Arkansas, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina and Tennessee), to gain more information about the racial and geographical health disparities and mortality rate differences that exist.

For the current study, Roth and his colleagues identified REGARDS participants who defined themselves as either Black or white Americans, who died between 2013 and 2015 due to natural causes (excluding sudden death), and whose records were linked to Medicare claims. They examined patients who received hospice care for three or more days in the last six months of life, and if these people had multiple hospitalizations, made any emergency department visits, or were given intensive medical procedures during the same time period. Ultimately, their study population contained 1,212 participants (31.2% Black and 48% female, with a mean age of 81).

The researchers found that 34.9% of Black study participants who died used hospice services over the study period, compared with 46.2% of white participants. Black Americans were significantly less likely than white Americans to use three or more days of hospice. Also, Black Americans were more likely to have multiple emergency room visits and hospitalizations, or to undergo intensive treatments in the last six months of life — regardless of the cause of death. This was especially true for noncancer deaths.

“Despite tremendous growth in palliative care and hospice use in the United States, our work highlights a pressing need to address racial disparities in end-of-life care,” says study lead author Katherine Ornstein, Ph.D., M.P.H., director of research for the Institute of Care Innovations at Home at Mount Sinai and associate professor of geriatrics and palliative medicine at Mt. Sinai’s Icahn School of Medicine in New York.

The study team recommends that more sustained efforts be made to reduce disparities in end-of-life-care through efforts to better educate and train health care providers and to promote the discussion of personal values and treatment preferences for the end of life in Black populations.

In addition to evidence that has shown that hospice care is more medically beneficial to patients in the end of life, hospice care, the researchers say, may also cost less than emergency or invasive treatments at the end stages of a person's life. [A 2013 study \(https://www.hopkinsmedicine.orghttps://www.healthaffairs.org/doi/full/10.1377/hlthaff.2012.0851\)](https://www.hopkinsmedicine.orghttps://www.healthaffairs.org/doi/full/10.1377/hlthaff.2012.0851) found \$2,561 in savings to Medicare for each patient enrolled in hospice 53–105 days before death, compared with a matched, nonhospice control. Even higher savings were seen with more common, shorter enrollment periods: \$2,650, \$5,040 and \$6,430 per patient enrolled 1–7, 8–14 and 15–30 days prior to death, respectively.

Along with Roth and Ornstein, the study team included COAH's Jin Huang, Ph.D., and Orla Sheehan, M.D., Ph.D., as well as Johns Hopkins Bloomberg School of Public Health associate Chanee Fabius, Ph.D. Additional researchers included Emily Levitan, Sc.D., and J. David Rhodes, M.P.H., from the University of Alabama at Birmingham, and Monika Safford, M.D., from Weill Cornell Medicine.

This research project is supported by cooperative agreement U01 NS041588 from the National Institute of Neurological Disorders and Stroke and the National Institute on Aging. Additional funding was provided by R01 HL80477 from the National Heart, Lung, and Blood Institute.

## Media Contacts

### **Tony Teano**

[tony.teano@jhu.edu](mailto:tony.teano@jhu.edu) (<https://www.hopkinsmedicine.orgmailto:tony.teano@jhu.edu>)

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## Topics

[Geriatric Medicine \(https://www.hopkinsmedicine.org/news/newsroom/news-releases?topic=Geriatric%2bMedicine\)](https://www.hopkinsmedicine.org/news/newsroom/news-releases?topic=Geriatric%2bMedicine)

[Health Wellness \(https://www.hopkinsmedicine.org/news/newsroom/news-releases?topic=Health%2bWellness\)](https://www.hopkinsmedicine.org/news/newsroom/news-releases?topic=Health%2bWellness)



## 1. [Health Equity](#)

# Acknowledging Barriers and Implementing Strategies to Reach Black People with Serious Illness

Updated June 14, 2022 | By Helen Bhagwandin, Stacie Sinclair, Chelsea Perez, and Brittany Chambers

Interview highlights from CAPC's environmental scan, [Equitable Access to Quality Palliative Care for Black Patients](#)



## Introduction

A growing body of research demonstrates [disparities in access](#) to palliative care services, [care quality](#), and [outcomes](#) for Black patients living with a serious illness. The need for decisive and sustained action to reduce health care [disparities](#) is not new; however, it was elevated in recent years by three [high-profile murders](#) and the devastating impact of the [COVID-19 pandemic](#) on [Black](#) (as well as [Latino](#) and [American Indian/Alaska Native](#)) communities.

In response, CAPC launched [Project Equity](#), an initiative to create tools for meaningful change in the care of those in traditionally oppressed communities living with a serious illness. One of the first efforts in this project is "[Equitable Access to Quality Palliative Care for Black](#)

[Patients: A National Scan of Challenges and Opportunities.](#)" In its simplest form, this scan seeks to answer two questions:

- What goes wrong in health care for Black people living with a serious illness?
- What interventions have been tested to address disparities in the care of Black people living with a serious illness?

## Interviews with subject matter experts (SMEs)

As part of this scan, CAPC staff conducted 25 interviews with 27 subject matter experts (SMEs) in health equity and serious illness from August to October 2021. The SMEs included clinicians, researchers, policy experts, payment experts, and six people who identified as patients or caregivers (although several professionals also shared their personal experiences as patients and caregivers). In addition, we interviewed the 12 members of CAPC's [Health Equity Project Advisory committee](#). We thank the [National Patient Advocate Foundation](#) for their help recruiting patient and caregiver interviewees.

### Interview themes fell under the following categories:

1. Barriers to accessing palliative care for Black patients living with serious illness, both historically and during the COVID-19 pandemic
2. Strategies for engaging Black patients (and their caregivers)
3. Promising interventions to improve care for Black patients living with a serious illness and their families
4. Policy levers to address systemic racism and barriers to quality health care access
5. Measurement priorities to ensure that health equity work leads to meaningful improvements

This blog provides highlights from the **first two themes**, and lays the foundation for future publications on CAPC's interview series.

## Barriers to equitable care

Prolonged focus on barriers creates a tendency to "admire the problem" without working toward solutions. However, we started our interviews here in order to:

1. Better understand the scope and scale of the challenges that Black patients with serious illness face;
2. Identify root causes of disparities so that, as we encounter promising interventions and develop recommendations, we can map them to the factors that will make an impact; and
3. Cultivate an awareness of patient and family experience that will guide CAPC's work.

Interviewees described many barriers to receiving palliative care for Black patients living with a serious illness. These barriers ranged from individual/interpersonal to systemic and structural; those that derive from historical oppression to new barriers being erected today; those specific to health care and those that stem from social determinants of health.

"Interviewees described many barriers to receiving palliative care for Black patients living with a serious illness."

Interviewees cautioned CAPC to consider health care delivery beyond access to palliative care (for example, care delivered to Black patients with serious illness in primary care settings). We acknowledge the wisdom of this advice—while we firmly believe that equitable access to high-quality palliative care is a right, patients and families interact with myriad care settings and care providers, and all of these interactions contribute to the experience of serious illness. While this article takes a focus on specialty palliative care as a starting point for CAPC's *Project Equity* initiative, future activities will expand the focus beyond care delivered by palliative care specialists.

## What must go "right" for Black patients to access palliative care

Interviewees identified the number of things that must go "well" for a Black patient with serious illness to receive palliative care (see Figure 1). While not an exhaustive list, we heard the need to overcome structural, social, and cultural barriers. These included the patient's ability to recognize the symptoms of a serious illness and seek care, enter and navigate a fragmented and complex health care system, find the right provider, get an accurate diagnosis, receive a palliative care referral, and see the team. Whether or not palliative care specialists are available can come down to an [accident of geography](#).

"[Barriers] included the patient's ability to recognize the symptoms of a serious illness and seek care, enter and navigate a fragmented and complex health care system, find the right provider, get an accurate diagnosis, receive a palliative care referral, and see the team."

Interviewees highlighted that obstacles to health care—including but not limited to palliative care—can also include basic health literacy, language, vocabulary, ability to take time from work, need for child/dependent care, transportation, and the [costs of care](#). For palliative care teams, this means that taking steps to understand the barriers to care facing the patients in one's community—and taking steps to address barriers—is critical to ensuring equitable access to palliative care services.

### A starting list of what must go "right" for Black people living with a serious illness

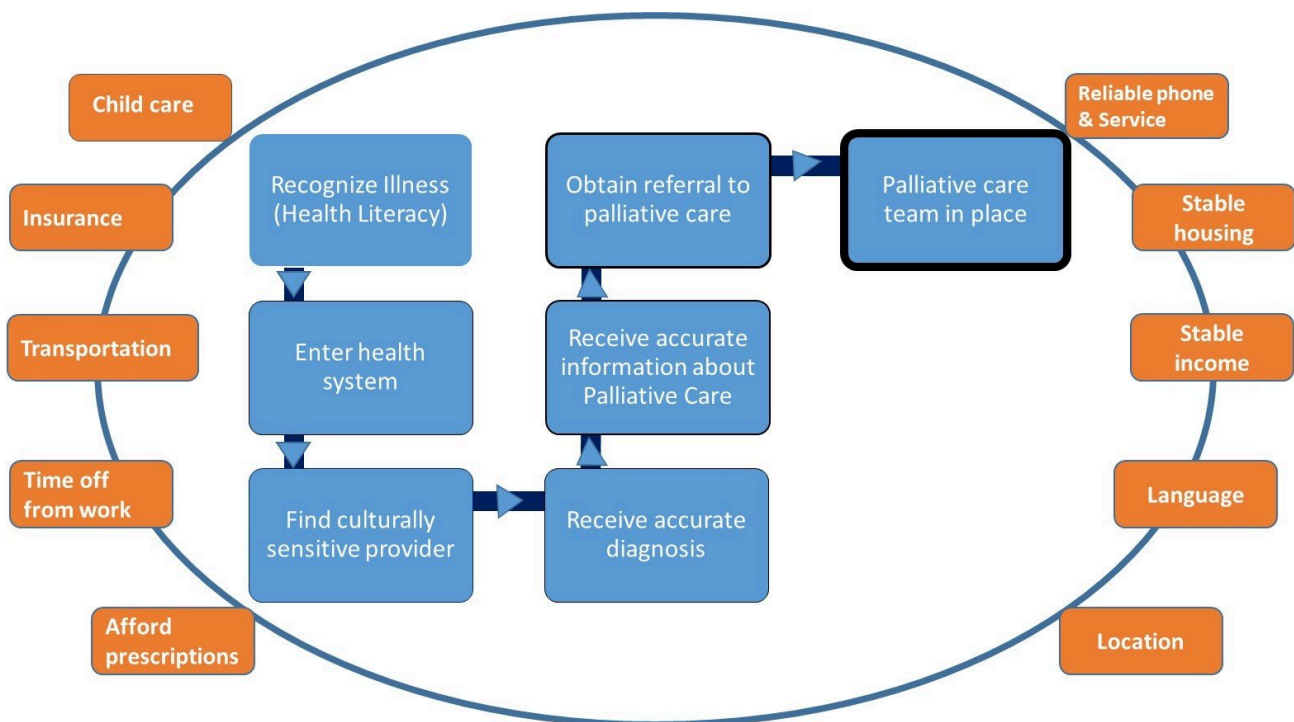


Figure 1: A starting list of what must go "right" for Black people living with serious illness to be connected to palliative care, gleaned from discussions with subject matter experts.

While many of the barriers discussed were systemic, some interviewees also highlighted the behaviors of individual clinicians. Interviewees noted [implicit](#) and sometimes explicit bias among health care clinicians, including a failure to see Black patients as co-equals. This paves the way for clinicians to make [stereotypical assumptions](#) about patients, and those preconceptions inform care – including whether or not patients are referred to palliative. Interviewees pointed to the problematic nature of claims such as "I don't see race" or "we treat all patients the same," since these stances negate the impact that race has on the experiences of Black patients, and interfere with an important opportunity to tailor care.



## Breaking through obstacles

SMEs emphasized that many Black patients and their families have grown to mistrust the health care system due to systemic racism that is embedded in our health care system. Several interviewees cited the [Tuskegee Experiment](#) and [Henrietta Lacks](#), and others saw the racial disparities in COVID-19 morbidity and mortality as a watershed event [unto itself](#). One interviewee observed, "It is difficult to change the narrative of systemic racism, health disparities, and exclusion from palliative care when: a) direct experiences are **not** in the distant past; b) there are so few current/compelling examples that care has changed."

Our interviewees identified strategies that palliative care teams can implement to better engage, support, and earn trust among Black people living with serious illness and their families. Key themes included **timing**, **messaging**, and the use of **trusted messengers** to convey the benefits of palliative care.

### Timing

Interviewees emphasized that patients **should not** hear about palliative care for the first time in the context of an emergency. The need for pre-education has been particularly significant during the COVID-19 pandemic, given the rapid illness progression of the virus, the pronounced disparities in incidence and outcomes based on race and ethnicity, and a heightened landscape of misinformation and mistrust. Although we often state the goal of introducing palliative care at the point of diagnosis, interviewees noted that it would be preferable to learn about its benefits—ideally multiple times—during usual/primary care or even in communities settings (e.g. religious institutions, community centers, etc.).

### Messaging

Interviewees noted that the phrase "palliative care" does not resonate with many Black people living with serious illnesses. While this issue is [not unique](#) to Black patients, to date there has not been enough research and testing to identify messages that would better engage different populations. In the meantime, SMEs suggested using simpler messaging that focused on what palliative care does, rather than terminology.

One interesting line of discussion also focused on the need for market research to analyze the components of palliative care messaging by patient demographic. For example, words such as "help" and "support" that are commonly used to describe palliative care may land differently based on the audience. SMEs shared that many Black patients have spent their lives fighting inequity and disparities and, as a result, may consciously or unconsciously uphold concepts like independence and self-reliance as defense mechanisms in their interactions with the health care system. For some patients, asking for help—particularly from individuals outside of their community—signals weakness or feels like a threat to their dignity.

### Trusted messengers

For interviewees, the "when" and "what" of palliative care messaging was far outweighed by the "who". SMEs focused on the need for person-led, high-touch outreach, and stated that for many Black patients living with serious illnesses, palliative care education is best received from peers and credible leaders who resemble their audience. Several SMEs identified faith leaders as the best potential partners in messaging efforts. However, a few cautioned against overburdening faith communities during an already challenging COVID era. Some suggested engaging other community partners such as local businesses (e.g., barbershops, beauty salons) to "meet people where they are." There was even a discussion about partnering with local grocery stores as a component of a holistic community intervention.

Some SMEs referenced other modalities for message delivery. Recent public health messaging has relied heavily on the internet and virtual communication; however, given [digital](#)

[inequities](#), it is important to utilize other media such as print media, radio and television spots, bus ads, etc.

"The best way for palliative care teams to 'break through' and build credibility is to deliver consistently on the promise of better care."

As SMEs proposed strategies to deliver the message about palliative care and its benefits further upstream, we learned from these discussions that there is no fast track to building trust. Given the barriers described above, most health care providers are working against a trust deficit. Therefore, the best way for palliative care teams to "break through" and build credibility is to [deliver consistently](#) on the promise of better care. To provide [individualized, culturally competent](#), unbiased care does not happen by accident. It requires training, practice, and [intention](#).

## Conclusion

Our discussions with these subject matter experts provided critical context for the larger project on "Equitable Access to Quality Palliative Care for Black Patients." A foundational challenge—as heard in the interviews and in responses from CAPC's recent national [questionnaire](#)—is that not all clinicians have a comprehensive understanding of systemic racism and its impact on health care and outcomes for Black patients. Everyone is entering this discussion from a different starting point, but knowledge is power. Understanding the historical basis of present-day inequity helps clinicians to recognize the disparities around them, and to take action. Without this understanding, we risk perpetuating the cycle of harm.

Hearing first- and second-hand about the barriers that Black people living with a serious illness and their families face, as they try to access palliative care, reinforces why efforts to advance health equity are vitally important. As the CAPC team proceeds—guided by our Equity Steering Committee and in partnership with other experts across the country—these interviews will continue to guide our thinking and efforts to identify promising interventions to address disparities, develop technical assistance to scale these models, and build long-term health equity strategies for our field.

## Acknowledgements

Thank you to the following people who contributed their expertise to inform the writing of this blog:

- Dr. Marcia Lowe, PhD, MSN, BSN, RN-BC, 2nd VP, Membership Chair, and End of Life Committee Chair, National Black Nurses Association (NBNA)
- Diane Deese, Vice President Community Affairs, VITAS Healthcare
- Gloria Thomas Anderson, PhD, LMSW; Karen Bullock, PhD, LCSW, APHSW-C; Rev. Cynthia Carter-Perrilliat, MPA; Sandy Cayo, DNP, FNP, BC; Komal Chandra, PhD, MMH; Zara Cooper, MD, MSc, FACS; Diane Deese; Faye Hollowell, BS, MTh; Jacquelyn Lambert-Davis, DNP, RN; Marcia A. Lowe, PhD, MSN, BSN; Elder Angela Overton, MDiv.; Danetta E. H. Sloan, PhD, MSW, MA

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*Edited by Melissa Baron. Clinical review by Andrew Esch, MD, MBA.*



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[Associate Director, Policy and Care Transformation](#)





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[Director, Health Equity and Special Initiatives](#)

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doi: [10.1089/jpm.2013.9468](https://doi.org/10.1089/jpm.2013.9468)

PMID: [24073685](https://pubmed.ncbi.nlm.nih.gov/24073685/)

## Racial and Ethnic Disparities in Palliative Care

[Kimberly S. Johnson](#), MD, MHS<sup>1,2</sup>

### Abstract

Racial and ethnic disparities in health care access and quality are well documented for some minority groups. However, compared to other areas of health care, such as disease prevention, early detection, and curative care, research in disparities in palliative care is limited. Given the rapidly growing population of minority older adults, many of whom will face advanced serious illness, the availability of high-quality palliative care that meets the varied needs of older adults of all races and ethnicities is a priority. This paper reviews existing data on racial and ethnic disparities in use of and quality of palliative care and outlines priorities for future research.

### Introduction

CURRENTLY, 8.1 MILLION or 20% of older adults are racial or ethnic minorities—8.4% are African Americans, 6.9% Hispanics of any race, 3.5% Asians or Pacific Islanders, and less than 1% American Indians. Over the next two decades the growth in the proportion of minority older adults will substantially outpace that of Non-Hispanic whites. Specifically, the population of older Non-Hispanic whites is expected to increase by only 59% compared to 160% for older minorities—202% for Hispanics, 114% for African Americans, 145% for American Indians, and 145% for Asians and Pacific Islanders.<sup>1</sup> Given the influence of cultural beliefs and preferences on the experience of serious illness and death,<sup>2-4</sup> and the disproportionate burden of pain,<sup>5</sup> disability,<sup>1,6</sup> and advanced disease<sup>1,7-9</sup> among some minority groups, research aimed at eliminating racial and ethnic disparities in palliative care is essential. As the evidence base for the benefits of palliative care continues to grow<sup>10-14</sup> it is imperative that these services are equally accessible, of similar quality, and meet the needs of older adults of all races and ethnicities.



## Available Evidence on Racial and Ethnic Disparities in Palliative Care

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Broadly defined, disparities in health care are differences in the presence of disease, health outcomes, quality of care, and access to care that exist across racial and ethnic groups. Health care disparities are widely documented for African Americans and Hispanics compared to whites across a range of diseases, including cancer and cardiovascular disease.<sup>7-9</sup> While much of the research in this area has focused on disease prevention, early diagnosis, and curative treatment, there is growing evidence that racial and ethnic disparities also exist in access to palliative care and in clinical outcomes such as symptom management and communication.<sup>5,15,16</sup> As in other areas of disparities research, the body of work in palliative care has largely focused on differences between whites and African Americans, and to a lesser extent, Hispanics. The discussion below mirrors this tendency, but also includes what is known about disparities related to other minority groups when data are available.

### Disparities in the Quality of Care

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A number of studies document lower-quality palliative care for minorities across multiple domains, including satisfaction, communication, and pain management. In a national survey of bereaved family members, surrogates of African Americans were less satisfied with the quality of end-of-life care and more often reported concerns about provider communication.<sup>15</sup> Similarly in other studies, compared to whites, African Americans report less satisfaction with the quality of communication, including the extent to which providers listen and share information, with greater disparities in racially discordant patient-provider relationships.<sup>17,18</sup> Further, there is evidence from a prospective study of cancer patients that outcomes of communication differ by race, with end-of-life discussions between physicians and their African American (versus white) patients less likely to result in care consistent with patient preferences.<sup>16</sup> A large body of research documents disparities in the assessment and treatment of pain for African Americans and Hispanics versus whites across age groups, diagnoses, and settings, with similar trends for Asians and Native Americans in nursing homes. Also, minorities face challenges in access to pain medicines, as pharmacies in some predominantly minority neighborhoods are less likely to stock adequate supplies of opioids.<sup>5,19</sup>

Other research on disparities in outcomes of care for seriously ill patients has examined differences in the intensiveness of care and documentation of treatment preferences. Compared to whites, minorities are more likely to die in the hospital, and African Americans and Hispanics are more likely to be hospitalized and to receive intensive aggressive care in the last six months of life.<sup>20,21</sup> While there are some inconsistencies, in most studies, compared to whites, African Americans, Hispanics, and Asians are less knowledgeable about advance directives and less likely to complete them.<sup>22-24</sup>

### Disparities in the Use of Palliative Care Services

Studies consistently document lower rates of hospice use for minority older adults than for whites across diagnoses, geographic areas, and settings of care, including nursing homes.<sup>25-31</sup> Among Medicare beneficiaries who died in 2010, 45.8% of whites used hospice compared to 34% of African Americans, 37% of Hispanics, 28.1% of Asian Americans, and 30.6% of Native North Americans.<sup>32</sup> Data on disparities in the experiences of minority hospice enrollees are limited. There is some evidence that disparities in the quality of care are smaller between whites and African Americans enrolled in hospice compared to those in the general population.<sup>33</sup> Other studies document higher rates of hospice disenrollment for African Americans than whites and more concerns about care coordination and quality among hospices with a higher proportion of African American enrollees.<sup>34-36</sup> Overall, hospice lengths of stay tend to be similar across racial and ethnic groups or longer for minorities than whites.<sup>34,37,38</sup>

Research is minimal on disparities in the use of nonhospice-based palliative care. Small studies of home-based palliative care and inpatient palliative care consultation have reported favorable outcomes for African Americans, Hispanics, and Asians/Pacific Islanders, including increased satisfaction, greater rates of home deaths and hospice referrals, and increased documentation of treatment preferences.<sup>39-42</sup> In contrast, a single study of cancer patients at a supportive care clinic found persistent disparities in symptom burden, with Hispanics and African Americans less likely than whites to report improvement in pain or fatigue at follow-up.<sup>43</sup>

## Factors Contributing to Disparities in Palliative Care and Interventions

Factors contributing to disparities in the use of palliative care are not well understood. Research in this area has focused on racial and ethnic differences in knowledge, cultural beliefs, and treatment preferences as barriers to the use of palliative care. Studies document a disproportionate gap in knowledge about palliative care among minority older adults.<sup>44-48</sup> Other research suggests that among African Americans in particular, spiritual and religious beliefs may conflict with the goals of palliative care, and mistrust of the health care system due to past injustices in research and ongoing disparities may lead to concerns about forgoing curative care as required by the Medicare Hospice Benefit.<sup>49,50</sup> Further, studies consistently document greater preference for life-sustaining therapies regardless of prognosis among African Americans and Hispanics compared to whites, while preferences for Asians vary with acculturation.<sup>3,22,51</sup> However, research suggests that among African Americans with advanced cancer stated preferences for care are not consistently related to actual treatment received.<sup>16</sup> Other cultural beliefs that may present a barrier to the use of palliative care include less positive attitudes toward disclosure of terminal illness among Asians and Hispanics.<sup>22</sup> While empiric research is minimal, potential organizational barriers to the use of palliative care by racial and ethnic minorities include the absence of minority staff, interpreters, and community outreach to diverse communities.<sup>52,53</sup>

There are few studies of interventions to reduce disparities. Research has included the development of culturally competent hospice educational materials,<sup>54</sup> videos to improve health literacy,<sup>55,56</sup> and patient navigation to address disparities in care for African Americans and Latinos.<sup>57</sup> Other work has examined how peer support can extend care to African Americans with advanced cancer.<sup>58</sup>

## Content and Methodological Gaps

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Although there is increasing interest in disparities in palliative care, the overall body of research is narrow in focus. There are limitations and gaps in which groups have been studied, what has been studied, and how the research has been conducted.

As in research in health care disparities in general, studies in disparities in palliative care have largely focused on African Americans and to a lesser extent Hispanics, the two largest minority groups; there are considerably fewer studies that include other minorities. Additionally, cancer patients, often in outpatient settings, are relatively well represented in the current literature, while there is less research examining disparities in palliative care for minority older adults with other highly prevalent conditions, such as heart failure or dementia, or across care settings, such as nursing homes or assisted living facilities. Despite the importance of informal caregivers in assisting with decision making and providing care, particularly for minority older adults, there is little research examining disparities in their experience.

Although there is a sizable body of literature documenting disparities in hospice enrollment, data on racial and ethnic disparities in access to and use of nonhospice-based palliative care are lacking. There are few studies examining disparities in quality (e.g. symptom management, psychosocial support) for those receiving hospice or nonhospice-based palliative care. There are even fewer studies examining potential determinants of disparities or variability within rather than between racial and ethnic groups. That is, little research has attempted to identify moderators and mediators of disparities among patients (e.g., health literacy, socioeconomic status); providers (e.g., communication skills); organizations (community partnerships); or regions (supply of other health care resources). Studies of the rigorous development and testing of interventions with measurement of outcomes, such as reduced disparities or improved quality, are also absent.

There are significant methodological limitations in the published work. The most commonly used methods include small to large secondary data analyses, retrospective studies of surrogates, qualitative studies of patients' beliefs and preferences, cross-sectional analyses of small convenience samples, and surveys with investigator-developed measures, often with little validation in minority groups. Many studies do not report race and ethnicity discretely and include only a small number of minority older adults and so have inadequate power to examine differences in outcomes by age ( $\geq 65$  versus  $< 65$ ) and race or ethnicity. While plentiful, studies examining cultural beliefs and preferences that may impact decision making have often included only community dwelling, well, older minority adults rather than those with serious illness actively facing treatment decisions. The absence of prospective, longitudinal studies including adequate numbers of seriously ill minority older adults with appropriate measurement of patient, provider, and health system or organizational variables does not allow for a full exploration of factors that may contribute to racial disparities or provide an evidence base for the design of effective interventions.

## Priorities for Future Research

Research on health care disparities includes three phases: detecting differences in health and health care, understanding the determinants that underlie disparities, and intervening to eliminate them.<sup>59</sup> Given gaps in current work, efforts to reduce disparities in palliative care for older adults necessitate research in all of these phases. [Table 1](#) lists priorities for future research in each area. The success of this work will depend on the ability and commitment of palliative care researchers to recruit racial and ethnic minority study participants. This is especially challenging considering the difficulty of enrolling seriously ill patients in research in general, and the lower rates of research participation among minorities. Recruiting and retaining adequate numbers of minorities will require multisite study designs and targeted strategies, such as community engagement, culturally diverse staff, clear articulation of benefits of research, and other efforts to address barriers to participation.<sup>60</sup>

Table 1.

Research Priorities for Racial and Ethnic Disparities in Palliative Care

<i>Research priority</i>	<i>Objective</i>	<i>Setting</i>	<i>Sample</i>	<i>Design</i>
<b>Detecting disparities</b>	Examine disparities in utilization of nonhospice-based palliative care Examine disparities in the quality of hospice- and nonhospice-based palliative care	Inpatient Outpatient Long-term care Home-based	Racially and ethnically diverse older adults with serious illness	Secondary analysis of large datasets (e.g., Medicare claims, health system data) Prospective or retrospective studies of patient and caregiver experiences using appropriate quality measures
<b>Understanding the determinants of disparities</b>	Identify modifiable factors associated with disparities in utilization and quality of palliative care			Prospective, longitudinal studies of seriously ill patients with collection of potential moderators and mediators of disparities across multiple levels—patient, provider, health system, health policy
<b>Eliminating disparities</b>	Develop and test interventions to reduce disparities in utilization and quality based on evidence resulting from research in understanding disparities			Pilot studies, randomized control trials, and pragmatic trials of patient, provider, community, health system, and health policy interventions

### Detecting disparities in palliative care

Most of the work in detecting disparities in palliative care has focused on hospice. With the growth in nonhospice-based palliative care, one priority is to examine disparities in access to and use of these services. Secondary analyses of existing large datasets (e.g., Medicare claims, health care system databases) are often used to examine differences in service utilization; however, in some cases this will require more consistent documentation and coding of palliative care encounters for seriously ill patients across settings of care. Additionally, because of variation in the presence and extent of disparities, similar analyses of smaller populations of racially and ethnically diverse older adults within a common region, health system, state, or community are also useful for identifying

best practices (no disparities) and targeting areas for intervention (large disparities). This work should move beyond simply documenting disparities in utilization to examining disparities in quality—that is, determining whether there are equally favorable outcomes for all older adults who access palliative care. Using prospective or retrospective study designs, this work should examine disparities in appropriate measures of quality (e.g., symptom management, communication, psychosocial support) for seriously ill older adults and their caregivers of all races and ethnicities across care settings (nursing home, inpatient, home, hospital).

### Understanding the determinants of disparities in palliative care

Research is needed to understand the determinants of disparities in palliative care. This work should include prospective, longitudinal studies of seriously ill patients actively involved in medical decision making who are receiving or who may benefit from palliative care. Studies in this phase should measure potential moderators and mediators of disparities at multiple levels: patient (e.g., sociodemographics, preferences, spiritual beliefs, illness severity, knowledge, acculturation); provider (e.g., knowledge, attitudes, bias, communication skills); and health care system or organization (e.g., community outreach, racial/ethnic makeup of staff, goals and culture pertinent to diversity and inclusion). These studies should also consider the context in which palliative care is provided, including setting of care, regional factors associated with treatment intensity (e.g., supply of other health care resources), health care policies and models for providing palliative care. With an eye towards intervening to improve the delivery of palliative care for minority older adults of all racial and ethnic groups, research in this area should rigorously examine those factors that may be most amenable to change via well-designed interventions (i.e., health literacy, communication skills, models of care).

### Eliminating disparities

The ultimate goal of research in health care disparities is to reduce or eliminate them. Ideally, the work proposed above in understanding modifiable factors associated with disparities in palliative care should inform areas for intervention. One important priority in this area is to develop and test models of care that accommodate a range of cultural beliefs and values and integrate palliative care across the continuum of care. Rather than supporting a narrow approach to the provision of palliative care (e.g., care focused on either cure or comfort), these models should consider the varied needs and preferences of older adults across and within racial and ethnic groups. Other research priorities include the development and testing of interventions based on existing and evolving evidence in the field and successful interventions in other areas of health care disparities, targeting patients, providers, organizations, health systems, and policy.<sup>58</sup> Examples include efforts to increase patient knowledge about palliative care, improve health literacy, address language barriers for specific groups of older minorities, improve provider communication skills, and promote community-based partnerships with stakeholders and leaders in minority communities while increasing access to resources to support the delivery of palliative care (e.g., availability of pain meds). These studies should move towards measuring the effect of the interventions at reducing disparities and improving the quality of care, not just intermediate outcomes such as improved knowledge or skills.



Although reducing and eliminating disparities is an important priority, improving the care of seriously ill older adults requires that we not only examine differences in utilization and quality between racial and ethnic groups but that we also examine outcomes within groups. Even in the absence of disparities, interventions are needed to improve care when outcomes are similarly poor for whites and minorities, such as similarly low rates of hospice enrollment for whites and African Americans in a common geographic area. Models of care that demonstrate favorable outcomes across racial and ethnic groups should be tapped for their ability to serve as best practices. Where outcomes are poor for one group and not another, interventions should target that group.<sup>61</sup> Finally, work to eliminate disparities cannot end with developing and testing interventions in the context of rigorous research designs, but must move to implementing interventions in real-life settings and communities, evaluating their effectiveness, and refining them to meet the needs of their target group.

## Conclusions

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Existing research documents disparities in palliative care for minorities living with serious illness; however, there are significant gaps in content and methodological limitations in the current body of work. Additional research is needed to examine differences in utilization and quality of palliative care, understand the determinants of disparities, and develop and test interventions to reduce disparities and improve the care of seriously ill minorities. This work should consider the full spectrum of racial and ethnic groups, across diagnoses and settings of care. Efforts to reduce disparities should target patients, providers, health systems, communities, and health policy and ensure that new models of care accommodate the range of needs and preferences of a rapidly growing racially and ethnically diverse population of older adults.

## Author Disclosure Statement

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## References

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1. Greenberg S U.S. Department of Health and Human Services Administration on Aging. *A Profile of Older Americans*. 2011. [Jan 26;2013 ]. [www.aoa.gov/aoaroot/aging\\_statistics/Profile/2011/docs/2011profile.pdf](http://www.aoa.gov/aoaroot/aging_statistics/Profile/2011/docs/2011profile.pdf)
2. Hopp FP. Duffy SA. Racial variations in end-of-life care. *J Am Geriatr Soc*. 2000;48:658–663. [[PubMed](#)] [[Google Scholar](#)]
3. Blackhall LJ. Frank G. Murphy ST. Michel V. Palmer JM, et al. Ethnicity and attitudes towards life-sustaining technology. *Soc Sci Med*. 1999;48:1779–1789. [[PubMed](#)] [[Google Scholar](#)]
4. Crawley L. Payne R. Bolden J. Payne T. Washington P, et al. Palliative and end-of-life care in the African-American community. *JAMA*. 2000;284:2518–2521. [[PubMed](#)] [[Google Scholar](#)]

5. Anderson KO. Green CR. Payne R. Racial and ethnic disparities in pain: Causes and consequences of unequal care. *J Pain*. 2009;10:1187–1204. [[PubMed](#)] [[Google Scholar](#)]
6. Coustasse A. Bae S. Arvidson C. Singh KP. Trevino F. Disparities in ADL and IADL disabilities among elders of Hispanic subgroups in the United States: Results from the National Health Interview Survey 2001–2003. *Hosp Top*. 2009;87:15–23. [[PubMed](#)] [[Google Scholar](#)]
7. Smedley BD, editor; Stith AY, editor; Nelson AR, editor. Institute of Medicine Committee on Understanding and Eliminating Ethnic and Racial Disparities in Healthcare, Board of Health Sciences Policy. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Washington, DC: National Academic Press; 2003. [[Google Scholar](#)]
8. National Institutes of Health, National Heart, Lung, and Blood Institute. *Morbidity and Mortality: 2012 Chart Book on Cardiovascular, Lung, and Blood Diseases*. Feb, 2012. [Jan 26;2013 ]. [www.nhlbi.nih.gov/resources/docs/2012\\_ChartBook\\_508.pdf](http://www.nhlbi.nih.gov/resources/docs/2012_ChartBook_508.pdf)
9. Howlader N. Noone AM. Krapcho M. Neyman N. Aminou R, et al. *SEER Cancer Statistics Review, 1975–2009*. Bethesda, MD: National Cancer Institute; [Feb 5;2013 ]. [[Google Scholar](#)]
10. Teno JM. Clarridge BR. Casey V. Welch LC. Wetle T, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004;291:88–93. [[PubMed](#)] [[Google Scholar](#)]
11. Temel JS. Greer JA. Muzikansky A, et al. Early palliative care for patients with metastatic non-small cell lung cancer. *N Engl J Med*. 2010;363:733–742. [[PubMed](#)] [[Google Scholar](#)]
12. Morrison RS. Penrod JD. Cassel JB, et al. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168:1783–1790. [[PubMed](#)] [[Google Scholar](#)]
13. Gelfman LP. Meier De. Morrison RS. Does palliative care improve quality? A survey of bereaved family members. *J Pain Symptom Manage*. 2008;36:22–28. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
14. Casarett D. Johnson M. Smith D. Richardson D. The optimal delivery of palliative care: A national comparison of outcomes of consultation teams vs. inpatient units. *Arch Intern Med*. 2011;171:649–655. [[PubMed](#)] [[Google Scholar](#)]
15. Welch LC. Teno JM. Mor V. End-of-life care in black and white: Race matters for medical care of dying patients and their families. *J Am Geriatr Soc*. 2005;53(7):1145–1153. [[PubMed](#)] [[Google Scholar](#)]
16. Mack JW. Paulk ME. Viswanath K. Prigerson HG. Racial disparities in the outcomes of communication on medical care received near death. *Arch Intern Med*. 2010;170(17):1533–1540. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
17. Smith AK. Davis RB. Krakauer EL. Differences in the quality of the patient-physician relationship among terminally ill African-American and White patients: Impact on advance care planning and treatment preferences. *J Gen Intern Med*. 2007;22:1579–1582. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
18. Gordon HS. Street RL. Sharf BF. Soucek J. Racial differences in doctors' information-giving and patients' participation. *Cancer*. 2006;197:1313–1320. [[PubMed](#)] [[Google Scholar](#)]
19. Cintron A. Morrison RS. Pain and ethnicity in the United States: A systematic review. *J Palliat Med*. 2006;9(6):1454–1473. [[PubMed](#)] [[Google Scholar](#)]
20. National Center for Health Statistics. *Health, United States, 2010: With Special Feature on Death and Dying*. Hyattsville, MD: National Center for Health Statistics; 2011. [Jul 12;2013 ]. [[PubMed](#)] [[Google Scholar](#)]
21. Hanchate A. Kronman AC. Young-Xu Y. Ash AS. Emanuel E. Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites? *Arch Intern Med*. 2009;169(5):493–501. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]

22. Kwak J. Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist*. 2005;45(5):634–641. [[PubMed](#)] [[Google Scholar](#)]
23. Kwak J. Salmon JR. Attitudes and preferences of Korean-American older adults and caregivers on end-of-life care. *J Am Geriatr Soc*. 2007;55(11):1867–1872. [[PubMed](#)] [[Google Scholar](#)]
24. Kelley AS. Wenger NS. Sarkisian CA. Opinions: End-of-life care preferences and planning of older Latinos. *J Am Geriatr Soc*. 2010;58(6):1109–1116. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
25. National Hospice and Palliative Care Organization. *NHPCO Facts and Figures: Hospice Care in America*. Oct, 2012. [Feb 22;2013 ]. [www.nhpco.org/sites/default/files/public/Statistics\\_Research/2012 Acts\\_Figures.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012 Acts_Figures.pdf)
26. Greiner KA. Perera S. Ahluwalia JS. Hospice usage by minorities in the last year of life: Results from the National Mortality Followback Survey. *J Am Geriatr Soc*. 2003;51:970–978. [[PubMed](#)] [[Google Scholar](#)]
27. Connor SR. Elwert F. Spence C. Christakis NA. Racial disparity in hospice use in the United States in 2002. *Palliat Med*. 2008;22:205–213. [[PubMed](#)] [[Google Scholar](#)]
28. Ngo-Metzger Q. Phillips RS. McCarthy EP. Ethnic disparities in hospice use among Asian-American and Pacific Islander patients dying with cancer. *J Am Geriatr Soc*. 2008;56:139–144. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
29. Lackan NA. Ostir GV. Freeman JL. Kuo YF. Zhang DD, et al. Hospice use by Hispanic and Non-Hispanic White cancer decedents. *Health Serv Res*. 2004;39(4 Pt 1):969–984. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
30. Lepore MJ. Miller SC. Gozalo P. Hospice use among urban Black and white U.S. nursing home decedents in 2006. *Gerontologist*. 2011;51:251–260. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
31. Givens JL. Tjia J. Zhou C. Emanuel E. Ash AS. Racial and ethnic differences in hospice use among patients with heart failure. *Arch Intern Med*. 2010;170(5):427–432. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
32. Medicare Payment Advisory Council. *Report to Congress Medicare Payment Policy*. Washington, DC: Mar, 2012. Hospice services; p. 288. [[Google Scholar](#)]
33. Rhodes RL. Teno JM. Connor SR. African American bereaved family members' perceptions of the quality of hospice care: Lessened disparities, but opportunities to improve remain. *J Pain Symptom Manage*. 2007;34:472–479. [[PubMed](#)] [[Google Scholar](#)]
34. Rhodes RL. Xuan L. Halm EA. African American bereaved family members' perceptions of hospice quality: Do hospices with high proportions of African Americans do better? *J Palliat Med*. 2012;15:1137–1141. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
35. Kapo J. MacMoran H. Casarett D. “Lost to follow-up:” Ethnic disparities in continuity of hospice care at the end of life. *J Palliat Med*. 2005;8:603–608. [[PubMed](#)] [[Google Scholar](#)]
36. Johnson KS. Kuchibhatla M. Tanis D. Tulskey JA. Racial differences in hospice revocation to pursue aggressive care. *Arch Intern Med*. 2008;168:218–224. [[PubMed](#)] [[Google Scholar](#)]
37. Hardy D. Chan W. Liu CC. Cormier JN. Xia R, et al. Racial disparities in length of stay in hospice care by tumor stage in a large elderly cohort with non-small cell lung cancer. *Palliat Med*. 2012;26:61–71. [[PubMed](#)] [[Google Scholar](#)]
38. Park NS. Carrion IV. Lee BS. Dobbs D. Shin HJ. Becker MA. The role of race and ethnicity in predicting length of hospice care among older adults. *J Palliat Med*. 2012;15:149–153. [[PubMed](#)] [[Google Scholar](#)]

39. Holley APH. Gorawara-Bhat R. Dale W. Hemmerich J. Cox-Hayley D. Palliative access through care at home: Experiences with an urban, geriatric home palliative care program. *J Am Geriatr Soc.* 2009;57:1925–1931. [[PubMed](#)] [[Google Scholar](#)]
40. Ciemins EL. Stuart B. Gerber R. Newman J. Bauman M. An evaluation of the Advanced Illness Management (AIM) Program: Increasing hospice utilization in the San Francisco Bay area. *J Palliat Med.* 2006;9:1401–1411. [[PubMed](#)] [[Google Scholar](#)]
41. Zaide GB. Pekmezaris R. Nouryan CN. Mir TP. Sison CP, et al. Ethnicity, race, and advance directives in an inpatient palliative care consultation service. *Palliat Support Care.* 2012;6:1–7. [[PubMed](#)] [[Google Scholar](#)]
42. Bell CL. Kuriya M. Fischberg D. Hospice referrals and code status: Outcomes of inpatient palliative care consultations among Asian Americans and Pacific Islanders with cancer. *J Pain Symptom Manage.* 2011;42:557–564. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
43. Reyes-Gibby CC. Anderson KO. Shete S. Bruera E. Yennurajalingam S. Early referral to supportive care specialists for symptom burden in lung cancer patients: A comparison of non-Hispanic whites, Hispanics, and non-Hispanic blacks. *Cancer.* 2012;118:856–863. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
44. Born W. Greiner KA. Eldonna S. Butler J. Ahluwalia JS, et al. Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J Palliat Med.* 2004;7:247–256. [[PubMed](#)] [[Google Scholar](#)]
45. Jang Y. Chiriboga DA. Allen JY. Kwak J. Haley WE. Willingness of older Korean-American adults to use hospice. *J Am Geriatr Soc.* 2010;58:352–356. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
46. Johnson KS. Kuchibhatla M. Tulsy JA. Racial differences in self-reported exposure to information about hospice care. *J Palliat Med.* 2009;12(10):921–927. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
47. Rhodes RL. Teno JM. Welch LC. Access to hospice for African Americans: Are they informed about the option of hospice? *J Palliat Med.* 2006;9:268–272. [[PubMed](#)] [[Google Scholar](#)]
48. Fishman JM. Ten Have T. Casarett D. Is public communication about end-of-life care helping to inform all? Cancer news coverage in African American versus mainstream media. *Cancer.* 2012;118:2157–2162. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
49. Johnson KS. Elbert-Avila K. Tulsy JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans. *J Am Geriatr Soc.* 2005;53:711–719. [[PubMed](#)] [[Google Scholar](#)]
50. Cort MA. Cultural mistrust and use of hospice care: Challenges and remedies. *J Palliat Med.* 2004;7:63–71. [[PubMed](#)] [[Google Scholar](#)]
51. Barnato AE. Anthony DL. Skinner J. Gallagher PM. Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med.* 2009;24:695–701. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
52. Lorenz KA. Ettner SL. Rosenfeld KE. Carlisle D. Liu H, et al. Accommodating ethnic diversity: A study of California hospice programs. *Med Care.* 2004;42:871–874. [[PubMed](#)] [[Google Scholar](#)]
53. Reese DJ. Melton E. Ciaravino K. Programmatic barriers to providing culturally competent end-of-life care. *Am J Hosp Palliat Care.* 2003;21:357–364. [[PubMed](#)] [[Google Scholar](#)]
54. Enguidanos S. Kogan AC. Lorenz K. Taylor G. Use of role model stories to overcome barriers to hospice among African Americans. *J Palliat Med.* 2011;14:161–168. [[PubMed](#)] [[Google Scholar](#)]
55. Volandes AE. Ariza M. Abbo ED. Paasche-Orlow M. Overcoming educational barriers for advance care planning in Latinos with video images. *J Palliat Med.* 2008;11:700–706. [[PubMed](#)] [[Google Scholar](#)]

56. Volandes AE, Paasche-Orlow M, Gillick MR, Cook EF, Shaykevich S, et al. Health literacy not race predicts end-of-life care preferences. *J Palliat Med*. 2008;11:754–762. [[PubMed](#)] [[Google Scholar](#)]
57. Fisher SM, Sauaia A, Kutner JS. Patient navigation: A culturally competent strategy to address disparities in palliative care. *J Palliat Med*. 2007;10:1023–1028. [[PubMed](#)] [[Google Scholar](#)]
58. Hanson LC, Armstrong TD, Green MA, Hayes M, Peacock S, et al. Circles of care: Development and initial evaluation of a peer support model for African Americans with advanced cancer. *Health Educ Behav*. 2013;40:536–543. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
59. Kilbourne AM, Galen S, Hyman K, Crowley-Matoka M, Fine MJ. Advancing health disparities research within the health care system: A conceptual framework. *Am J Public Health*. 2006;96:2113–2131. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
60. Diaz V. Encouraging participation of minorities in research studies. *Ann Fam Med*. 2012;10(4):372–373. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
61. Baiker K, Chandra A, Skinner J. Geographic variation in health care and the problem of measuring racial disparities. *Perspect Biol Med*. 2005;48(1 Suppl):S42–S53. [[PubMed](#)] [[Google Scholar](#)]





# NHPCO Facts and Figures

## 2023 EDITION

*Published December 2023*



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

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The findings in this report reflect only those patients who received care through 2021, provided by the hospices certified by the Centers for Medicare and Medicaid Services (CMS) and reimbursed under the Medicare Hospice Benefit.

# Section 1: Introduction

## About this Report

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

- Hospice patient characteristics
- Location and level of care
- Medicare hospice spending
- Hospice provider characteristics
- Quality of care

Currently, most hospice patients have their costs covered by Medicare through the Medicare Hospice Benefit.

## Impact of COVID-19

This year continues to see the impact of COVID-19 on patient care and the effect of the COVID-19 waivers on the traditional delivery of hospice care. These waivers included increased telehealth services. 2020 saw decreases in hospice usage in many areas due to the number of deaths outpacing hospice use ([see Section 3](#)).

## 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 loved ones 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 hospice facilities, hospitals, nursing homes, assisted living facilities, or other long-term care facilities. Hospice services are available to patients with any terminal illness. Hospices promote inclusivity 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 hospice services.

## How is hospice care delivered?

Typically, a loved one 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



# Introduction (continued)

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 (IDT), 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; spiritual care providers; and trained volunteers. In addition to the IDT, the hospice will support physical, psychosocial, and spiritual needs of the beneficiary.

## What services are provided?

The hospice interdisciplinary team:

- Manages the patient's pain and other symptoms
- Assists the patient and loved ones with the emotional, psychosocial, and spiritual aspects of dying
- Provides medications and medical equipment
- Instructs the informal caregivers on how to care for the patient
- Provides grief support and counseling to the patient as well as the surviving family and friends for up to 13 months after death
- 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

## Location of Care

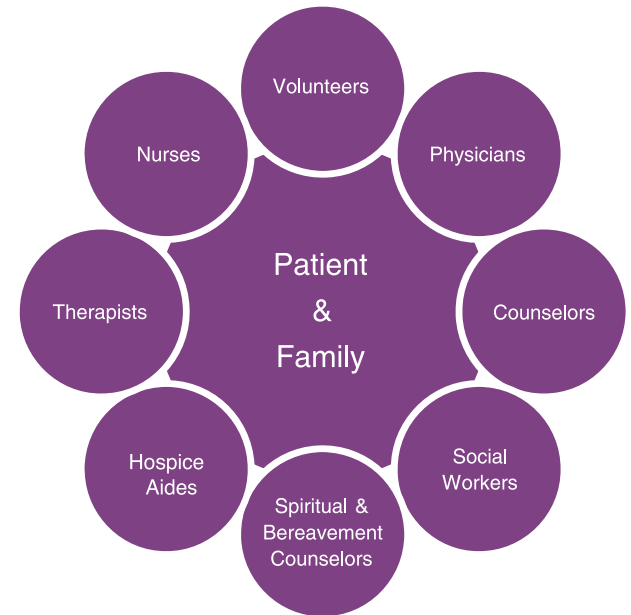
The majority of hospice care is provided in the place the patient calls home. In addition to private residences, this includes nursing homes, assisted living facilities, and residential facilities. Hospice care may also be provided in freestanding hospice facilities and hospitals (see Levels of Care).

## 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.

**Figure 1: Structure of the interdisciplinary team**





## Introduction (continued)

- **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 eight 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.
- **Respite Care (also referred to as 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 with 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 nursing facility with a registered nursing available 24 hours a day to provide direct patient care.

### 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 as it is the only Medicare provider which requires volunteers to provide at least five percent 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 to support patient care and clinical services ("clinical support")
- Engaging in a variety of activities such as fundraising, outreach and education, and serving on a hospice's board of directors (general support)

### Bereavement Services

Counseling or grief support for the patient and their 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 in addition to supporting patients and their families.



## Introduction (continued)

### Quality of Care

In 2010, the Patient Protection and Affordable Care Act (ACA) mandated the initiation of a quality reporting program for hospices known as the Hospice Quality Reporting Program (HQRP). All Medicare-certified hospices must comply with HQRP reporting requirements; failure to comply results in a percentage point reduction to the Annual Payment Update (APU) for the corresponding fiscal year.

CMS determines the quality measures hospices must report and the processes they must use to submit data for those measures. In addition, data from HQRP measures are displayed on Care Compare, the official CMS website for publicly reported healthcare quality measures. Currently, the measures included in the HQRP are the Hospice Item Set Comprehensive Assessment Measure at Admission, Hospice Visits in Last Days of Life, the Hospice Care Index, and the CAHPS® Hospice Survey.

### Medicare Advantage Value-Based Insurance Design (VBID)

The Medicare Advantage (MA) value-based insurance design (VBID) is a model with the goal of providing innovation, more choices, and high-quality, person-centered care to Medicare beneficiaries. The hospice benefit component (sometimes referred to as the hospice carve-in) in MA plans participating in VBID must include palliative care and transitional concurrent care in addition to hospice services. The palliative and concurrent care eligibility and services are designed by each MA organization. The Hospice Benefit component began in 2021 and is currently set to end in 2030.

See [appendix](#) for details on methodology, limitations, and data sources, including cited references within the report.

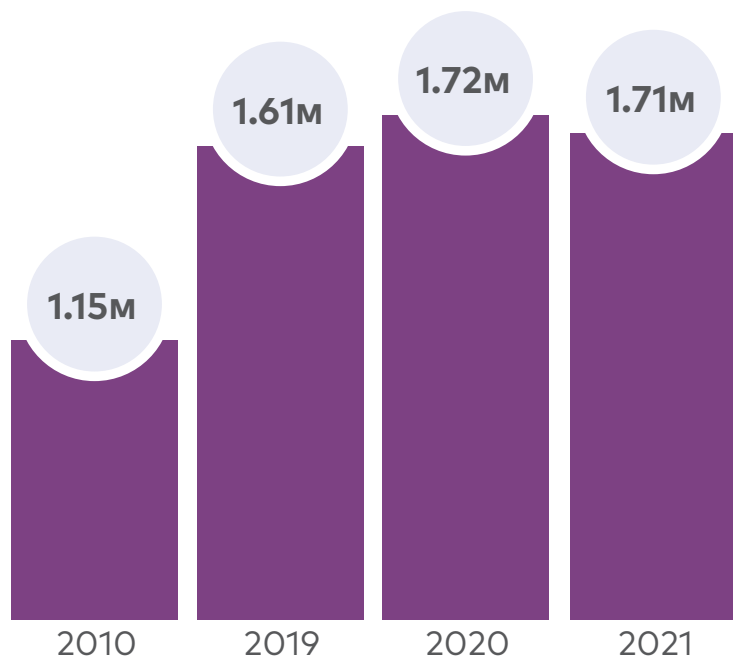
# Section 2: Who Receives Hospice Care?

## How many Medicare beneficiaries received care?

As seen in Figure 2, 1.71 million Medicare beneficiaries were enrolled in hospice care for one day or more in calendar year (CY) 2021. This is flat from 2020. This includes patients who:

- Died while enrolled in hospice
- Were enrolled in hospice in 2020 and continued to receive care in 2021
- Left hospice care alive during 2021 (live discharges)

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



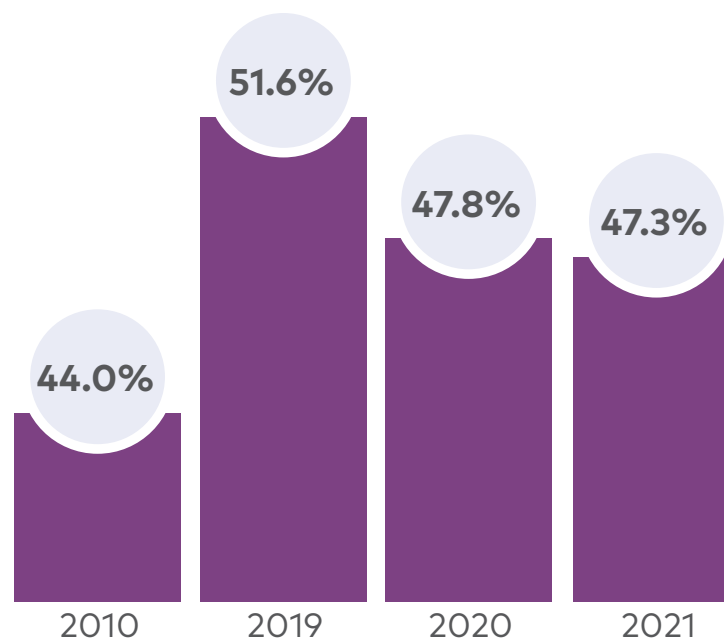
Source: MedPAC March 2023 Report to Congress, 10-4

## What proportion of Medicare decedents were served by hospice?

Of all Medicare decedents<sup>1</sup> in CY 2021, 47.3% received one day or more of hospice care and were enrolled in hospice at the time of death. This continues the downward trend from 2020. This decrease was likely due to death continuing to outpace the growth in hospice due to COVID-19.

<sup>1</sup> Decedents refers to Medicare beneficiaries who have died.

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



Source: MedPac March 2023 Report to Congress, Table 10-3



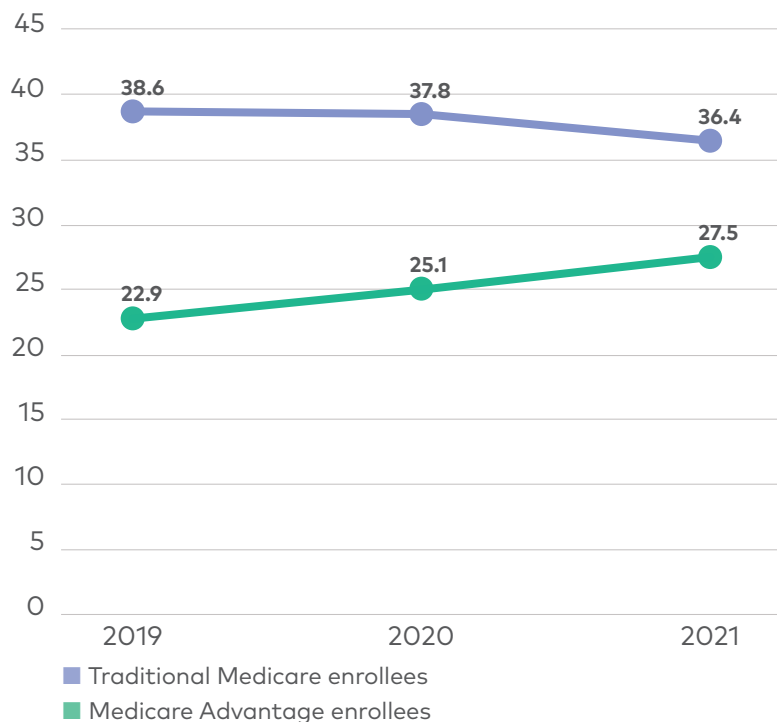
# Who Receives Hospice Care? (continued)

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

In CY 2021, Medicare Advantage (MA) continued growing into a larger portion of the Medicare population as seen in Figure 4. To access hospice, MA beneficiaries must be in a value-based insurance design (VBID) plan or shift to Traditional Medicare to utilize the Medicare Hospice Benefit. Most beneficiaries switch to Traditional Medicare.

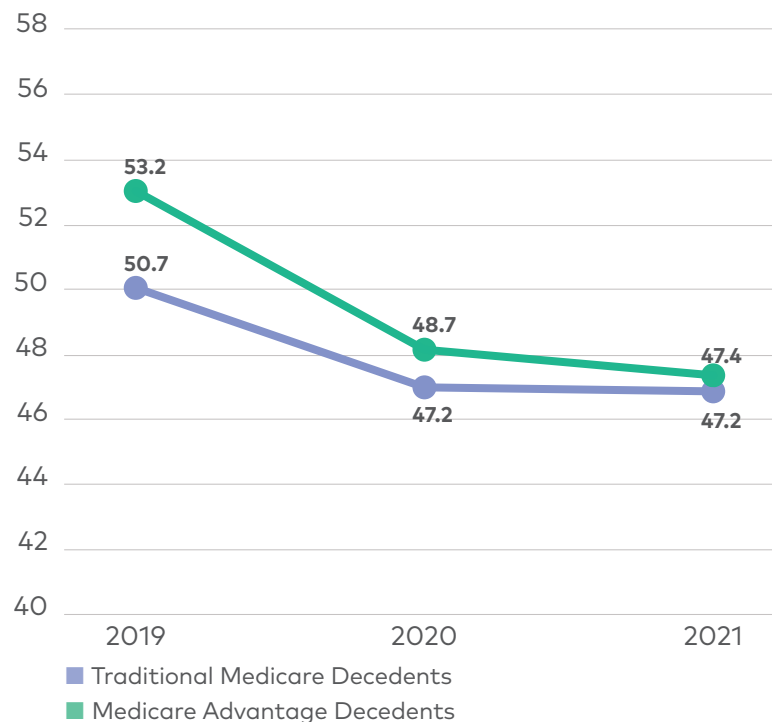
As demonstrated in Figure 5, utilization of the hospice benefit remains slightly higher among decedents originally enrolled in MA plans than among Traditional Medicare users. However, the percentage of MA beneficiaries utilizing hospice decreased (-1.3 percentage point) while Traditional Medicare beneficiaries were flat from CY 2020.

**Figure 4: Medicare Advantage v. Traditional Medicare beneficiaries (in millions)**



Source: Medicare Enrollment, June 2023  
(<https://data.cms.gov/tools/medicare-enrollment-dashboard>)

**Figure 5: Medicare Advantage v. Traditional Medicare hospice use (percentage)**



Source: MedPac March 2023 Report to Congress, Table 10-3

# Who Receives Hospice Care? (continued)

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

### Medicare Beneficiary and Decedent Characteristics

In CY 2021, approximately 2.8 million Medicare (both Traditional and Medicare Advantage) beneficiaries died which includes both the 1.7 million who elected hospice care and those who did not use hospice. When reviewing hospice specific demographic information, it is necessary to understand the larger population of Medicare beneficiaries and decedents as detailed in Table 1 below.

**Table 1: CY 2021 Medicare beneficiaries and decedents, by characteristics**

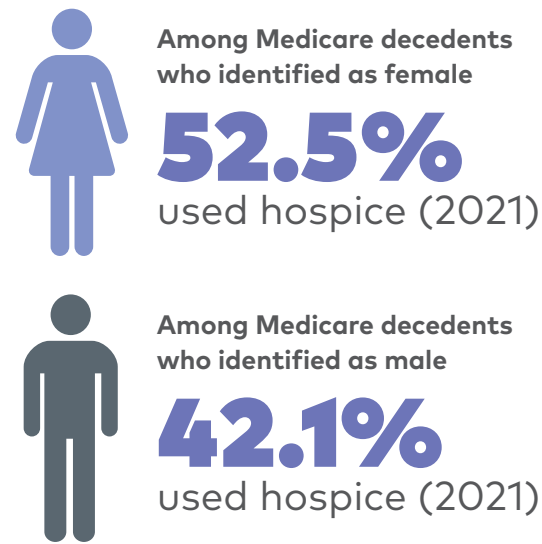
Demographic Characteristic	Total Medicare Enrollees	Decedents
<b>Total</b>	<b>63,892,626</b>	<b>2,750,141</b>
<b>Age</b>		
Under 65 Years	8,041,304	236,041
65-74 years	31,812,889	712,518
75-84 Years	17,379,347	843,160
85-94 years	5,908,242	765,942
95 years and Over	750,844	192,480
<b>Sex</b>		
Male	29,159,084	1,373,655
Female	34,733,542	1,376,486
<b>Race</b>		
Non-Hispanic White	46,504,697	2,088,893
Black (or African-American)	6,716,021	301,423
Asian/Pacific Islander	2,349,223	69,294
Hispanic	6,222,827	234,121
American Indian/Alaska Native	258,058	14,993
Other	546,619	19,574
Unknown	1,295,182	21,843

Source: CMS Program Statistics - Medicare Deaths

### Beneficiary Gender

In CY 2021, when presented with a binary question, beneficiaries who identified as female and died in 2021, 52.5% used hospice. Among beneficiaries who identified as male and died in 2021, 42.1% used hospice. Both groups saw a drop in usage of less than one percentage point from 2020.

**Figure 6: Share of Medicare decedents who use hospice, by gender**



Source: MedPac March 2023 Report to Congress, Table 10-3

**This section refers to shares of decedents which is calculated as:**

*number of beneficiaries in the group who both died and received hospice*

*total number of beneficiaries in the group who died*

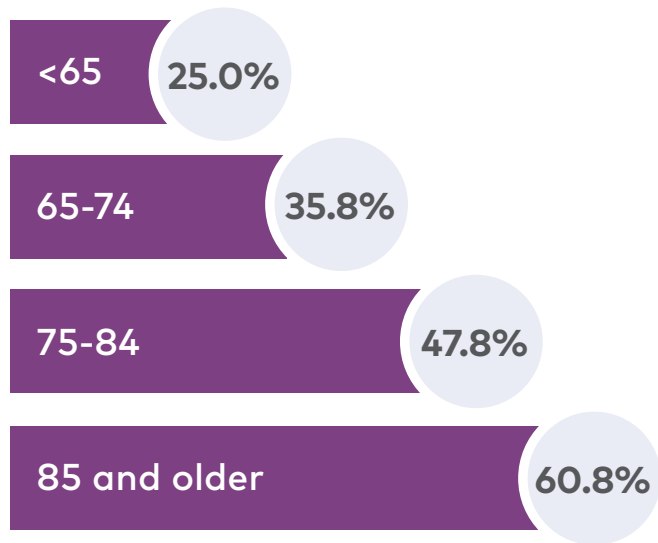
This calculation compares how each group accesses hospice but does not compare size of the groups or health disparities or inequities factors which can impact the those who access Medicare.

# Who Receives Hospice Care? (continued)

## Beneficiary Age

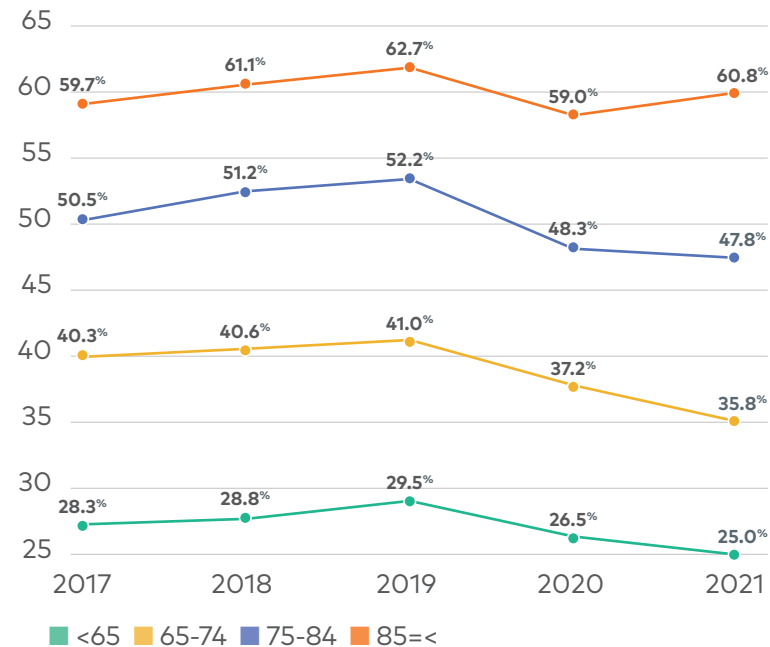
In CY 2021, as shown in Figure 7, 60.8% of Medicare decedents age 85 years and older utilized the Medicare Hospice Benefit, while progressively smaller percentages of decedents in younger age groups received hospice care. Figure 8 highlights beneficiaries over 85 were the only age group who saw an increase in usage in CY 2021, but no age group has returned to pre-COVID-19 levels.

**Figure 7: Share of Medicare decedents who used hospice, by age 2021 (percentage)**



Source: MedPAC March 2023 Report to Congress, Table 10-3

**Figure 8: Share of Medicare decedents who used hospice, by age 2017-21 (percentage)**



Source: MedPAC March 2023 Report to Congress, Table 10-3 & MedPAC March 2022 Report to Congress, Table 11-3

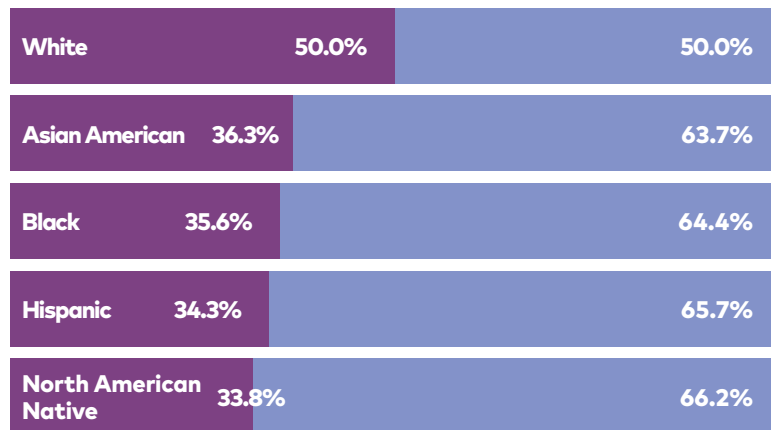
# Who Receives Hospice Care? (continued)

## Patient Race/Ethnicity

In CY 2021, 50.0% of White Medicare decedent beneficiaries used the Medicare Hospice Benefit. 36.3% of Asian American Medicare decedent beneficiaries and 35.6% of Black Medicare decedent beneficiaries enrolled in hospice in 2021. 34.3% of Hispanic and 33.8% of North American Native Medicare decedents used hospice in 2021.

2. North American Native is an updated term for the previously used American Indian/Alaska Native.

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

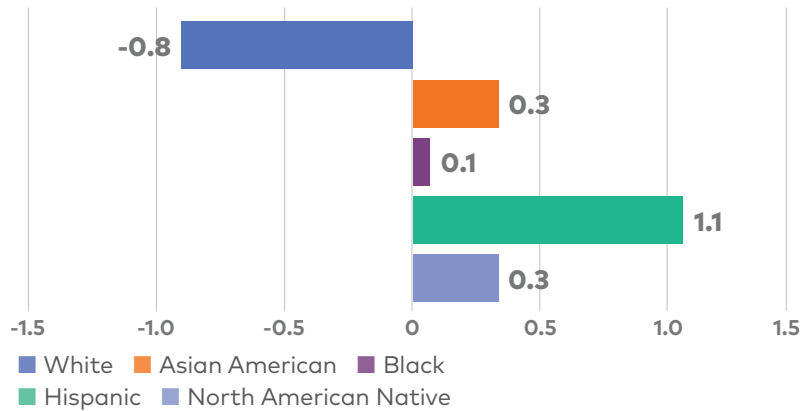


■ Medicare Decedents who utilized hospice  
 ■ Medicare Decedents who did not utilize hospice

Source: MedPAC March 2023 Report to Congress, Table 10-3

CY 2021 saw an increase in hospice utilizations by all race/ethnicity groups except White beneficiaries which saw a -0.8 percentage point decrease. Despite this rebound from the 2020 decrease, no group has returned to pre-COVID-19 utilization percentages.

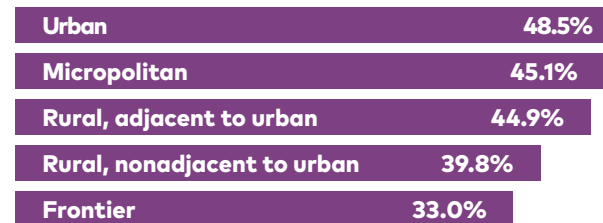
**Figure 10: Percentage point change of decedents who use hospice, by race**



## Beneficiary Location

In CY 2021, a higher percentage of decedent beneficiaries located in an urban area (48.5%) utilized hospice compared to rural (44.9%, 39.8%) or frontier (33.0%) decedent beneficiaries. Despite multiple rural classifications, rural decedents near an urban community are more similar to urban decedents; whereas rural decedents not near an urban community have a utilization rate more similar to frontier decedents. However, micropolitan decedents saw the largest decrease from 2020 to 2021 (-1.7 percentage points).

**Figure 11: Share of Medicare decedents who use hospice, by location**



Source: MedPAC March 2023 Report to Congress, Table 10-3



# Who Receives Hospice Care? (continued)

## Principal Diagnosis

The principal hospice diagnosis is the diagnosis (based on ICD-10 codes) determined to be the most contributory to the patient's terminal prognosis. While cancer is in the top 20 diagnoses twice, it is tied with Alzheimer's/nervous system disorders/organic psychosis as the top category of diagnosis (24%). Although COVID-19 accounts for only 2% of primary diagnoses, it may still have been a secondary or contributory diagnosis.

**Table 2: FY 2022 Top 20 Principal Hospice Diagnoses, by ICD-10 code**

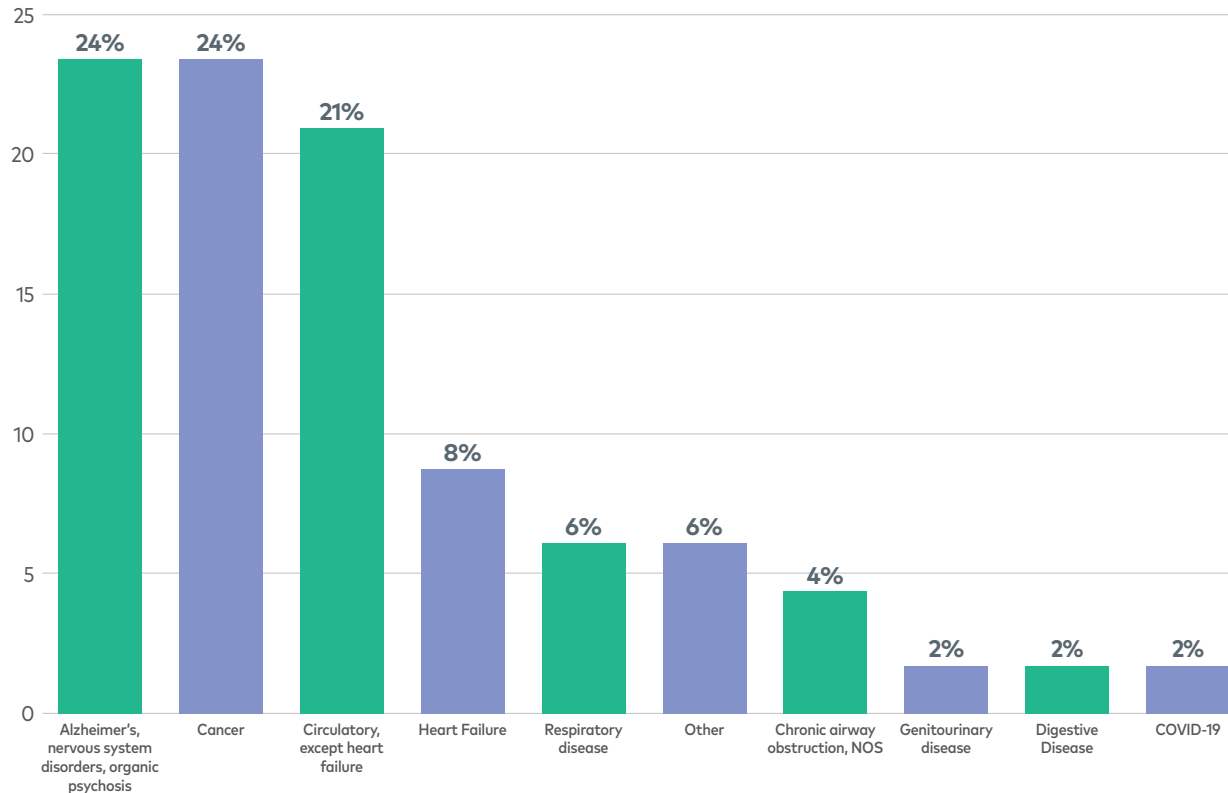
Rank	"International Classification of Diseases, Tenth Revision (ICD-10)/Reported Principal Diagnosis"	Number of Beneficiaries	Percentage of all Reported Principal Diagnoses
1	G30.9-Alzheimer disease, unspecified	135,910	7.4%
2	G31.1-Senile degeneration of brain, not elsewhere classified	124,365	6.8%
3	J44.9-Chronic obstructive pulmonary disease, unspecified	78,630	4.3%
4	G30.1-Alzheimer disease with late onset	63,980	3.5%
5	I50.9-Heart failure, unspecified	52,375	2.8%
6	G20-Parkinson disease	52,155	2.8%
7	"I25.10-Atherosclerotic heart disease of native coronary artery without angina pectoris"	47,117	2.6%
8	"C34.90-Malignant neoplasm of unspecified part of unspecified bronchus or lung"	44,093	2.4%
9	U07.1-Emergency use of U07.1	43,505	2.4%
10	I67.2-Cerebral atherosclerosis	38,543	2.1%
11	I11.0-Hypertensive heart disease with (congestive) heart failure	36,860	2.0%
12	I67.9-Cerebrovascular disease, unspecified	35,120	1.9%
13	E43-Unspecified severe protein-energy malnutrition	33,111	1.8%
14	I63.9-Cerebral infarction, unspecified	29,291	1.6%
15	"I13.0-Hypertensive heart and renal disease with (congestive) heart failure"	27,455	1.5%
16	C61-Malignant neoplasm of prostate	24,806	1.3%
17	N18.6-End stage renal disease	24,565	1.3%
18	J96.01-Acute respiratory failure with hypoxia	23,329	1.3%
19	C25.9-Malignant neoplasm: Pancreas, unspecified	22,128	1.2%
20	"J44.1-Chronic obstructive pulmonary disease with acute exacerbation, unspecified"	20,928	1.1%

Source: FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 2

# Who Receives Hospice Care? (continued)

As seen in Figure 13, patients with a neurological primary diagnosis have the longest average length of stay (155 days) followed by chronic obstructive pulmonary disease (COP) with 140 days. While cancer is in the top 20 diagnoses twice, it is tied with Alzheimer's/nervous system disorders/organic psychosis as the top category of diagnosis (24%). Although COVID-19 accounts for only 2% of primary diagnoses, it may still have been a secondary or contributory diagnosis.

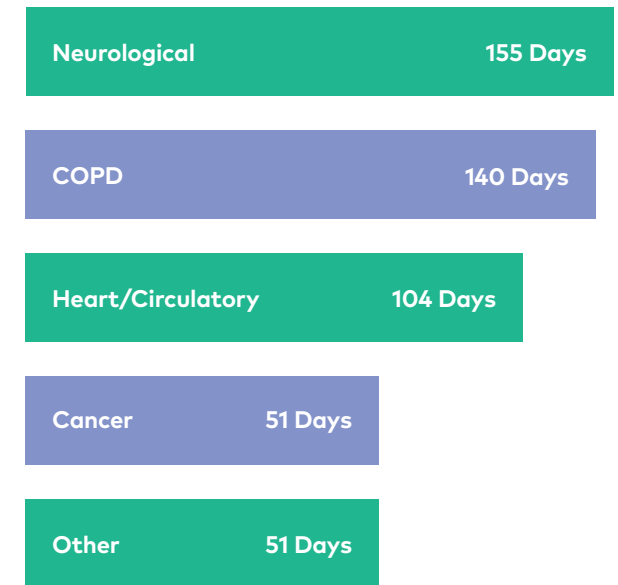
**Figure 12: CY 2021 Hospice cases by primary diagnosis (percentage)**



**Note:** Note: NOS (not otherwise specified). Cases include all patients who received hospice care in 2021, not just decedents. "Diagnosis" reflects primary diagnosis on the beneficiary's last hospice claim in 2021. Subgroups may not sum to 100 percent due to rounding.

**Source:** FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 2

**Figure 13: CY 2021 Average length of stay, in days, by diagnosis**



**Source:** MedPAC July 2023 Data Book, Chart 11-14

# Section 3: How Much Care Is Received?

## Length of Stay

The average lifetime length of stay (LOS) for Medicare decedents enrolled in hospice in 2021 was 92.1 days; a decrease from 2020 which saw the highest increase in five years. The median lifetime length of stay (MLOS) was 17 days which is a decrease from the consistent 18 days over the last five years.

**Table 3: Average lifetime length of stay, in days**

Year	Average lifetime length of stay among decedents (in days)	Median lifetime length of stay among decedents (in days)	Number of Medicare decedents who used hospice (in millions)
2010	87.8	18	0.87
2019	92.5	18	1.20
2020	97.0	18	1.31
2021	92.1	17	1.29

**Note:** 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.

**Source:** MedPAC March 2023 Report to Congress, Table 10-4

## Days of Care by Lifetime Length of Stay in 2020

- 10% of patients were enrolled in hospice for two days or less.
- 25% of patients were enrolled in hospice for five days or less.
- 50% of patients were enrolled for 17 days or less.
- 75% of patients were enrolled for 79 days or less.
- The top 10% of patients were enrolled for more than 264 days.

**Figure 14 CY 2021 days of care by length of stay, in days**



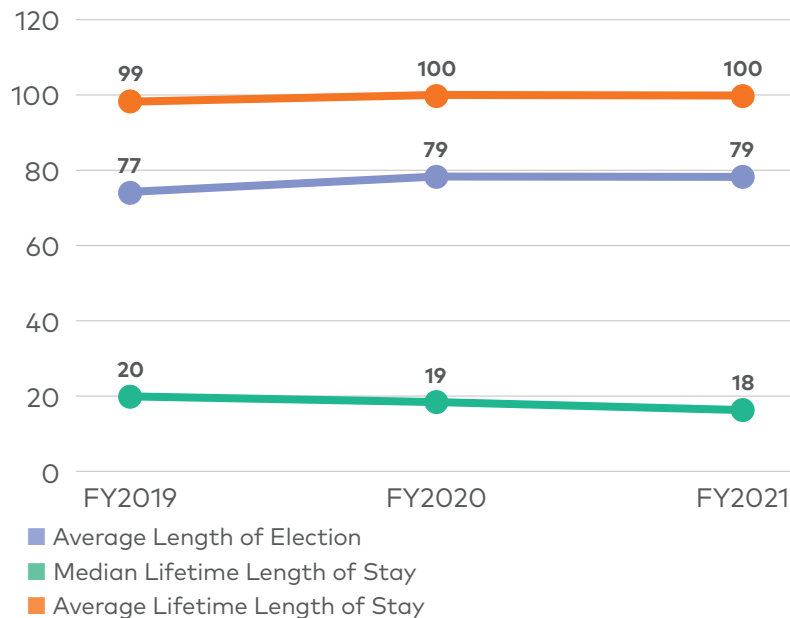
**Source:** MedPAC July 2023 Data Book, Chart 11-13

# How Much Care Is Received? (continued)

## Days of Care

Figure 15 depicts the variation in length of stay between median and average lifetime (includes all elections of hospices) and election (a patient may be included twice if they had multiple elections). The difference in the median and the average shows how despite some patients having very long lengths of stay (due to a variety of factors), most patients have a short length of stay on hospice.

**Figure 15: Average lifetime lengths of stay, average length elections, and median lifetime lengths of stay, in days**



Source: FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 4

## Discharges

In CY 2021, 17.2% percent of all Medicare hospice discharges were live, which was a return to pre-pandemic level. All hospice discharges saw an increase in 2021 except for discharges for cause which did not change.

**Table 4: Rates of hospice live discharge and reported reason for discharge, CY 2019–2021 (percentage)**

Reason for Discharge	2019	2020	2021
All live discharges	17.4%	15.4%	17.2%
<b>Patient-Initiated Live Discharges</b>			
Revocation	6.5	5.7	6.3
Transferred hospice providers	2.3	2.2	2.4
<b>Hospice-Initiated Live Discharges</b>			
No longer terminally ill	6.5	5.6	6.3
Moved out of service area	1.7	1.6	2
Discharge for cause	0.3	0.3	0.3

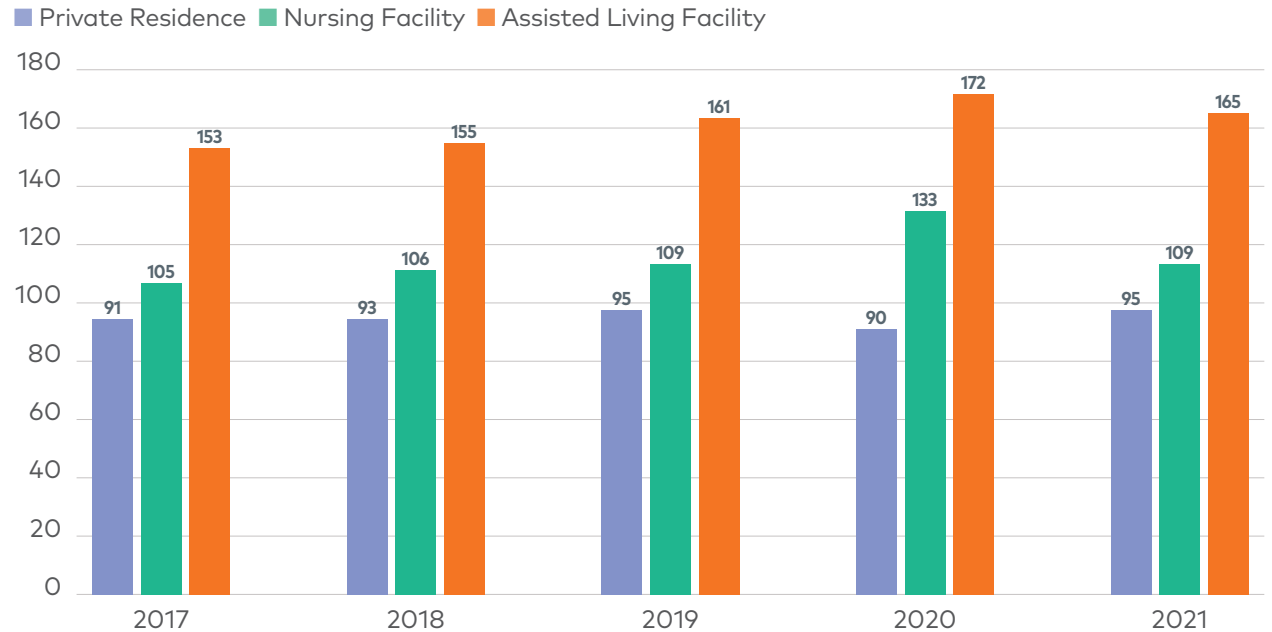
Source: MedPAC July 2023 Data Book, Chart 11-19

# How Much Care Is Received? (continued)

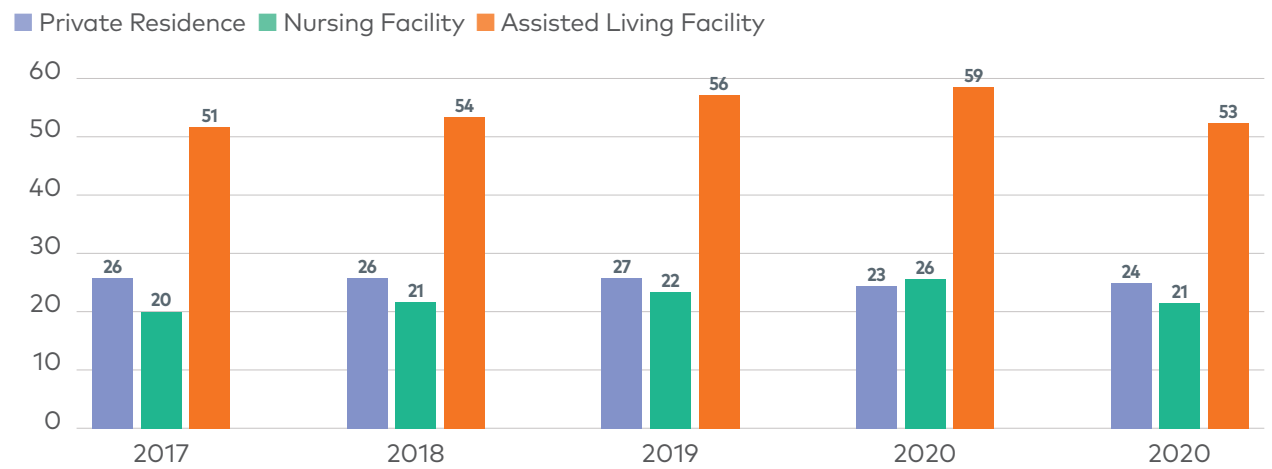
## Location of Care

Average length of stay by location of care as shown in Figure 16 was 95 days at a private residence, 109 days in nursing facilities, and 165 days in assisted living facilities. Median length of stay by location of care, shown in Figure 17, were 24 days at a private residence, 21 days in nursing facilities, and 53 days in assisted living facilities. The variance between average and median lengths of stay indicates that although some patients have long lengths of stay, most patients have short hospice stays.

**Figure 16: Average length of stay by location of care, in days**



**Figure 17: Median days by location of care, in days**

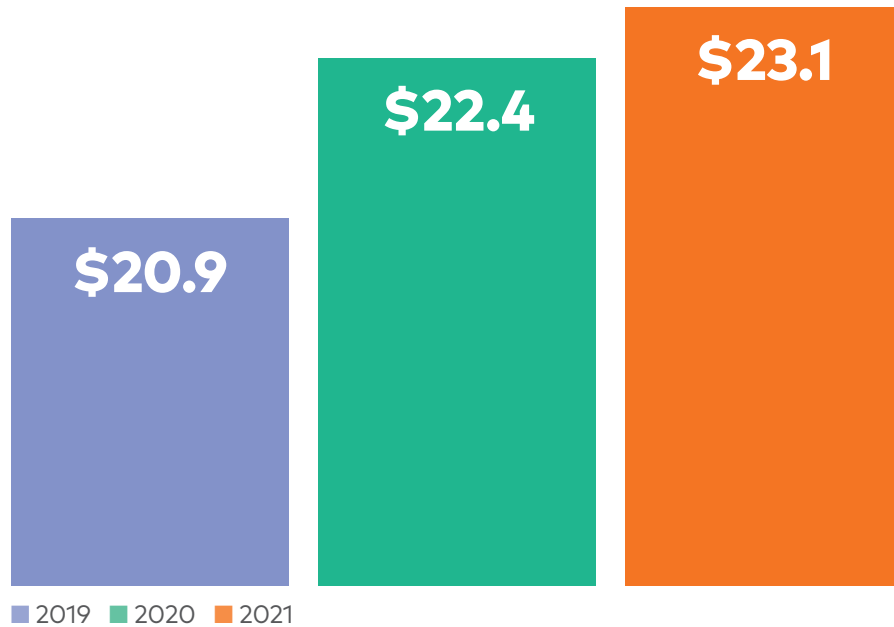


Source: MedPAC July 2023 Data Book, Chart 11-14; MedPAC March 2022 Report to Congress, Table 11-7

# Section 4: How Does Medicare Pay for Hospice?

Medicare paid hospice providers a total of \$23.1 billion dollars for care provided in CY 2021, representing an increase of 2.8% over the previous year. This is slower growth compared to 2019-2020.

**Figure 18 Medicare spending (billions of US dollars)**



Source: MedPAC March 2023 Report to Congress, table 10-4

## Spending by Level of Care

In FY 2022, the vast majority of Medicare days of care were at the routine home care (RHC) level of care for both percent of payments made and percent of days of care provided. The greatest change since FY 2013 is the decrease in both payments and days of continuous home care (CHC) and general inpatient (GIP); whereas, days and payments were stable for inpatient respite care.

**Table 5: Percent of payment, by level of care**

Percent of Payment by Level of Care	2013	2022
Routine home care	90.6%	93.7%
Continuous home care	1.8%	0.6%
Inpatient respite care	0.3%	0.7%
General inpatient care	7.3%	5.0%

**Table 6: Percent of days, by level of care**

Percent of Days by Level of Care	2013	2022
Routine home care	97.5%	98.8%
Continuous home care	0.4%	0.1%
Inpatient respite care	0.3%	0.3%
General inpatient care	1.8%	0.9%

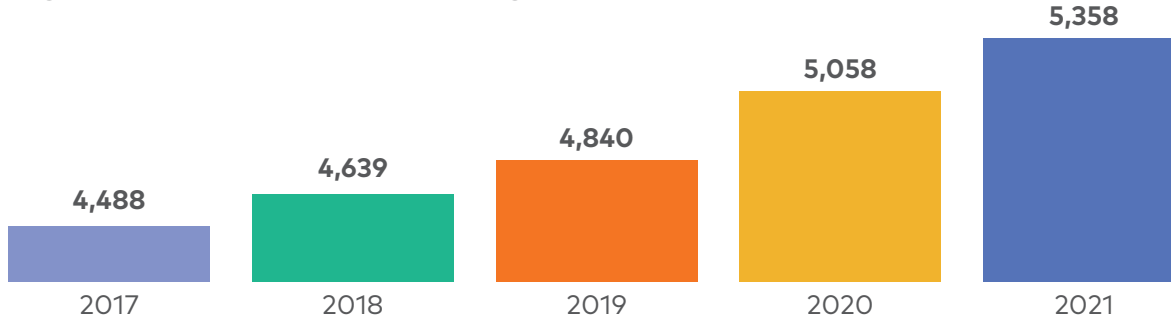
Source: FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 3

# Section 5: Who Provides Care?

## How many hospices were in operation in 2021?

In CY 2021, there were 5,358 Medicare certified hospices in operation based on claims submitted. This is an increase of 300 hospices from 2020 and outpaced the average annual percent change since 2017.

**Figure 19: Number of operating Medicare certified hospices**



Source: MedPAC March 2023 Report to Congress, Table 10-2

## What are the characteristics of Medicare certified hospices?

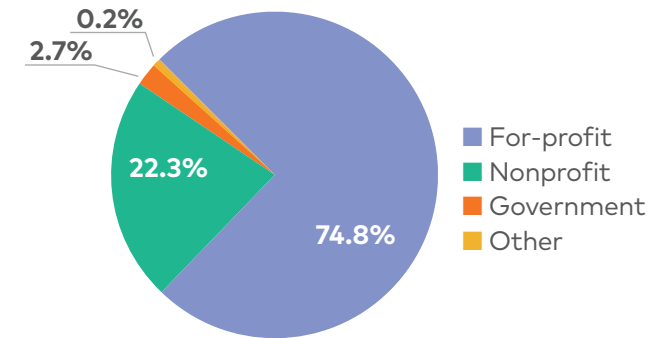
As shown in Table 7, the growth in hospice ownership in CY 2021 is being driven by the growth in for-profit (8.6%), freestanding (7.7%), and urban providers (7.4%). The largest decreases were with government (-2.1%), skilled nursing facility (SNF) based (-10.5%), and rural providers (-0.9%).

**Table 7: Characteristics of Medicare certified hospices**

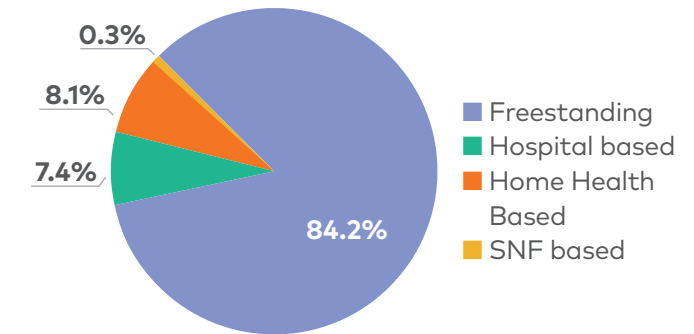
Category	2020	2021	Percent change 2020–2021
For profit	3691	4008	8.6%
Nonprofit	1220	1195	-2.0%
Government	146	143	-2.1%
Freestanding	4189	4511	7.7%
Hospital based	413	396	-4.1%
Home health based	437	434	-0.7%
SNF based	19	17	-10.5%
Urban	4196	4505	7.4%
Rural	853	845	-0.9%

Source: MedPAC March 2023 Report to Congress, Table 10-2

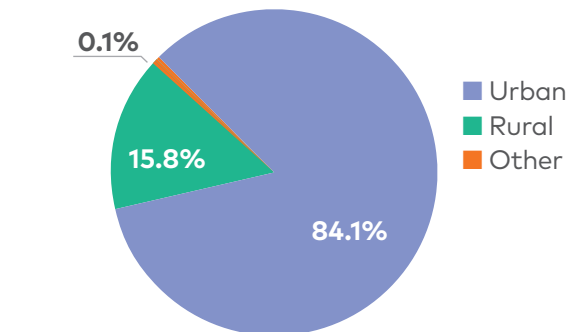
**Figure 20: Tax status**



**Figure 21: Hospice structure**



**Figure 22: Hospice location**

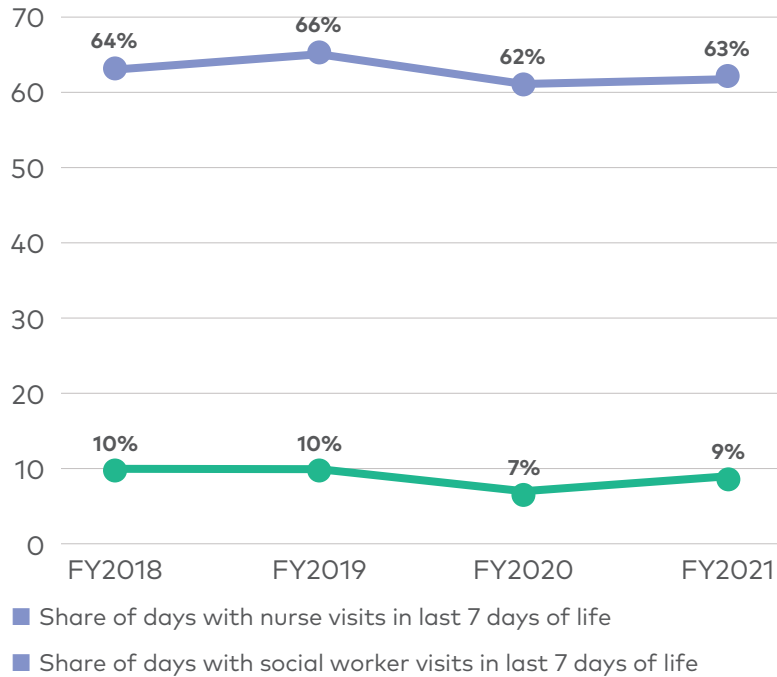


Source: MedPAC March 2023 Report to Congress, Table 10-2

# Section 6: What is the Quality of Hospice Care?

CY 2021 saw an increase in visits in the last days of life by both nurses and social workers after a decline in 2020.

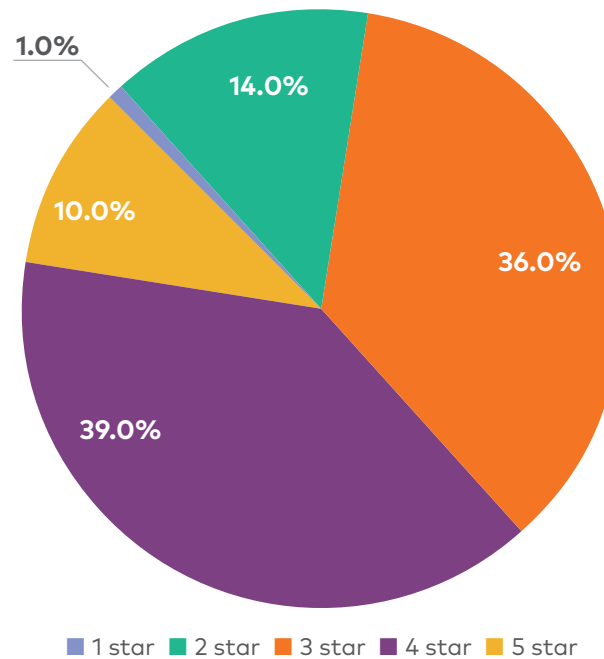
**Figure 23: Share of days with visits in last seven days of life (percentage)**



Source: MedPAC March 2023 Report to Congress, Table 10-9

In the most recently available data (April 2019-December 2019, July 2020-September 2021), 49.0% of participating providers received four or five stars on the CAHPS® (Consumer Assessment of Healthcare Providers and Systems) survey. The CAHPS® survey assesses the experiences of patients who died while receiving hospice care and their primary informal caregivers.

**Figure 24: Breakdown of hospice star ratings (percentage)**



Source: MedPAC March 2023 Report to Congress, Table 10-8



# Special Focus: Value-Based Insurance Design (VBID)

Value-based insurance design (VBID) is a CMS Innovation Center (CMMI) model with the goal of providing innovation, more choices, and high-quality, person-centered care to Medicare beneficiaries through Medicare Advantage (MA). Starting in 2021, MA plans could voluntarily add a hospice benefit to their VBID plans. VBID beneficiaries are not included in the data on beneficiaries who utilize the Traditional Medicare Hospice Benefit.

From CY 2021 to 2022, there was an increase in both participating providers and beneficiaries as well as an increase in the percentage of use of in-network providers.

**Table 8: Participating hospice providers**

Participating hospice providers	2021	2022
In network hospice providers	17%	22%
Out of network hospice providers	83%	78%
<b>Total providers</b>	<b>596</b>	<b>1,168</b>
VBID hospice beneficiaries	2021	2022
Beneficiaries who utilized in network hospices	37%	48%
Beneficiaries who utilized out of network hospices	63%	52%
<b>Total beneficiaries</b>	<b>9,630</b>	<b>19,065</b>

*Source: CMS Value-Based Insurance Design Model, Findings at a Glance, 2021-2022*

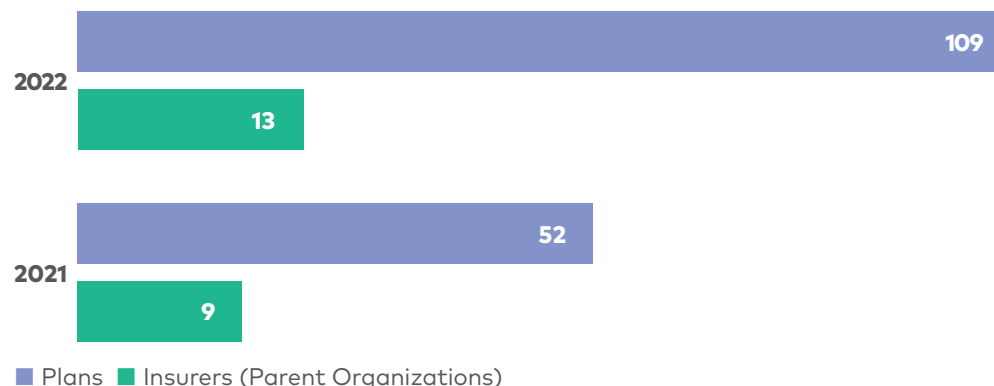
**Table 9: VBID hospice beneficiaries**

Characteristics	In Network Providers		Out of Network	
	#	%	#	%
For-profit	177	68.1%	655	68.1%
Nonprofit	58	22.3%	195	20.3%
Other	25	9.6%	93	9.7%
Rural	22	8.5%	83	8.6%
Non-rural	238	91.5%	879	91.4%

*Source: CMS Value-Based Insurance Design Model, Findings at a Glance, 2021-2022*

From CY 2021 to CY 2022, there was also an increase in the number insurers (MA parent organizations) and plans participating in VBID. However, some participating insurers and plans did not continue after 2021.

**Figure 25: Medicare Advantage plan participation, CY 2021-2022**



*Source: CMS Value-Based Insurance Design Model, Findings at a Glance, 2021-2022*

# Appendix

## Citations

[MedPAC March 2023 Report to Congress, Chapter 10: Hospice services](#)

[MedPAC July 2023 Data Book, Section 11: Other services](#)

[FY 2024 Hospice Wage Index and Quality proposed rule \(CMS-17787-9\)](#)

[MA VBID Model Phase II: Second Annual Evaluation Hospice At-A-Glance Report](#)

[CMS Program Statistics – Medicare Deaths](#)

## Limitations

For this report, only sources with comprehensive national level claims data were utilized. More detailed information may be available but did not include all Medicare hospice claims for the time period of this report's review.

In addition, data reported may be in calendar year (January through December) or fiscal year (October through September).

Finally, the data utilized is limited by the format of data collected by the Centers for Medicare and Medicaid Services; specifically, the limited language describing gender and race/ethnicity.

## 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/](http://www.nhpco.org/hospice-care-overview/hospice-facts-figures/)

**Email:** [Communications@nhpco.org](mailto:Communications@nhpco.org)

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**NHPCO**

National Hospice and Palliative  
Care Organization

**NHPCO**

1731 King Street  
Alexandria, VA 22314

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**DECEMBER 2023**



# National Minority Health Month: Health Disparities in Rural America

By: Jessica Seigel | 4/05/18

The Department of Health and Human Services honors the month of April as National Minority Health Month, an opportunity to highlight the unique needs of minority populations across the United States.

Rural communities face unique challenges, from limited resources and geographic isolation, to low population density and persistent poverty. Rural Americans are at disproportionate risk of being uninsured, lacking access to care, and experiencing worse health outcomes, but even within rural populations there are disparities based on gender and race/ethnicity. Recently, the Center for Disease Control (CDC) found that rural communities have increasing racial diversity, increasing the importance of understanding the demographics of rural America and the breakdown of health disparities to identify how best to eliminate these disparities and improve the health of all rural Americans.

## **Economic Opportunity Effects Outcomes**

Lack of economic opportunity in rural America effects health choices and outcomes. Poverty and health are inextricably linked the result of a multitude of factors both directly related to health care such as access to providers and those impacting health such as access to healthy foods.

18% of rural populations are living below the poverty threshold, compared to less than 16% in urban areas (HRSA Health Equity Report 2017)

62% of rural Black Americans and 53% of rural Hispanic Americans are living in poverty (income under \$25,000 annually) compared to



As a result, 25% of Black Rural Adults and 23% of Hispanic Rural Adults were unable to see a doctor in the past year (study from 2012-2015) because of the cost (compared to 15% of White Rural Adults). While only 16% of rural White Adults have no health coverage, 27% of rural Black Adults, 39% of Hispanic Adults, and 15% of Native American Adults have no health coverage.

While access to care is an issue for all rural populations, it is of greater issue in majority minority rural communities. Twenty percent of Americans live in rural areas, while only nine percent of the nation's physicians practice in these areas. While 3 of 5 rural white Americans live in Health Professions Shortage Areas (HPSAs), a shocking 3 out of 4 rural minority Americans do (71% Blacks, 76% Hispanics, 73% Native Americans).

Access to care and utilization of available care services are directly related to outcomes. While all rural Americans are more likely than urban Americans to report fair or poor health status, rural minority populations report even higher rates of fair or poor health status: 19% of rural White Adults, 29% of rural Black Adults, 28% of rural Hispanic Adults, and 29% of rural Native American Adults.

### **Maternity Care and Infant Mortality**

HRSA's 2017 Health Equity Report showed that the difference in urban and rural life expectancy begins at birth: the highest infant mortality rate occurs in small rural communities. Infant mortality rates are 15% higher in rural counties, and the most rural counties have the highest infant mortality rate, 32% higher than the lowest rate for suburban areas. Yet, between 2004 and 2014 more than 200 rural hospitals stopped providing labor and delivery services. When distance to maternity care is directly correlated with outcomes, this care shortage has a devastating effect on the health of both the mother and the infant.

Rural counties with higher percentages of African American women



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obstetric services between 2004-2014.

### **Substance Use and Treatment**

Substance Use Disorder (SUD) and substance abuse related deaths have grown exponentially in recent years in rural America as the spread of opioids, fentanyl, and heroin have created a growing epidemic. Overall, substance use rates are higher in minority populations in rural communities: 23% of rural Native Americans, and 16% of both rural Hispanic and Black Americans engage in binge drinking.

While the opioid epidemic is often portrayed as an issue primarily for White Americans, Native American communities, almost entirely rural, have been gravely impacted by the crisis. By 2014, the CDC reported that Native Americans had the highest death rate from opioids. Rates of opioid related deaths have increased in White, Native, Hispanic and Black communities in rural America.

### **Seeking Solutions for Rural Minority Communities**

Attention to racial and ethnic disparities in care has increased among policymakers; however, there is little agreement on what can or should be done to reduce these disparities. NRHA previously published a Policy Paper on Racial and Ethnic Health Disparities in Rural America and found that there are some key solutions that can begin to improve outcomes for rural minority populations including: telemedicine, cultural competency training, improved data collection, and grassroots community involvement.

The elimination of these disparities in health status will require important changes in the ways health care is delivered, financed, and documented. This Minority Health Month and throughout the year, NRHA will continue to advocate for access to health care for all rural Americans, especially for particularly vulnerable populations such as ethnic and minority populations living in rural and medically underserved areas. Ensuring access to care for all rural Americans will help us move forward to greater health equity.



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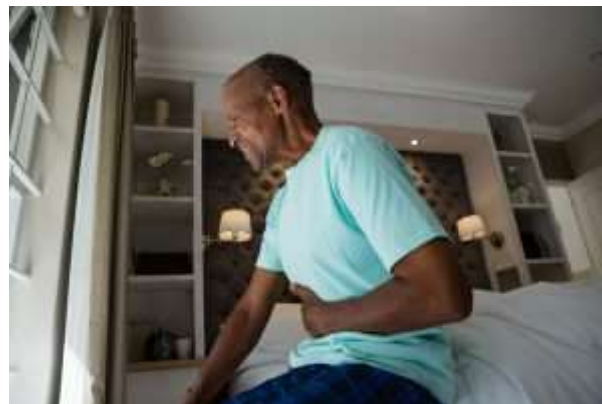
## ARTICLE

# Hospice Use Lower Among African Americans

[▶ Geriatrics](#)

By Tim Pittman

Published January 15, 2018



African Americans use hospice services at far lower rates than whites and are more likely to experience untreated pain at the end of their lives, according to Duke geriatric researchers.

The disparities experienced by African Americans across the health spectrum are also evident as those patients reach the end of their lives, says Kimberly S. Johnson, MD, a Duke researcher and specialist in both geriatric and palliative medicine.

African Americans are more likely to report dissatisfaction with care and problems in communicating with providers, Johnson says, although hospice use improves the care experience for patients and their caregivers.

The most commonly cited barriers to hospice use for African Americans include preferences for life-sustaining therapies, lack of knowledge about hospice, general mistrust of the health care

barriers is critical to increase the overall quality of life for this population, Johnson says.

Citing data from the National Hospice and Palliative Care Organization, Johnson says that African Americans make up only about 8% of hospice patients, while whites account for more than 80%. In the United States, the population of African Americans exceeds 12%. This statistic is particularly surprising, Johnson says, because African Americans are more likely to have many of the conditions common to hospice care such as cancer and heart disease.

Johnson notes, however, that as hospice use has increased over time, African American and white Medicare beneficiaries have benefitted, but African Americans continue to use hospice services less frequently. In 2014, about 50% of white Medicare patients were in hospice care at the time of death. Less than 40% of African American patients were enrolled.

The gap between white and African American proportional use of hospice should send a strong signal to hospice owners to improve outreach in their service areas.

Johnson's most recent project, [published](#) in the *Journal of Palliative Medicine* in February 2016, surveyed 118 eligible hospices in North and South Carolina as part of a cross-sectional survey to identify channels for more effective outreach to African Americans.

She encourages hospice owners to recruit more African American staff to help with outreach and to identify such community institutions as churches and primary care providers to recruit more patients.

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## Barriers to End-of-Life Care for African Americans From the Providers' Perspective: Opportunity for Intervention Development

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### Abstract

Research has shown that African Americans (AAs) are less likely to complete advance directives and enroll in hospice. We examined barriers to use of these end-of-life (EOL) care options by conducting semi-structured interviews with hospice and palliative medicine providers and leaders of a national health care organization. Barriers identified included: lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance. Providers believed that acceptance of EOL care options among AAs could be improved by increasing cultural sensitivity through education and training initiatives, and increasing staff diversity. Respondents did not have programs currently in place to increase awareness of EOL care options for underrepresented minorities, but felt that there was a need to develop these types of programs. These data can be used in future research endeavors to create interventions designed to increase awareness of EOL care options for AAs and other underrepresented minorities.

### Keywords

African Americans; hospice and palliative care; underutilization; barriers; disparities; interventions

### Introduction

Although African Americans (AAs) make up 12% of the US population,<sup>1</sup> they make up only 8.5% of hospice patients.<sup>2</sup> Many studies have shown that AAs and members of other underrepresented groups tend to utilize hospice less often than their white counterparts,<sup>3–10</sup>

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### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

and research suggests that AAs are also less likely to complete advance directives.<sup>11–15</sup> Still other studies report that AAs prefer more aggressive therapies at the end of life (EOL),<sup>16,17</sup> including mechanical ventilation and feeding tube use among the cognitively impaired patients.<sup>18,19</sup>

Barriers that may explain these racial/ethnic disparities in EOL care have been documented in the literature. Factors that contribute to racial differences in EOL care include lack of knowledge about hospice as an option for care, preferences for more aggressive therapies at the EOL, conflict between patients' spiritual beliefs and the hospice and palliative medicine philosophy of care, and mistrust in the medical system.<sup>17,20–23</sup> Although these barriers have been identified, few interventions have been designed to reduce the racial differences that have been observed.

The participants in these semistructured interviews are health care providers with experience in providing care for patients enrolled in hospice and palliative care programs. These providers had varying degrees of experience in hospice and palliative medicine—particularly with AA patients. They also came from a variety of disciplines, including social work, pastoral care, nursing, and medical practice. The primary objective of this study was to identify barriers to EOL care (advance care planning, palliative care, and hospice care) and possible intervention strategies to reduce disparities in EOL care from their perspectives. Data were collected as part of the formative research necessary to design targeted, culturally sensitive interventions that will increase awareness of EOL care options such as completion of advance directives, palliative care, and hospice among AAs and other underrepresented minorities.

## Methods

Following the approach of “typical case” purposeful sampling<sup>24</sup> and covering a diverse set of institutions and regions, 10 hospice and palliative medicine providers and 2 representatives of a national health care organization were identified and recruited to participate in the interviews. Participants were interviewed in person or by phone, and all 12 participants gave verbal consent prior to answering interview questions per institutional review board (IRB)-approved protocol. Before importation into online qualitative software, all identifying information was removed from transcripts, including mention of the participant's institution and a code assigned for each participant on the transcript of his or her responses. The IRB at UT Southwestern Medical Center University of Texas Southwestern approved all study procedures.

## Sampling Strategy

In qualitative research, purposeful sampling is intended for selecting *information-rich* cases for surveying in depth.<sup>24</sup> Typical case sampling is a strategy to identify typical cases within a population. The individuals interviewed, by sharing their views in response to a set of questions, help to develop a qualitative profile that includes the criteria best exemplifying the typical AA patient who faces choices for care at the EOL. The profile will assist in sampling members of the AA population for further knowledge generation regarding the obstacles and facilitators to the appropriate use of advance directives and hospice in EOL decision making

in this population. The data from this study will also inform the question guide for interview of members of the population of interest. Participants also contributed their relevant observations in interactions with AAs, as they relate to patient and family dynamics in EOL care.

### Question Guide

The interview guide was made up of 13 questions, including 1 regarding the typical patient seen by the practitioner/institution and others exploring the participants' experiences working with AAs patients at the EOL and their families. They were also asked their opinion of important considerations when developing interventions that will inform and support AAs as they make EOL decisions regarding advance directives, palliative care, and hospice.

### Data Collection

Participants participated in a semistructured interview. The interview guide was developed with input from all members of the study team and included open-ended questions about participants' experiences in caring for AAs at the EOL. Demographic information (race/ethnicity, years of experience in hospice and palliative medicine, discipline, etc) was collected, and initial questions were designed to examine participants' perceptions of barriers to EOL care among their AA patients. Additional questions were asked to examine assets to EOL care among AAs, the perceived amount of cultural sensitivity employed by their respective programs or organizations, whether they had programs in place to increase awareness of EOL care options among their AA patients or knew of programs, and suggestions for components of possible future interventions to address racial differences in EOL care. Patients were enrolled until thematic saturation was reached, and no more merging themes were identified.

### Coding of Data

All interviews were transcribed and coded by 2 individuals (RLR, KB) using the Dedoose qualitative analysis program. At periodic intervals, they discussed the data and refined the coding scheme. Disagreements were resolved through these discussions, and although a third individual was available to resolve any disagreements, the 2 coders were able to come to consensus on the coding scheme. A total of 70 codes were identified, many of which fell under the categories of assets and challenges to addressing EOL issues, including family dynamics, spirituality, and attitudes about the use of medications for pain management.

### Results

The health care provider participants included 6 physicians, 1 nurse practitioner, 1 registered nurse, a social worker, and chaplain all of whom worked in hospice and/or palliative medicine. They represented 1 hospice (in the northeast) and 2 palliative medicine programs (in southern states). The health organization participants were associated with the advocacy, public policy, and palliative care offices of a national health care organization that represents health care facilities across the country—including some hospices, home health agencies, and long-term care facilities. The average interview was 43 minutes (range 31–62 minutes).

There was 1 male physician participant, all other participants were female. Of the participants, 1 female physician participant self-identified as AA, while all other participants were caucasian. Years of experience in hospice and palliative medicine varied from 2 to 20 years, see Table 1.

## Types of patients

Health care providers reported that the percentage of AAs in their programs varied from less than 5% to 50%. Respondents reported that they mainly cared for adult patients, and cancer was the most common primary diagnosis. Some providers cared for more indigent patients that had no form of health care coverage or relied on county assistance programs for care, while others cared for patients who were mostly insured.

## Barriers to Hospice and Palliative Medicine for EOL Care

### Family Barriers

Providers felt that AA families were very supportive; however, the complexity of the family dynamic also proved to be challenging. When asked what barriers contributed to racial differences in use of hospice and palliative care among AAs, many cited family members' resistance to enrollment in hospice and use of palliative care as an obstacle. Providers often felt that though patients were ready to move toward comfort instead of cure, they did not because family members encouraged them to continue to seek more aggressive alternatives for care. One provider said, "I feel like the patient is very concerned about their family. They want to try. If the family wants them to try, they want to try. So they're not willing to give up in their eyes."

### Conflict With Spiritual Beliefs

Although spirituality and faith were strengths mentioned by hospice and palliative medicine providers, they noted that patients' spiritual beliefs often conflicted with their perceptions of the hospice and palliative medicine philosophy of care. Patients often expressed a desire to "leave it in God's hands" or believed that "God will take care of" them. A medical director of a hospice and palliative medicine program noted that though this did not apply to all AA patients, spirituality, an integral component of the dying experience for AAs, made having discussions about EOL care more challenging. She said:

It has sometimes been the case when I'm trying to have a conversation as a physician with a loved one and the patient. You have this wonderful, warm, comforting shield of faith that doesn't let them hear what you're trying to tell them or makes them feel that it's someone else that you must be talking about.

### Desire for Aggressive Care

Health care providers cited a desire for more aggressive care as a barrier to advance care planning, use of palliative care, and use of hospice. They described a sense that some AA patients felt that use of hospice meant that they were going to be denied treatment that others would be offered. They felt that patients did not like the idea of not being able to come back to the hospital, if their condition worsened. Changing goals of care from treatment to



comfort was particularly challenging. A provider said, “AAs seem to have more difficulties with changing goals of care to focus on comfort rather than cure . . . they’ve also had some difficulty in changing code status to do not resuscitate from being full code.”

### **Lack of Knowledge and Poor Perceptions of Hospice**

Lack of knowledge about prognosis, hospice, and palliative care, and poor perceptions of hospice and palliative care were additional barriers identified by providers. Providers sometimes felt that their AA patients were not aware of the severity of their illness. A provider said, “[Acceptance of palliative care or hospice] depends on if [providers] have told the family where they are in their illness, a lot of times they are in the dark, and then they’re hit all of a sudden with this.” Another provider also endorsed a lack of knowledge about prognosis as a barrier by stating, “I think it’s because of a lack of information about severity of illness given to those who have to make the decision to enroll.”

Providers also acknowledged a lack of knowledge about hospice and palliative medicine or misconceptions about hospice and palliative medicine. One provider believed that a barrier to hospice use was “myths about what [hospice providers] do that patients don’t understand.” Another provider reported, “I think there are some pretty popular misconceptions out there. I think one is that hospice sort of bumps people off.” Hospice was viewed by some AAs as “giving up,” and as such, one hospice physician chose to take a different approach to having discussions about hospice enrollment. This provider said, “I often have to present hospice as a mechanism of care. It can’t seem like a destination, it can never seem like we’re giving up.” Another identified theme dealt with fear of morphine or other opioids for pain and symptom management. Providers cited patients’ fears of addiction and an association with morphine as a “terminal drug” that hastened death. A hospice nurse reported “There’s very much a stigma to the ‘M’ word. I think that when they hear the word morphine, they think they’re going to die.”

### **Medical Mistrust**

Patients’ mistrust in the medical system was also a perceived barrier to EOL care options cited by providers, though some providers did not believe that they had been perceived to be distrustful themselves. They felt that some AAs and other under-represented minorities feel that they are being treated unfairly, not being offered what other patients might get, or “not getting their due.” A hospice medical director said the following

From what I’ve read and what conventional wisdom states, there is a great mistrust in the health care system. There is evidence that white upper middle class patients are more likely to get heart bypasses and high tech, more aggressive surgery than low income or minority patients . . . So that they may be less likely to accept what they feel as being turned away from the hospital gates for their care at the end of life.

A palliative medicine physician stated

My experience has been that patients come in trusting the medical system, then they get screwed, and then they cease to trust the medical system . . . When we do untrustworthy things—when we have a system that fails time and time again—it is

appropriate for people not to trust. If people don't get a follow-up appointment, if they can't reach anybody when they need help, that's how they should act. So until we create a trustworthy system, I'm not going to blame the patient for having issues about it. It's appropriate. I do have people who come in and they come in swinging, and that's okay because they are doing what they have to do to look out for their family. Then once we get to know each other and we work together, if I am trustworthy, then they trust me. But if I'm not trustworthy, they are right to be leery.

### **Acknowledgment of Illness Hastens Death**

Providers noted a pattern in attitudes about death and dying among their AA patients. They reported that in some instances, patients felt that any acknowledgement of illness meant that it would speed up the dying process. A palliative medicine physician noted the following, "Sometimes you have people who will not even admit that they're sick. I mean, I've had patients with fungating breast wounds that come in with duct tape and paper towels around their chest that say, "I can't own this." That is the hardest challenge for me—the hardest thing for me to take care of." Other providers felt that this also applied to completion of an advance directive. A palliative care social worker said, "I see that there is sometimes a superstition in actually writing an advance directive because I've heard "if I write it down, it makes it happen".

## **Ways to Improve Access to EOL Care Options for AAs**

### **Cultural Sensitivity**

All respondents believed that cultural sensitivity is needed to provide EOL care to AAs and members of other underrepresented groups. Most stated that they have had education and training in cultural sensitivity but believed that more education and training in cultural sensitivity are needed. They felt that education could come in the form of lectures, in-services, self-learning, and learning from colleagues of diverse racial/ethnic backgrounds. They believed that cultural sensitivity could also be increased by hiring staff of diverse racial and ethnic backgrounds, though hiring persons of diverse racial/ethnic backgrounds has been challenging. One provider stated, "When I've recruited in the past, I have not been able to find someone who wanted to do the clinic work. I don't know of any AA nurses that wanted to work in my role. I've talked to some of them and they say, 'I don't want to do what you do'".

### **Useful EOL Care Communication Strategies**

Many providers described approaches that they have used in caring for and communicating with AA patients and their families. Most providers believed that communication about the EOL was a gradual process that often required ongoing conversation. Given the strong influence of faith and spirituality among AA patients and their families, providers often felt that should be addressed. Some did not feel comfortable addressing that issue and relied heavily on a chaplain to provide spiritual support, while others were comfortable with including the topic in their conversations with patients. A palliative medicine physician described the approach to addressing spirituality and advance directives in the following manner:

Talking about advance directives is not against God's will. It's not anybody trying to take anything away from you. This is your chance. This is here to protect you. So here is what this can do. You tell your doctor what you want and that way we can make sure that's what you get. I think if it was sort of a self-empowering thing that would be helpful.

Another provider felt that though palliative care and hospice services are created, patients should not be pressured into choosing those services for care at the EOL. This provider said:

I think hospice is very useful for people who want hospice, but I don't think that everybody should be coerced into doing it. If it's not the right thing for the patient, leave it alone. It bugs me to ask people, "Is this what you want? Do you want comfort care or do you want aggressive treatment?" And if they want aggressive treatment, we try and talk them out of it. People should be allowed to do what they want to do. We have to meet them where they are.

### Possible Interventions

None of the participants had current programs in place to increase awareness of options for EOL care among AAs or other underrepresented minorities, and they could not identify programs sponsored by other programs or health care organizations. They did, however, acknowledge that they believed that AA patients would be receptive to educational programs—particularly if they were culturally sensitive and delivered in a way that patients could understand. They felt that AA patients would be receptive to informational videos that were culturally tailored, and they felt that specific barriers such as conflict with spirituality, lack of knowledge about EOL care options, and advance care planning should be addressed. A hospice physician stated:

If I were making tapes for educational purposes, they would be short and interactive, such as "here is the patient and here is the culturally appropriate doctor or nurse having the conversation about pain." Or about advance directives or something like that. I think I would have it in snippets and in a very short, well-acted interaction and not lecture style.

To address medical mistrust, respondents felt that having someone on the team with whom patients could identify culturally would be helpful. One respondent stated, "If you have somebody who comes in and is just like you—a normal person, speaking your language, having similar life experiences with good solid information—that would be helpful." Some felt that having someone who worked outside of the health care system, such as an AA lay health advisor with specific training in EOL care communication, would also address medical mistrust. Others, however, did cite concerns about the lay health advisor approach—particularly with regard to a lay person's lack of medical training as a potential barrier, and felt that the introduction of another individual may be overwhelming to patients. A hospice nurse said, "Patients can get to where they don't want to hear anymore, so somebody coming in to talk about advance directives is a step further down, but it's still along the same vein. It could be too much."

## Discussion

Using semistructured interviews of hospice and palliative medicine health care providers of various disciplines, we identified barriers to use of EOL care options including advance directives, palliative care, and hospice among AAs. We found that previously identified barriers continue to be associated with underutilization of hospice and advance care planning among AAs, including lack of knowledge about prognosis and EOL care options, conflict with patients' desires for aggressive treatment, and mistrust in the medical system.<sup>17,20–23</sup> The family structure and strong sense of spirituality have often been cited as strengths among members of the AA community; however, these constructs were also perceived by respondents to be barriers to their discussions about EOL care.

The interviews conducted in our study also revealed various methods that could be used to traverse those barriers that were identified. Providers felt that cultural sensitivity is needed when communicating with patients and families about EOL care, and cultural sensitivity could be enhanced through education initiatives, training, and hiring practices. They also believed that including spirituality in their discussions with patients or having pastoral care staff integrally involved would enhance these conversations.

Previous research has examined barriers to hospice and palliative care among underrepresented groups; however, few studies have been identified that evaluate interventions to reduce those disparities. Our study extends this work by not only evaluating underuse of EOL care alternatives from the points of view of a multidisciplinary sample of providers experienced in EOL care but provides some of the groundwork necessary to design and implement culturally sensitive, behavioral interventions with the goal of increasing knowledge and awareness of EOL care options (ie, advance care planning, palliative care, and hospice care) among persons who have historically underutilized these services.

There are certain limitations that should be taken into account. This study was conducted at 1 hospice and 2 palliative medicine programs. Although we tried to capture a sample that represented providers of multiple disciplines, years of experience, and regions of the country, the experiences of providers in other areas may differ. Finally, although multidisciplinary in scope, our sample was predominantly caucasian. As a result, we were unable to explore potential differences in perceptions of providers by race or ethnicity. Despite these limitations, common themes were identified that have been identified in prior studies, and targeted programs can be developed to address these barriers.

Intervention design and development is an important area that has been underutilized in EOL care research—particularly in disparities in EOL care; however, some educational interventions designed for use in EOL care and other domains have been successful.<sup>25</sup> Educational videos have been used to address health literacy about advanced dementia in the elderly patients,<sup>26</sup> and tailored audiovisual materials have also been used successfully in interventions designed to improve physician–patient communication.<sup>27</sup> Additionally, although not targeted at a specific population, EOL decision aids have been designed for patients facing advanced or terminal illness.<sup>28</sup> The lay health advisor model has also been

used successfully in intervention design to improve outcomes in various clinical conditions including pediatric asthma and cardiovascular disease.<sup>29,30</sup> Culturally sensitive interventions utilizing both audiovisual materials and the lay health advisor model could certainly be used to increase awareness of options for EOL care among the underrepresented groups, and the providers interviewed in this study believe that the patients they serve may be receptive to these methods.

The overall goal of this research was to identify barriers to care at the EOL among AAs and to perform the formative research necessary to design a culturally sensitive intervention to inform AAs with advanced illness of their end-of-life care options in a culturally sensitive manner. The providers interviewed believed that patient education programs could be effective—particularly if the program was delivered in a culturally sensitive way. They believed that AA patients would be receptive to audiovisual materials, though they would need to be tailored to fit the audience. They also felt that the lay health advisor model may be an effective method, though some expressed concern about the lay health advisor’s potential lack of medical knowledge. These factors should be taken into consideration for future research endeavors that center around EOL care among members of the AA community, and interventions should be designed to better inform AAs and other underrepresented minorities of their options for care at the EOL. We realize that barriers may continue to exist; however, efforts should continue to be made to improve the process of shared decision making. Health care providers must meet patients and families where they are and assist them with the often difficult transitions associated with the EOL.

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## References

1. US Census Bureau. State and County Quick Facts. US Department of Commerce; 2010. <http://quickfacts.census.gov/qfd/states/00000.html> [Accessed May 25, 2012]
2. NHPKO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization; 2012. [http://www.nhpco.org/files/public/statistics\\_research/hospice\\_facts\\_figures\\_oct-2010.pdf](http://www.nhpco.org/files/public/statistics_research/hospice_facts_figures_oct-2010.pdf) [Accessed April 4, 2013]
3. Cohen LL. Racial/ethnic disparities in hospice care: a systematic review. *J Palliat Med.* 2008; 11(5): 763–768. [PubMed: 18588409]
4. Connor SR, Elwert F, Spence C, Christakis NA. Racial disparity in hospice use in the United States in 2002. *Palliat Med.* 2008; 22(3):205–213. [PubMed: 18477714]
5. Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National mortality follow-back survey. *J Am Geriatr Soc.* 2003; 51(7):970–978. [PubMed: 12834517]
6. Hardy D, Chan W, Liu CC, et al. Racial disparities in the use of hospice services according to geographic residence and socioeconomic status in an elderly cohort with nonsmall cell lung cancer. *Cancer.* 2011; 117(7):1506–1515. [PubMed: 21425152]



7. Hardy D, Chan W, Liu CC, et al. Racial disparities in length of stay in hospice care by tumor stage in a large elderly cohort with non-small cell lung cancer. *Palliat Med.* 2012; 26(1):61–71. [PubMed: 21606129]
8. Kwak J, Haley WE, Chiriboga DA. Racial differences in hospice use and in-hospital death among Medicare and Medicaid dual-eligible nursing home residents. *Gerontologist.* 2008; 48(1):32–41. [PubMed: 18381830]
9. Lepore MJ, Miller SC, Gozalo P. Hospice use among urban Black and White U.S. nursing home decedents in 2006. *Gerontologist.* 2011; 51(2):251–260. [PubMed: 21076085]
10. Ludke RL, Smucker DR. Racial differences in the willingness to use hospice services. *J Palliat Med.* 2007; 10(6):1329–1337. [PubMed: 18095812]
11. Carr D. Racial differences in end-of-life planning: why don't Blacks and Latinos prepare for the inevitable? *Omega (Westport).* 2011; 63(1):1–20. [PubMed: 21748919]
12. Degenholtz HB, Arnold RA, Meisel A, Lave JR. Persistence of racial disparities in advance care plan documents among nursing home residents. *J Am Geriatr Soc.* 2002; 50(2):378–381. [PubMed: 12028224]
13. Johnson KS, Kuchibhatla M, Tulsy JA. What explains racial differences in the use of advance directives and attitudes toward hospice care? *J Am Geriatr Soc.* 2008; 56(10):1953–1958. [PubMed: 18771455]
14. Rich SE, Gruber-Baldini AL, Quinn CC, Zimmerman SI. Discussion as a factor in racial disparity in advance directive completion at nursing home admission. *J Am Geriatr Soc.* 2009; 57(1):146–152. [PubMed: 19170791]
15. Smith AK, McCarthy EP, Paulk E, et al. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. *J Clin Oncol.* 2008; 26:4131–4137. [PubMed: 18757326]
16. Johnson KS, Elbert-Avila KI, Tulsy JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans: a review of the literature. *J Am Geriatr Soc.* 2005; 53:711–719. [PubMed: 15817022]
17. Wicher CP, Meeker MA. What influences African American end-of-life preferences? *J Health Care Poor Underserved.* 2012; 23(1):28–58. [PubMed: 22643461]
18. Braun UK, Rabeneck L, McCullough LB, et al. Decreasing use of percutaneous endoscopic gastrostomy tube feeding for veterans with dementia-racial differences remain. *J Am Geriatr Soc.* 2005; 53(2):242–248. [PubMed: 15673347]
19. Gessert CE, Curry NM, Robinson A. Ethnicity and end-of-life care: the use of feeding tubes. *Ethn Dis.* 2001; 11(1):97–106. [PubMed: 11289258]
20. Born W, Greiner KA, Sylvia E, Butler J, Ahluwalia JS. Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J Palliat Med.* 2004; 7(2):247–256. [PubMed: 15130202]
21. Bullock K. The influence of culture on end-of-life decision making. *J Soc Work End Life Palliat Care.* 2011; 7(1):83–98. [PubMed: 21391079]
22. Reese DJ, Melton E, Ciaravino K. Programmatic barriers to providing culturally competent end-of-life care. *Am J Hosp Palliat Care.* 2004; 21(5):357–364. [PubMed: 15510573]
23. Washington KT, Bickel-Swenson D, Stephens N. Barriers to hospice use among African Americans: a systematic review. *Health Soc Work.* 2008; 33(4):267–274. [PubMed: 19070274]
24. Patton, MQ. *Qualitative Research & Evaluation Methods.* 3. Saint Paul, MN: SAGE Publications, Inc; 2001.
25. Duke University Institute on Care at the End of Life. [Accessed February 3, 2012] Duke Divinity School. <http://divinity.duke.edu/initiatives-centers/iceol/resources/appeal>
26. Volandes AE, Ferguson LA, Davis AD, et al. Assessing end-of-life preferences for advanced dementia in rural patients using an educational video: a randomized controlled trial. *J Palliat Med.* 2011; 14(2):169–177. [PubMed: 21254815]
27. Skinner CS, Pollak KI, Farrell D, Olsen MK, Jeffreys AS, Tulsy JA. Use of and reactions to a tailored CD-ROM designed to enhance oncologist-patient communication: the SCOPE trial intervention. *Patient Educ Couns.* 2009; 77(1):90–96. [PubMed: 19321287]

28. Matlock DD, Keech TA, McKenzie MB, Bronsert MR, Nowels CT, Kutner JS. Feasibility and acceptability of a decision aid designed for people facing advanced or terminal illness: a pilot randomized trial [published online October 28, 2011]. *Health Expect*. 2011
29. DeHaven MJ, Ramos-Roman MA, Gimpel N, et al. The Good-NEWS (Genes, Nutrition, Exercise, Wellness, and Spiritual Growth) Trial: a community-based participatory research (CBPR) trial with African-American church congregations for reducing cardiovascular disease risk factors—recruitment, measurement, and randomization. *Contemp Clin Trials*. 2011; 32(5):630–640. [PubMed: 21664298]
30. Flores G, Bridon C, Torres S, et al. Improving asthma outcomes in minority children: a randomized, controlled trial of parent mentors. *Pediatrics*. 2009; 124(6):1522–1532. [PubMed: 19948624]

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**Table 1**

## Sample Demographics.

Role	Number		
Physician	6		
Nurse practitioner	1		
Nurse	1		
Social worker	1		
Chaplain	1		
Health care organization representative	2		
	Race/ethnicity		
	Nonhispanic white	Nonhispanic black	Other
Physician	5	1	1
Nurse practitioner	1		
Nurse	1		
Social worker	1		
Chaplain	1		
Health care organization representative	1		
	Gender		
	Male	Female	
Physician	1	5	
Nurse practitioner		1	
Nurse		1	
Social worker		1	
Chaplain		1	
Health care organization representative		2	
Experience with hospice/palliative care, years			
<1	2		
1–2	3		
3–5	2		
6–10	2		
11–15	2		
>15	1		
Estimated percentage of AA patients seen			
<5	2		
6–10	1		
11–20	0		
21–30	2		
31–40	3		
41–50	2		
>50	0		



Abbreviation: AA, African American.

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# 2022 Hospice Information Gathering Report

## *Health Equity in the Hospice Setting*



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## Table of Acronyms

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>AMA</b>	American Medical Association
<b>BIPOC</b>	Black, Indigenous, and People of Color
<b>CAHPS®</b>	Hospice Consumer Assessment of Healthcare Providers and Systems
<b>CMS</b>	Centers for Medicare and Medicaid Services
<b>COPD</b>	Chronic Obstructive Pulmonary Disease
<b>FR</b>	Final Rule
<b>FY</b>	Fiscal Year
<b>HDAH</b>	Healthy Days at Home
<b>HOPE</b>	Hospice Outcomes and Patient Evaluation
<b>HQRP</b>	Hospice Quality Reporting Program
<b>LGBTQ+</b>	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning and other sexual orientations and identities
<b>NHATS</b>	National Health and Aging Trends Survey
<b>NHPCO</b>	National Hospice and Palliative Care Organization
<b>RFI</b>	Request for Information
<b>SDOH</b>	Social Determinants of Health
<b>SOGI</b>	Sexual Orientation and Gender Identity
<b>SVI</b>	Social Vulnerability Index
<b>TEP</b>	Technical Expert Panel

## Executive Summary

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### **Background**

Many Americans rely on hospice care for end-of-life support. In 2019, more than 1.6 million Medicare beneficiaries received hospice care, with Medicare spending \$20.9 billion on hospice services (MedPAC, 2021). High quality hospice services are critical to terminally ill patients. CMS anticipates expanding its Hospice Quality Reporting Program (HQRP) over the next several years to include additional meaningful quality measures to help consumers make informed decisions when selecting a hospice for end-of-life support.

Since the release of Abt's 2021 Information Gathering Report, the agency released its [Framework for Health Equity](#) which considers addressing health disparities in all of its programs, including the HQRP. Additionally, CMS requested information on a potential structural measure to address health equity in the hospice setting.<sup>1</sup> After discussion with federal stakeholders and the hospice quality measure development team, Abt staff identified health-equity as a key area where additional information could support HQRP expansion.

This 2022 Information Gathering Report reflects four main information gathering activities:

1. Updating Abt's 2020 social determinants of health (SDOH) literature review
2. Conducting interviews with experts on health equity in the hospice setting
3. Conducting a literature review focused on health equity in the hospice setting
4. Conducting a literature review for recent quality-related hospice activities

And presents these findings using the following five themes:

1. Discussing health equity
2. Access to and enrollment in hospice
3. Receipt of hospice care
4. Addressing hospice inequities
5. Other recent hospice literature

### **Discussing Health Equity**

CMS defines health equity as “the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes”<sup>2</sup>. While this definition is widely accepted, linguistic choices that contribute to marginalizing some subpopulations remain prominent. Deficit-based language focuses on the absence of certain characteristics (e.g., non-white) or defining others by their least desirable characteristics (e.g., lacking trust). Reframing language in ways that do not “blame” the patient for such

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<sup>1</sup> See [87 FR 19422](#)

<sup>2</sup> <https://www.cms.gov/pillar/health-equity>

disparities may aid in dismantling implicit bias that can create barriers to equitable hospice care. Sometimes overly inclusive terms, even if well-intentioned, can reinforce marginalization by serving as “catch all” phrases that either substitute for deficit-based language, or further obscure the groups they intend to represent – masking important variations in sub-group hospice experiences and outcomes. Examples include “minority” and Black, Indigenous, and People of Color (BIPOC), which are often used as synonyms for non-white.

### ***Access to and Enrollment in Hospice***

Historically excluded populations, including Black, Hispanic, Asian, and Indigenous Americans, are less likely to use hospice care than their white counterparts. Differences in referral patterns do not seem to be a contributing factor. In fact, recent literature suggests that Black patients are more likely to receive hospice or palliative care referrals, though this finding was not consistent across all studies and differences appear to be more common across facilities than within facilities. Overall, white patients are more likely to be aware of hospice and its benefits, but the reasons historically excluded populations are less likely to use hospice are more nuanced and complex. Other sociodemographic factors associated with the likelihood of hospice use include gender, education levels, how disenfranchised a patient’s neighborhood is, income levels, rurality, primary language, hospice-specific characteristics, and patient preferences.

With respect to timing and type of enrollment, among patients that enroll in hospice, Black and Hispanic patients tend to enroll earlier than their white counterparts, though they may stay in the hospital longer before transitioning to hospice. Findings regarding factors associated with type of enrollment (i.e., home-based vs. facility-based hospice) are mixed. One study<sup>3</sup> found that hospice providers in neighborhoods with higher proportions of women or Hispanic beneficiaries were less likely to provide home hospice care than facility-based hospice care; similarly, another study<sup>4</sup> found that white patients were more likely to receive continuous home care than patients of other races. In contrast, a third study<sup>5</sup> found that Black, Hispanic, and female patients were more likely to receive home hospice care as compared to white patients, and an additional small qualitative study<sup>6</sup> found that Animist and Christian Hmong elders prefer at-home care.

### ***Receipt of Hospice Care***

Several studies have considered the patient experience for those enrolled in hospice care, though they reflect inconsistent findings. While Black and Hispanic patients and caregivers seem to experience lower-quality care, they report overall better satisfaction and caregiver confidence than white patients and caregivers. This suggests that even when patients and caregivers experience lesser patient care, individuals do not always recognize that their care could have been better. This may be because differences are more likely to be between hospices than within a given hospice. Furthermore, Black, Hispanic, and Asian hospice patients are more likely to experience adverse outcomes, such as emergency department admission, hospitalization, and live discharge, though these differences may be related to patient preferences or other patient-specific circumstances. Studies consistently reported Asian and

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<sup>3</sup> Osakwe, Z. T., Arora, B. K., Peterson, M. L., Obioha, C. U., & Fleur-Calixte, R. S. (2021). Factors Associated with Home-Hospice Utilization. *Home Healthc Now*, 39(1), 39-47.

<sup>4</sup> Wang, S. Y., Aldridge, M. D., Canavan, M., Cherlin, E., & Bradley, E. (2016). Continuous Home Care Reduces Hospice Disenrollment and Hospitalization After Hospice Enrollment. *J Pain Symptom Manage*, 52(6), 813-821. doi:10.1016/j.jpainsymman.2016.05.031

<sup>5</sup> Mendieta, M., & Miller, A. (2018). Sociodemographic Characteristics and Lengths of Stay Associated with Acute Palliative Care: A 10-Year National Perspective. *Am J Hosp Palliat Care*, 35(12), 1512-1517.

<sup>6</sup> Her-Xiong, Y., & Schroepfer, T. (2018). Walking in Two Worlds: Hmong End of Life Beliefs & Rituals. *J Soc Work End Life Palliat Care*, 14(4), 291-314. doi:10.1080/15524256.2018.1522288

Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, and other sexual orientation and identity (LGBTQ+) populations having poorer care experiences. A few small studies indicate that women, either as patients or caretakers, may have poorer experiences of care.

Pain management, a critical component of hospice care, may also have inequities in the hospice setting. Men and Black patients may have less access to pain medication, though other studies have found no difference. Some studies that focused on Hispanic and South Asian patients reported a cultural reluctance to acknowledge pain. In studies focused on caregivers, even though knowledge of or perceived barriers to pain management varied for different populations, the caregiver experience often did not.

### ***Addressing Hospice Inequities***

Studies consistently cited community engagement as essential to increasing hospice enrollment for historically excluded populations. However, effective engagement strategies vary for different populations. For example, studies suggested partnering with churches to reach Black patients, hiring Spanish-speaking staff for Hispanic patients whose primary language is Spanish, and increasing availability of local hospice providers for Indigenous Americans. For LGBTQ+ patients, studies recommended discussing gender identity and familial preferences rather than making assumptions. At the organizational level, hospices face both challenges and opportunities with respect to staffing and data collection. Hospices often struggle to recruit and retain diverse talent, and sometimes staff themselves may be subject to inequitable treatment by those for whom they care. This is particularly true for Black and LGBTQ+ staff. Diversifying leadership may provide additional support to those facing discrimination from patients. Several studies suggested that use of non-traditional care staff, such as community health workers, patient navigators, and social work students, can alleviate recruitment challenges. Use of these roles, for example, in helping patients understand hospice services, can be particularly advantageous for lower-resourced organizations.

Both studies and our experts noted insufficient data to effectively understand health inequities. This is particularly acute in LGBTQ+ communities and historically excluded racial and ethnic groups. Hospices do not collect sexual orientation or gender identity (SOGI) data, and if staff collect these data, they often do so through inference rather than a conversation with the patient to understand how they identify. Data beyond demographics, such as community-level demographic data and patient preferences, can facilitate an understanding of populations currently excluded from or receiving poorer quality hospice care. Qualitative data can help inform health equity in hospice, but experts cautioned against selection bias. Furthermore, for any data collection, validated tools may not be validated with historically excluded populations.

Few studies suggested specific measures or constructs related to health equity, though CMS asked for feedback on a health equity focused structural measure in their Fiscal Year (FY) 2023 Hospice Rule ([87 FR 19442](#)). In the months following this report, CMS will convene Technical Expert Panels (TEPs) that will reflect on the role CMS can play within its quality reporting programs to improve health equity in hospice and home health settings.

### ***Other Recent Hospice Literature***

To identify any emerging trends outside of our specific research questions, we conducted an environmental scan to identify literature related to the general quality of care in the hospice setting published in the last one to two years. Our results fell into three main categories: hospice care for dementia patients, use of new technologies in hospice, and approaches to staffing and services. One additional study explores a Health Days at Home (HDAH) measure.

### ***Conclusion***

Many studies have explored differential use of hospice care over the past seven years, with many focused on race and ethnicity. Historically excluded populations are less likely to use hospice, and often less likely



to be aware of hospice care and its benefits. This is despite some evidence suggesting that Black patients are referred to hospice more often than their white counterparts. Studies consistently reported Asian and LGBTQ+ populations having poorer care experiences. Addressing equity in hospice involves community engagement, recruiting and retaining diverse staff, and expanding available data. Few studies suggested specific measures or constructs related to health equity. In the months following this report, Abt Associates will convene TEPs that will reflect on the role CMS can play within its quality reporting programs to improve health equity in the hospice and home health settings. As for other emerging trends in hospice, in the past year the literature has focused on dementia patients, technology, hospice structures, and the novel HDAH measure.



## Background and Significance

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Many Americans rely on hospice care for end-of-life support. In 2019, more than 1.6 million Medicare beneficiaries received hospice care, with Medicare spending \$20.9 billion on hospice services (MedPAC, 2021). These services are critical to terminally ill patients. CMS continually strives to improve hospice quality and the experience of care for beneficiaries within the context of the [Meaningful Measures Framework](#), which prioritizes high-impact quality measure areas that are meaningful to patients, their families and caregivers.

CMS anticipates expanding the Hospice Quality Reporting Program (HQRP) over the next several years to include additional meaningful quality measures that assess the quality of care provided to hospice patients. The Abt team, under contract to CMS, supports this work. The HQRP currently includes a Hospice Item Set (HIS) quality measure, claims-based quality measures, and Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey measures. The Abt team is also developing and testing the Hospice Outcomes and Patient Evaluation (HOPE), a draft patient assessment instrument that, when finalized in rulemaking, will support assessment-based quality measure.

The Hospice Information Gathering Reports support these efforts by reviewing available resources to inform HOPE development and related quality measures. The [2019 Information Gathering Report](#) used stakeholder input, environmental scans, literature reviews, and focus groups to establish a candidate list of domains for HOPE inclusion. The [2020 Information Gathering Report](#) used similar methods to explore specific areas where additional information was needed to support HOPE and quality measure development. Specifically, it addressed potential adaptation of the Integrated Palliative Outcome Scale (IPOS) for HOPE, the most clinically up-to-date signs and symptoms of a patient who is actively dying, and additional information on pain and dyspnea management to support related quality measures. The [2021 Information Gathering Report](#) narrowly focused on hospice-specific quality measurement and data collection research related to current HOPE activities. Topics included treatment of moderate to severe pain, patient preferences, spiritual and psychosocial assessment and care, medication management, and any recent quality measurement and reporting activities in the hospice setting.

Since CMS released the last Information Gathering Report, the agency released its [Framework for Health Equity](#) which considers addressing health disparities in all of its programs, including the HQRP. In its FY 2023 Proposed Rule ([87 FR 19442](#)), CMS requested information on a structural measure intended to make hospice care more equitable. In support of CMS' health equity work, the 2022 Information Gathering Report reflects four main information gathering activities:

- **Updating our 2020 SDOH literature review:** In the [2020 Information Gathering Report](#), we completed a brief literature review focused on the social determinant of health that may be most applicable to the hospice setting. Those findings suggested that there are differences in pain treatment by both race and gender, that lived experience influences patient preferences, and that there is widespread geographic access to hospice services. We repeated this literature review to more narrowly focus on the hospice setting and to account for both improvements in our methods and any new material published since 2020.
- **Conducting expert interviews:** In the spring of 2022, the Information Gathering Team spoke with several experts familiar with health equity in the hospice setting. Our discussions focused on understanding how these experts are thinking about and addressing health equity in the hospice setting and informing future health equity-related information gathering activities, including our health equity literature review. Additional information on our experts and our methods, refer to Appendix I: Methods.

- **Conducting a health equity focused literature review:** As this is the first major exploration of health equity undertaken by the HQRP to date, the Abt team was broadly inclusive of items related to hospice. We categorized our results into three main themes:
  - Access to and enrollment in hospice
  - Receipt of hospice care
  - Addressing hospice inequities
- **Conducting a literature review for recent quality-related hospice activities:** To better inform HQRP measurement and reporting activities, the Abt Team gathered information on recent quality measurement and reporting activities in the hospice setting.

Given that the content of these activities overlapped significantly, the report presents integrated findings rather than summarizing results by activity. The sections of this report are as follows, largely aligning with the aforementioned themes of our health equity literature review:

- **Discussing health equity:** Here we summarize conversations with our experts in which they reflected upon how health equity should be discussed and the importance of specific language in these discussions.
- **Access to and enrollment in hospice:** Here we present findings from our literature searches and our experts about how hospice use varies among different populations. We further present information on what might contribute to that variance, including referral patterns, knowledge of hospice, and cultural, historical and environmental influences. For those who elect hospice, we also report on findings related to differences in the timing of hospice enrollment and the type of hospice in which patients enroll.
- **Receipt of hospice care:** Here we present findings from our literature searches and our experts on the experiences of those in hospice and their families and caregivers, including a dedicated section about differences in pain management.
- **Addressing hospice inequities:** Here we present findings from our literature searches and our experts on how hospice providers can address the disparities identified in earlier sections. This section includes a discussion of community engagement, organizational improvement efforts such as staffing and data collection, and next steps.
- **Other Recent Hospice Literature:** Here were present findings from our literature review focused on recent hospice publications and reports.

## Methods

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To address this year's information gathering topics, we searched for and reviewed both peer-reviewed and grey literature. We also conducted a limited set of expert interviews that included representatives of diversity, equity, and inclusion initiatives from hospice provider associations as well as health services researchers with relevant expertise.

For our literature reviews, we used MEDLINE/PubMed® database, supplemented with searches in Google Scholar, using pre-developed search terms (e.g., MeSH) specific to the topic. For grey literature, we established a list of well-known resources and applied key words from our topics to find relevant information. We limited our results to US articles published within the past seven years, except for the general hospice activities topic, where we used a shorter period of one year.

For our expert interviews, we created a brief, semi-structured interview guide to facilitate our discussion that included health equity focused questions on both receipt of and access to hospice care. We probed on topics such as key health equity terms and concepts, use of data, cultural gaps, hospice referral and enrollment, and increasing representative hospice staff.

Throughout the process we consulted key stakeholders to clarify the purpose or intent of the research questions and confirm expected sources of information, as needed. For more details on our methods refer to **Appendix I**. We present a summary of search results for each section in **Appendix II**, and complete literature review tables for each section in **Appendix III**.

## Discussing Health Equity

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CMS defines health equity as “the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes”<sup>7</sup>. A main topic area for expert interviews was how to think about and discuss health equity in the hospice setting. This both supported our development of a robust set of search terms for our literature review, and improved awareness of the importance of language as CMS works to address health inequities. Here we summarize this portion of our expert interviews.

Though not specific to the hospice setting, linguistic choices that contribute to the marginalization of some subpopulations remains prominent. Deficit-based language focuses on the absence of certain characteristics or defining others by their least desirable characteristics. Examples include “non-white” and “non-Hispanic” which implicitly reflects what the specific group or person is not, rather than what they are, which would be a strength-based approach to identifying diverse attributes. Certain phrases like “underserved” and “lack of trust in the medical system” also convey deficiency on the part of the patient, family and/or community. Often, describing a patient as “underserved” rather than “historically excluded” suggests the patient had access to services, but did not use the service or care. Reframing language in ways that do not “blame” the patient for such disparities may aid in dismantling implicit bias that can create barriers to equitable care. Similarly, describing a group of people as “lacking trust” implies that the onus is on the patient, rather than the medical system, to develop that trust and fails to recognize that for historically marginalized and excluded patient populations a lack of trust is rational and justified.

Sometimes overly inclusive terms, even if well-intentioned, can reinforce marginalization by serving as “catch all” phrases that either become proxy terms that substitute for deficit-based language, or further obscure the groups they intend to represent. An example of the former is “minority,” which is mostly, if not exclusively, used to refer to race or as a replacement for non-white. Minority is rarely, if ever, used to describe white people—even when white people are the minority (e.g., in Detroit or the District of Columbia)<sup>8</sup>. Moreover, terms like BIPOC, though intended to be a more inclusive term, poses their own challenges. BIPOC is used so generally that often those who use it do not recognize its intent to represent racial groups. One interviewee described an encounter with a conference presenter who, when asked who she was referring to with the term BIPOC, struggled to answer the question and ultimately replied “biracial people.” In this example, BIPOC has substituted for minority, which itself has substituted for non-white. Even labels such as African American can be too broad. Not all Black people identify as African American. As one expert noted: “My grandmother who was born in the 1800s was

**“Minority is not a race, it’s a status. We should not be referring to people as minorities.” – Interviewed Expert**

**“Equity has to do with being more inclusive, and yet that’s not always the case with these acronyms.” – Interviewed Expert**

*one step removed from enslavement, as a sharecropper, in the rural south. Her lived experiences, in the U.S. were very different experiences from my Black colleague who emigrated from the Continent of Africa by choice with an abundance of resources and formal education. My colleague also reminds me that she identifies as Nigerian American, not as African American. The cultural*

*differences and healthcare decision-making preferences can vary widely.”*

While we recognize the significance of language and its role in health equity, much of this report compiles research conducted by others. We believe that in some cases the researchers we cite here,

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<sup>7</sup> <https://www.cms.gov/pillar/health-equity>

<sup>8</sup> <https://www.census.gov/quickfacts/fact/table/DC,detroitcitymichigan/RHI725221>

particularly those conducting interviews with their subjects, took care to represent their participants in a way that respected participant identities. However, other research, particularly research which uses aggregate data from which researchers cannot ascertain patient preferences, was not sensitive to or aware of some of the potentially stigmatizing or marginalizing language we discuss above. Where the content of this report is that of its authors we have conformed with the American Medical Association's (AMA) [Advancing Health Equity: A Guide to Language Narrative and Concepts](#) wherever possible. The AMA guidelines include, for example, white not being capitalized as other races are and using terms such as "historically excluded" rather than "underserved." However, for our descriptions of other's research we have used the terms its authors used, both to be sure we accurately represent their work and to respect instances where the authors likely accurately reflected their participants' identities. For this reason, the reader may see the same or similar populations referred to differently throughout this document (e.g., both Black and African American, or Indigenous American and American Indian), or use of language that may reinforce marginalization of certain communities.

## Access to and Enrollment in Hospice

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### **Hospice Use**

Several studies reported that certain populations are less likely to use hospice care than other populations. Most of these focused on historically excluded races and ethnicities relative to white populations, though some looked at factors such as gender, education level, neighborhood characteristics, income, and region. Some of these studies have specifically explored why certain populations are less likely to use hospice care. For example, some have studied differences in awareness of hospice and its benefits among various populations. Several additional qualitative studies provided further insight into perceptions of hospice for different populations. For example, evidence suggests those who receive a palliative consultation are more likely to use hospice care. Patients who received an inpatient palliative care consultation are up to four times more likely to enroll in hospice than those who did not receive this consultation (Starr et al., 2020; Johnson et al., 2020). Some studies found no significant associations between race and hospice enrollment among patients who received a palliative care consultation (Worster et al., 2018; Starr et al., 2021). Here we discuss findings related to hospice use among different populations, and why their use patterns may differ.

Our experts also reflected on reasons why patients may not be referred to or enrolled in hospice. Many interviewees noted that clinicians typically lack training on hospice and are often uncomfortable discussing end-of-life care with patients. This is especially true if the clinician does not perceive the patient to have a caregiver. As one expert noted, many clinicians assume people of color won't be interested in hospice care, and do not have that conversation. End-of-life conversations take time and require cultural training that facilitates talking about topics that may be taboo. For example, one expert noted that patients may believe hospice is just for AIDS or cancer patients, or be hesitant to have people in their home, and overcoming these misconceptions and concerns takes time. However, these conversations about hospice are crucial for earlier referrals to hospice. Doctors that share a cultural background with their patients may find these conversations easier and may be more likely to make a hospice referral.

**“If we went to a doctor for a pain or a lump, they would not hesitate to refer you to an oncologist. However, there’s a lot of hesitation around hospice referrals because the clinician doesn’t understand everything that hospice entails.” – Interviewed Expert**

### **Racial and Ethnic Differences in Hospice Use**

Studies that addressed hospice use by different races and ethnicities primarily reported differences between Black patients and white patients. Often, they looked at specific diagnoses or groups of diagnoses, largely cancer related. In almost all cases, Black, Hispanic, Asian, and Indigenous American patients were less likely to use hospice care than their white counterparts. Differences in referral patterns did not seem to be a contributing factor. In fact, some studies suggested that Black patients were more likely to be referred to hospice than non-Black patients even though they seem to use hospice less. Differences in referrals were more likely across facilities than within facilities. Overall, white patients were more likely to be aware of hospice and its benefits, but the reasons patients of other races and ethnicities were less likely to use hospice were more nuanced and complex.

### **Hospice Use among Black Patients**

Several studies reported on hospice use among patients with cancer. Two studies of Medicare patients looked at cancer generally, with one finding that Non-Hispanic Black patients who died from cancer were less likely to enroll in hospice than white patients (Koroukian et al., 2017). The other found no racial difference in hospice use for cancer patients but did find that Black patients without cancer were less likely to enroll in hospice than white patients (Samuel-Ryals et al., 2021).

Eleven additional studies looked at specific types of cancer. Black patients were less likely to enroll in or die in hospice than their white counterparts for brain metastasis (Mehanna et al., 2020; Shenker et al., 2022); ovarian cancer (Mullins et al., 2021; Taylor et al., 2017); pancreatic cancer (Paredes et al., 2021); small cell lung-cancer (Du et al., 2015), malignant glioma (Forst et al., 2018); breast cancer (Check et al., 2016); and head and neck cancer (Stephens et al., 2020). Two studies reported no racial difference in hospice use. A study of patients with cervical cancer found that place of death (hospice or hospital) did not vary between Black and white patients (Sheu et al., 2019). Another study of New Jersey Medicaid patients with breast or colorectal cancer found no racial differences in hospice use, but also found that Black patients had almost twice the odds of receiving aggressive end-of-life care than white patients (Yang et al., 2020).

All identified studies that focused on non-cancer diagnoses reported Black patients were less likely to use hospice care than their white counterparts. These included Black patients with severe acute brain injury (Jones et al., 2021), dementia (Lin et al., 2022; Oud et al., 2017), chronic obstructive pulmonary disorder (COPD) (Yaqoob et al., 2017), and those on dialysis (Foley et al., 2018). Additionally, a Florida survey of older adults found that for African American patients, an increasing number of functional disabilities was associated with decreased willingness to use hospice (Park et al., 2016).

Additional research explored potential reasons why Black patients are less likely to use hospice. Some research suggests that Black patients are more likely to want aggressive end-of-life treatment. A 2017 Kaiser Family Foundation and Economist survey found that while few Americans viewed living as long as possible as “extremely important,” the share of Black respondents who felt this way (45%) was higher than that of white respondents (18%) (Hamel et al., 2017). Another survey of Black American older adults in North Carolina found they were less likely to prefer or request hospice support than their white counterparts (Cagle et al., 2016). African American decision makers for dementia patients elected life-sustaining treatments more than comfort-focused care (Hart et al., 2022). Additionally, advance directives increase the odds of a discharge to hospice, and African American patients are less likely to complete advance directives (Haines et al., 2021). One of our experts noted that in her Black American community, there may be more collective decision-making preferences. She described her mother not understanding why she would need a written advanced directive if her daughter was there to advocate on her behalf.

Other research suggests the Black patients may be unaware of hospice care and its benefits. For example, African American decision makers for dementia patients often did not use hospice fully due to a lack of information and preparedness (Hart et al., 2022), and a California-based study found Black people were less likely than non-Hispanic white peoples to be aware of hospice (Bazargan et al., 2021). Qualitative research among African American church members indicated that lack of knowledge of hospice services and spiritual beliefs were the top two contributing factors to underutilization of hospice care (Townsend et al., 2017). Further, additional interviews with African American church leaders found their congregants were unfamiliar with the terms “hospice” and “palliative care,” while also harboring beliefs, perceptions, and feelings about death and dying that they had not communicated to their family members or providers. Those who had positive perceptions of hospice care were uncertain how to approach their health care providers about it (Johnson et al., 2016). A study of African American adults in Alabama’s “Black belt” region found that those who were worried about stable housing or were more socially isolated were less likely to be aware of hospice care (Noh et al., 2021). Meanwhile, adults with better perceived health and higher levels of physical and social activity were more likely to have accurate knowledge of hospice. This was true for both Black adults and white adults, except for the physical activity finding which the author did not find for white patients (Noh et al., 2018).

Interestingly, recent literature suggests that Black patients are more likely to receive hospice or palliative care referrals, though this finding was not consistent across all studies and differences appear to be more common across facilities than within facilities. For example, Johnson and colleagues looked across four urban hospitals and found African American patients received more palliative care consultation referrals



than both white and Hispanic patients, though there was no difference within hospitals (Johnson et al., 2020). A Chicago hospital-based study also found African American patients more likely to be referred to hospice than white patients (Sharma et al., 2015). However, a study of patients with metastatic cancer in New Jersey hospitals found Black patients were less likely to receive hospice referrals than white patients (Nicholson et al., 2022). A study of cancer centers found that minority patients were less likely to receive a hospice referral than their white counterparts, but there were no significant differences within hospitals (Wasp et al., 2020).

In a series of interviews, Rhodes and colleagues found that though African American respondents perceived hospice to be beneficial to patients and family, they also perceived cultural differences, a lack of knowledge about hospice, spiritual or religious conflicts with hospice, and mistrust in the medical system as barriers (Rhodes et al., 2017). Similarly, Dillon and Basu found that African American people's experience of discrimination or mistreatment by the healthcare system has led to a mistrust of hospice, in addition to the perception of hospice as incongruent with their cultural values and practices. Dillon and Basu also noted that African American people experience inconsistent access to medical care. This, combined with some avoiding the medical system, can lead to late diagnosis of terminal illness, thereby limiting the opportunity to receive hospice care (Dillon and Basu, 2016).

Our experts provided particularly illustrative details on why Black patients may elect not to participate in hospice even when referred. One expert illuminated how the collective experience of Black Americans has shaped their attitudes towards hospice. In addition to a medical system that has fostered distrust (e.g., the [USPHS Syphilis Study at Tuskegee](#) and [J. Marion Sims' gynecological experiments](#) on enslaved women), other cultural attitudes and beliefs affect participation. She recounted her own research on end-of-life care at an urban hospital and her inability to find a sufficient sample of Black patients to match the number of white patients who had died at that hospital, to conduct a retrospective study of the end-of-life experiences in a hospital setting. She realized that the Black American patients in that community were seeking their care at a hospital across town—a legacy that remained after decades of having been legally denied access to hospitals where only white patients received care during segregation. This translates to primary care as well. She noted that Black people may prefer aggressive treatment for illness, as they distrust the motives of those providing primary care. She further described Black Americans, particularly of older generations, relying on home remedies rather than pharmacological interventions and care, reflecting the practices they used before they had access to primary care settings. The mistrust of the medical system, influenced by historical racism, structural and systemic, makes it difficult for Black Americans to choose hospice as a culturally acceptable care option. The benefit of having a stranger provide care in the home is culturally incongruent for many Black people in the U.S. The lack of hospice enrollment and hospice utilization compounds the challenge of achieving equity, as few Black Americans elect hospice care this means there are fewer lived examples for others in the community to share, affirm and reinforce its benefits.

**“The whole philosophy of hospice care is challenging for Black older adults” – Interviewed Expert**

### ***Hospice Use among Hispanic Patients***

As with Black patients, research suggests that Hispanic patients are less likely to use hospice than non-Hispanic white patients. Hispanic patients with brain cancer, ovarian cancer, and malignant glioma were less likely to use hospice than white patients (Mehanna et al., 2020; Mullins et al., 2021; Taylor et al., 2017; Forst et al., 2018). However, as with Black patients, Sheu and colleagues found no variance in place of death (hospice or hospital) for Hispanic patients (Sheu et al., 2019). Non-cancer related diagnoses exhibit the same pattern. Hispanic patients with severe acute brain injury (Jones et al., 2021), dementia (Lin et al., 2022), and those on dialysis (Foley et al., 2018) were all less likely to use hospice care than their non-Hispanic white counterparts.



As with Black patients, the 2017 Kaiser Family Foundation and Economist survey found a higher share of Hispanic patients (28%) viewing living as long as possible as “extremely important,” compared to 18% of white respondents (Hamel et al., 2017). As in other populations, Latino caregivers who held a strong belief that hospice care means giving up on life were less likely to consider using hospice care for their loved ones (Ko, et al., 2017). Other research finds more nuanced reasons for Hispanic patients not using hospice care. The two identified studies focused specifically on Mexican identities, and neither supported cultural barriers as the main reason these populations are less likely to use hospice care. Rising and colleagues interviewed US Mexicans with terminal cancer and found that they perceived referral to hospice as coercive in nature, unless they had an existing paternalistic view of healthcare that defers to the physician (Rising et al., 2021). Shepard and colleagues looked at Hispanic Estimate Population for Epidemiological Study of the Elderly (H-EPESE), H-EPESE Survey data, and CMS data, to determine what characteristics were associated with hospice use for Mexican Americans and found no association between hospice use and marital status, high-depressive symptoms, disability, church attendance, or seeing a physician in the last year of life. This led the authors to conclude that health system factors, rather than individual patient factors or community factors, were driving hospice use and referral variation (Shepard et al., 2022).

For referral to hospice, as with Black patients, studies were mixed. Nicholson and colleagues’ study of New Jersey hospital patients with metastatic breast cancer found Hispanic patients were less likely receive hospice or palliative care referrals than white patients, while Sharma and colleague’s work with Chicago hospitals found no difference in referral to hospice between Hispanic patients and white patients (Sharma et al., 2015). As mentioned previously, some studies have found no significant associations between race and hospice referral, with Worster and colleagues assessing the association between Hispanic patients and hospice referral specifically (Starr et al., 2021; Worster et al., 2018).

Qualitative studies suggest that providers are not adequately discussing end-of-life care options with Hispanic patients. A small number of interviews with caregivers of those enrolled in home hospice in rural US/Mexico border towns found that while most caregivers were informed about the patient’s terminal condition, only half had a discussion with a provider about hospice (Ko and Fuentes, 2020). A small survey found Hispanic people had less knowledge of about hospice than their non-Hispanic counterparts, such as believing that only those over 65 were eligible for hospice and not knowing that hospice helps family members as well as the dying person (Carrion et al., 2015). Additional work showed Hispanic people were less likely to be aware of hospice than non-Hispanic white people (Bazargan et al., 2021).

### ***Hospice Use among Asian Patients***

Several of the studies that reported hospice use among Black and Hispanic patients also presented findings for Asian patients. Here too, white patients were more likely to use hospice than their Asian counterparts. Asian patients with brain metastasis (Mehanna et al., 2020), malignant glioma (Forst et al., 2018), severe acute brain injury (Jones et al., 2021), and those on dialysis were less like to use hospice than white patients (Foley et al., 2018). Three additional studies specified inclusion of both Asian and Pacific Islander patients in their analysis, finding for brain cancer patients, head and neck cancer patients, and cervical cancer patients these populations were less likely to die at home or in hospice than white patients (Shenker et al., 2022; Stephens et al., 2020; Sheu et al., 2019, respectively). Notably, the Asian and Pacific islander population was the only population Sheu and colleagues identified as less likely to die at home or in hospice rather than a hospital. They found no variation in place of death for Black patients, Hispanic patients, or Native American patients relative to their white counterparts (Sheu et al., 2019).

Though most studies considered Asian patients a single population, Haines and colleagues disaggregated the Asian population to provide insights within different Asian identities. This work reported that Chinese

trauma patients were more likely to die in hospice than Japanese patients, Filipino patients, Indian patients, and Vietnamese patients. Korean patients were more likely to die in hospice than their Chinese counterparts (Haines et al., 2021).

As for referral to and knowledge of hospice, Shirsat and colleagues conducted a small survey of Indian Americans in Northern California to discern their knowledge of hospice. Ten percent of respondents knew someone in hospice care and ten percent were able to answer either four or five out of five questions that assessed their knowledge of hospice care. Once educated about hospice care, almost 70 percent agreed that they would consider enrolling an extremely ill family member in hospice, though 44 percent would not allow a stranger in their home, even if the stranger was with hospice (Shirsat et al., 2021). Additionally, advance directives increase the odds of a discharge to hospice, and Asian patients were less likely to complete advance directives (Haines et al., 2021). An expert we interviewed noted that for the Chinese community, older people, particularly those who do not speak English, may not have their decisions respected. For example, the patient's child may "talk over" them (intending to protect their senior patients) and older people may find it difficult to advocate for themselves in a medical setting even if the children's wishes are different than their own. Our expert described how advance care plans when an individual is still capable of talking and expressing their medical wishes can be of value, as they help clarify what the patient prefers while alleviating the decision-making burden on the children.

### ***Hospice Use among Native American Patients***

Native American populations were also less likely to use or die in hospice care than white patients in our identified studies. Studies reported this for American Indian patients and Alaska Native patients with metastatic cancer (Shiovitz et al., 2015), Native American patients with brain cancer (Shenker et al., 2022), and Native American patients on dialysis (Foley et al., 2018). Sheu and colleagues, when looking at cervical cancer patients, did not find variation in place of death between Native American patients and white patients, consistent with their findings for Black and Hispanic patients referenced in the previous section (Sheu et al., 2019).

Some qualitative studies explored potential barriers to use of hospice in Native American populations. For Great Plains Native Americans, there is not sufficient availability of hospice, resulting in long travel distances services; meanwhile, the workforce does not have adequate cultural familiarity with the Great Plains Native Americans. Historical racism and trauma further limit Great Plains Native Americans willingness to use hospice (Soltoff et al., 2022). Interviews with Elders of the Blackfeet Nations revealed that while some found "sickness should not be mentioned when it is bringing death," others felt end-of-life care was not against tradition (Colclough et al., 2019).

### ***Hospice Use among Non-specific Patient Populations***

Wherever possible, we have presented results with respect to specific racial and ethnic populations. However, many studies reported results without such specificity. These studies yielded similar results—white patients were more likely to use hospice than patients of other races or ethnicities. This held true for Medicare populations both in managed care plans and in fee-for-service Medicare (Ornstein et al., 2016; Elting et al., 2020). One study found race to be the strongest predictor of one's opinion about hospice, with white people having the most positive opinion (Lee and Cagle, 2017).

The differences are present across multiple diagnoses. White patients were more likely to use hospice than other races or ethnicities for hepatocellular carcinoma (Rice et al., 2021), gynecologic oncology (Taylor et al., 2016), and lung, esophageal, pancreatic, colon, and rectal cancers (Abbas et al., 2021). A study focused on cancer centers in the deep south found non-white cancer patients less likely to use hospice than whites (Turkman et al., 2019). Haines and colleagues found similar results for trauma patients (Haines et al., 2018).

Two studies explored reasons why some racial and ethnic groups may not use hospice. A small survey of hospice employees reported that they perceive cultural beliefs of racial and ethnic groups as barriers to their use of hospice care (Hughes and Vernon, 2020). Another study that surveyed hospice directors found that diverse populations may prefer to associate with their own cultural group, return to their home country as death approaches, or perceive hospice as “divergent to their cultural and religious beliefs or thinking” (Reese and Beckwith, 2015).

### ***Other Sociodemographic Differences in Hospice Use***

#### ***Gender***

Overall, female patients were more likely than male patients to use hospice. Again, this was true for brain cancer (Mehanna et al, 2020), malignant glioma (Forst et al., 2018), COPD (Yaqoob et al., 2017), and females with cancer in the deep south (Turkman et al., 2019). A small study of female patients with metastatic breast cancer at a Boston hospital found that only one third were referred to hospice after their last hospitalization (Shin et al., 2016).

#### ***Education***

Those with higher levels of education were more likely to use hospice than those with lower levels of education. Cancer patients and non-cancer patients alike were more likely to use hospice if they have higher levels of education (Ornstein et al., 2016; Koroukian et al., 2017; Forst et al., 2018). Cagle and colleagues found college education, as well as race and working in the medical industry, were predictors of hospice knowledge (Cagle et al., 2016). Higher health literacy was associated with awareness of hospice and hospice use (Noh et al., 2021; Ornstein et al., 2016). However, Ornstein and colleagues found that Medicare patients with a higher education level than their spouse were less likely to use hospice (Ornstein et al., 2016).

#### ***Socially Vulnerable Communities and Lower Income Patients***

Some studies used zip-codes, the [Social Vulnerability Index](#) (SVI), or other means to determine whether place of residence was associated with hospice use. Others looked at income and its relationship with hospice use. Most studies supported higher SVI communities and patients with lower incomes being less likely to use hospice care.

Abbas and colleagues looked at patients with specific cancers (lung, esophageal, pancreatic, colon, or rectal cancers) and found that those in high SVI areas (especially non-white residents) were less likely to enroll in hospice (Abbas et al., 2021). Similarly, for patients with hepatocellular carcinoma, the probability of hospice use declined for those in areas with higher social vulnerability (Rice et al., 2021). Riggs and colleagues focused on New York patients, finding that patients who received community-based palliative care and live in a zip code with a lower share of residents living in poverty were more likely to enroll in hospice (Riggs et al., 2016). Patients in areas with low health literacy were also less likely to use hospice (Luo et al., 2021).

As for income, its influence on hospice use was mixed. While Koroukian and colleagues found higher income patients who died of cancer were more likely to enroll in hospice than those with higher incomes (Koroukian et al., 2017), Forst and colleagues found that for patients with malignant glioma, lower income predicted hospice use (Forst et al., 2018). Similarly, Dhingra and colleagues, who compared New York to the nation, found that New York’s higher socioeconomic status was an independent predictor of their lower hospice use (Dhingra et al., 2022). Ornstein and colleagues also cited socioeconomic status as related to hospice use (Ornstein et al., 2016).

#### ***Region***

Several of studies we have referenced previously throughout this section also found regional differences in hospice use, particularly between urban and rural areas. Rural patients were less like to enroll or die in

hospice than their urban counterparts for cervical cancer (Sheu et al., 2019), malignant glioma (Forst et al., 2018), non-small cell lung cancer (Du et al., 2015), and cancer generally (Wang et al., 2016).

Fornehed and colleagues interviewed informants in rural Appalachia to better understand their attitudes towards palliative care and found that they make end of life decisions with family. The communication that encompasses family decision making for this population was both essential and complex, with education and economics influencing end-of-life decision making (Fornehed et al., 2020).

Other studies made more specific regional comparisons. Yaqoob and colleagues found that for patients with COPD, the likelihood of dying in hospice is highest in the south, at eight percent, and lowest in the Northeast, at four percent (Yaqoob et al., 2017). A Massachusetts report identified county level variation in hospice use, with particular inequities in the western part of the state, which is more rural (Massachusetts State Hospice Report, 2021).

### ***Language***

Two of our studies found that patients who spoke a primary language other than English were less likely to receive hospice referrals than their primarily English-speaking counterparts. One focused on patients with metastatic cancer in New Jersey hospitals, and the other focused on New York patients who received community-based palliative care (Nicholson et al., 2022; Riggs et al., 2016, respectively). Another study, based in Florida, generally found that non-Cuban Hispanic Floridians who were proficient in English were more willing to use hospice, but this was not true for Cuban Americans. The authors believe this may be because Cuban Americans have access to information about hospice in their native language in their communities (Park et al., 2016). Dressler and colleagues interviewed care end-of-life care providers in an Rhode Island community with a high proportion of non-English speakers and identified three key themes that contributed to language barriers in end-of-life care: structural barriers inhibiting access to interpreters, variability in how accurately end of life concepts can be translated, and the style and manner of the interpreter influencing efficacy during complex conversations. The latter two appear critical for hospice enrollment and care (Dressler et al., 2021).

### ***Other***

Additional works cited other factors related to hospice use, including facility characteristics. A higher proportion of for-profit hospices was positively associated with racial and ethnic minorities using hospice (Hughes and Vernon, 2019), and in the deep south, cancer patients seen at hospitals with inpatient palliative care beds were less likely to receive hospice care (Turkman et al., 2019). When investigating why New York State has low hospice utilization, Dhingra and colleagues found that, in addition to socioeconomic status, New York's higher number of physicians seen in the last years of life, larger number of skilled nursing facility beds, smaller number of for-profit skilled nursing facilities, and smaller number hospices relative to the nation overall independently accounted for differences in hospice utilization (Dhingra et al., 2022).

Additional factors that predicted a positive opinion of hospice include better health, greater familiarity with hospice, a high importance of pain control, the importance of fulfilling personal goals, a desire to have health-care professionals involved in one's care, and having engaged in advance care planning (Lee and Cagle, 2017). Expectations about death are also associated with hospice use (Ornstein et al, 2016).

### ***Timing of Hospice Enrollment and Hospice Type***

For patients that enroll in hospice, the time at which they enroll and the specific type of hospice services they received can vary for different populations. With respect to enrollment timing, white patients are enrolling later than other patient populations (Rice et al., 2021; Taylor et al., 2016; Turkman et al., 2019; Wallace, 2017; Ornstein et al., 2020). Rice and colleagues, who focused on patients with hepatocellular carcinoma, further found that as social vulnerability of an area increases, the likelihood of early hospice use among white patients decreases. Meanwhile, in this scenario, the likelihood of early hospice use

among non-white patients increases—suggesting that though they may have less access to hospice services, Black and Latino patients may be referred to or decide to enroll earlier in hospice when it is available (Rice et al., 2021). For American Indian and Alaska Native patients, the likelihood of late hospice use was not found to be significantly different than that of their non-Hispanic counterparts (Shiovitz et al., 2015). Wallace identified other factors associated with enrollment in the Southern US. Those receiving curative treatment, referred to hospice by a family rather than a physician, and with incomes over \$50,000 all took longer to enroll in hospice (Wallace, 2017). However, Haines and colleagues found that African American patients and Hispanic patients both stayed in the hospital longer than Caucasian patients when discharged to hospice—two and half days longer for Hispanic patients and nearly four days longer for African American patients (Haines et al., 2018).

A few studies examined the hospice types that different populations were likely to receive. Osakwe and colleagues used Medicare and American Community Survey data in a cross-sectional study focused on factors associated with home hospice use relative to facility-based hospice use. Hospice providers with higher proportions of women or dually eligible beneficiaries<sup>9</sup> were less likely to provide home hospice. For the dually eligible population, the authors believe this may reflect an institutional setting's ability to meet the higher care needs of dually enrolled patients more easily (Osakwe et al., 2021). They also analyzed the racial and ethnic makeup of a hospice's neighborhood. Specifically, higher proportions of Black patients in a hospice's neighborhood were not associated with provision of home hospice, while higher proportions of Hispanic patients in a hospice's neighborhood decreased the likelihood of the hospice providing home services (Osakwe et al., 2021). Two additional Medicare studies looked at the type of hospice care provided. One found that white patients were more likely to receive continuous home care than other races or ethnicities, and that receipt of continuous home care was associated with decreased hospice disenrollment (Wang et al., 2016). The other Medicare study found that African American patients, Hispanic patients, and female patients were more likely to receive home hospice care; white patients were more likely to receive facility-based hospice care; and for Asian patients there was no difference (Mendieta and Miller, 2018). However, a small qualitative study found that Animist and Christian Hmong elders prefer at-home care, when possible, as they felt out-of-home care facilities could not meet the spiritual and cultural needs they see as centrally integral to end-of-life care (Her-Xiong and Schroepfer, 2018).

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<sup>9</sup> Dually eligible beneficiaries are eligible for both Medicare and Medicaid

## Receipt of Hospice Care

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### ***Racial and Ethnic Differences in Patient Care***

Several studies have considered the patient experience for those enrolled in hospice care, though they reflect inconsistent findings. A Southwest caregiver survey found that racial minorities experience less satisfaction with the information and education they received, the patient care provided, and the emotional and spiritual support provided to families and caregivers during the hospice stay; however, race did not show a significant effect on overall satisfaction or caregiver confidence (Holland et al., 2015). This finding suggests that even when patients and caregivers experience lesser patient care, individuals do not always recognize that their care could have been better. Price and colleagues analyzed CAHPS® Hospice Survey data and found that Black and Hispanic patients were more likely than white patients to receive care from hospices that offered significantly poorer care experiences, though racial differences were mostly attributed to between-hospice differences rather than within-hospice differences (Price et al., 2017). However, within a given hospice, caregivers of Black and Hispanic hospice patients reported significantly better care experiences than those of white patients, except that caregivers of Black patients were less likely to recommend hospice and Hispanic patients were less likely to report receiving the right amount of emotional and religious support as compared to white counterparts (Price et al., 2017). Another study focused on the experience of Black and white caregivers in the Northeast and Midwest and found that, though there were social, demographic, and socioeconomic differences between the Black and white caregivers, they experienced similarly high levels of anxiety, depression, and burden, and had similar perceptions of hospice communication (Starr et al., 2022). Black hospice patients were also more likely to disenroll from hospice even when controlling for hospice level factors (Rizzuto et al., 2018). Collectively, these studies suggest that even when patients and caregivers experience poorer quality care, individuals do not always recognize that their care could have been better.

Asian patients seem to have poorer experiences of care than non-Hispanic white patients. Another study based on CAHPS® Hospice Survey for San Francisco caregivers found that Asian family members more often experienced a lack of respect for their cultural traditions and their religious and spiritual beliefs, did not receive as much information as they would have liked about what to expect in the last months of life, and did not receive the right amount of emotional support after their family member's passing (Kim et al., 2021).

A few qualitative studies explored the Hispanic experience of care. Beltran and colleagues conducted interviews with older Latinos enrolled in hospice, finding they often did not have a lot of experience with the US healthcare system (likely because of insufficient healthcare due to geographic or financial reasons); did not communicate directly with their health care providers because of low health literacy and language barriers, instead relying on family members to translate; and expected nursing care and medical supplies from hospice, but were not aware of other services provided (Beltran, 2022). Nuñez and colleagues interviewed family members of hospice patients, finding that cultural norms influence interactions between families, and that the family members considered the hospice-provided social supports helpful, but they often did not have health literacy around hospice care (Nuñez et al., 2019). Nuñez et al. also reported that family members of Hispanic hospice patients preferred religious and spiritual support that fit within their cultural values (Nuñez et al., 2019). These studies—combined with the studies cited earlier in this section that noted Hispanic patients and caregivers were less likely to be satisfied with the information, education, and spiritual and emotional support they receive—suggest that there is an unmet need in this population (Holland et al., 2015; Price et al., 2017).

The likelihood of adverse outcomes, such as emergency department admission, hospitalization, and live discharge, is also greater for several historically excluded groups. Black and Hispanic hospice patients are both more likely to be admitted to the emergency department than white hospice patients, even when controlling for hospice level factors (Lin et al., 2022; Rizzuto et al., 2018). Several hospice patient populations were more likely to be hospitalized than their white counterparts: Black patients (Phongtankuel



et al., 2017; Rizzuto et al., 2018), non-white and non-Black patients (Phongtankuel et al., 2017), Asian patients, and Hispanic patients (Russell et al., 2017). The results of Phongtankuel and colleagues' study held even after adjusting for patient and hospice level factors (Phongtankuel et al., 2017). Russell and colleagues analyzed electronic medical records at an urban New York hospice, finding that Black patients, Hispanic patients, and Medicaid patients were all disproportionately being discharged alive due to hospitalization (Russell et al., 2020). The disparity between Hispanic and non-Hispanic white patients was found in affluent communities rather than economically disadvantaged neighborhoods, whereas neighborhood characteristics did not affect the odds of live discharge for Black patients. Black hospice patients were also more likely to disenroll from hospice compared to white patients even when controlling for hospice level factors (Rizzuto et al., 2018). A small study by Taylor and colleagues also found Black patients more likely to disenroll from hospice prior to death than their white counterparts, though they found no difference for other racial or ethnic groups (Taylor et al., 2019). Another smaller based in New York found that Asian patients receiving home hospice care were more likely to revoke hospice care than their non-Hispanic white counterparts (Russell et al., 2017).

Most of these studies did not address whether increased likelihood of aggressive treatment reflected patient preferences. Russell and colleagues conducted supplemental interviews with caregivers of home hospice patients, finding that medical events, uncontrolled symptoms, imminent death, or inability to provide care safely at home all influenced decisions to pursue hospitalization (Russell et al., 2017).

### ***LGBTQ+ Differences in Patient Care***

Recent studies indicate that LGBTQ+ patients are experiencing discriminatory hospice care that does not respect their identities. A cross-sectional survey of hospice and palliative care providers found that 54 percent of providers believed that LGB patients were more likely than non-LGB patients to experience discrimination, with 24 percent having observed such discriminatory care. Sixty-four percent of respondents believed transgender patients were more likely than non-transgender patients to experience discrimination, with 21 percent having observed such discrimination. Additionally, 15 percent of respondents observed the spouse or partner of an LGBT patient have their treatment decisions disregarded or minimized, be denied or have limited access to the patient, and be denied private time with the patient, with 14 percent having observed the spouse or partner being treated disrespectfully (Stein et al., 2020). A qualitative study that interviewed older lesbian adults confirmed that discriminatory behavior exists, finding that patients who disclosed their sexual orientation or gender identity did not receive patient centered care, and that their loved ones may have experienced disenfranchised grief, which is grief that is not publicly acknowledged or viewed as legitimate (Candrian and Cloyes, 2021). Another set of interviews with older LGBTQ patients found that all participants reported a connection between their sexuality and their spiritual lives, yet few resources for hospice and palliative care explicitly outline the direct connection for LGBTQ patients (Fair, 2021).

### ***Gender Differences in Patient Care***

Gender also contributes to how patients and caregivers experience care. A small qualitative study examining gender dynamics in home hospice care found that, in some cases, nurses in resource-constrained settings shifted care responsibilities to female (but not male) caretakers and pushed back more against female caretakers' boundaries than against male caretakers' boundaries; female nurses and caregivers focused care efforts on female over male clients (Sutherland et al., 2016). In a small New York study women receiving home hospice care were more likely to be disqualified from hospice care than their male counterparts (Russell et al., 2017).

### ***Differences in Pain Management***

Pain management is a critical component of hospice care for both patients and caregivers. A study of Medicare patients found inequities in access to pain medication for hospice patients, with men less likely

to receive psychotropic and opioid medication prescriptions, and non-Hispanic Black patients less likely to receive nearly any class of medication (Gerlach et al., 2021). However, another study found no difference in pain management between African American patients and Caucasian American patients in hospice (Booker et al., 2020).

Two studies reported on caregiver experience with respect to pain management. One study analyzed family caregiver knowledge and experience of cancer pain management, finding rural caregivers had worse knowledge of pain management principles than their urban counterparts, but the caregiver experiences when managing cancer pain were not significantly different (Washington et al., 2019). Another study of cancer patients and their caregivers receiving home hospice analyzed their perceived barriers to pain management using the [Barrier Questionnaire 13](#). There was no difference in perceived pain management barriers between African American patients and caregivers and white patients and caregivers, or between male and female patients and caregivers. Hispanic patients did perceive more pain management barriers than non-Hispanic patients, though there was no difference among caregivers (Wilkie et al., 2017). A separate study found Hispanic patients were more likely to believe that admitting pain is a sign of weakness and that a “good” patient doesn’t talk about pain (Carrion et al., 2015). Untreated pain may have a disproportionate impact on Hispanic patients, as Hispanic hospice patients who experience pain have nearly four times the odds of experiencing restlessness at the end of life relative to non-Hispanic patients or Hispanic patients without pain (Beltran, 2018).

Like Hispanic patients, South Asian patients may be reluctant to address pain at the end-of-life. A small qualitative study of health care providers found that they perceived South Asian patients and families as reluctant to report or treat pain at the end of life. They suggested that patients may wish to avoid burdening others, have concerns about side effects or potential addiction to pain medication, find pain management medication inconsistent with their spiritual beliefs, or not be made aware of medication benefits (Khosla et al., 2016).



## Addressing Hospice Inequities

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### **Increasing Enrollment in and Engagement with Hospice**

To increase hospice enrollment, studies consistently recommended conducting community outreach to different racial and ethnic populations as well as low-income communities and creating educational materials that are clear and available in multiple languages (Hughes and Vernon, 2019). Hughes and Vernon also suggested that successful enrollment requires hospices with an inclusive culture and with a diverse staff (Hughes and Vernon, 2020). While these recommendations are broadly applicable, organizations should tailor community outreach and education to specific populations. Hospice leaders from varied organizations considered community outreach, when specifically tailored to its community, the most successful approach to increasing hospice use in minority populations and believed that the benefits of these programs outweigh the costs (Hughes et al., 2021). Having an advanced illness management program may also increase overall transition to hospice and increased length of hospice stays (Hostetter et al., 2018).

In addition to the research we cite below, our experts noted that hospices themselves may be able to increase referrals by talking with providers to understand what they find difficult about making hospice referrals. Hospice organizations could identify providers with low-referral rates and offer education and resources, such as prognostic indicator training, informational hospice training, and providing scripts to help physicians discuss hospice with their patients. Hospices can further monitor whether they see a corresponding increase in appropriate referrals, and any differences in the communities being served. Such differences reflect not only demographic or cultural groups, but the types of diagnoses that may have been previously under-referred and could benefit from more timely hospice care.

Our experts noted that hospices should use the demographic data of their communities to better understand who may benefit from increased access to or enrollment in hospice. Addressing that gap involves understanding why certain communities do not feel welcome, why they may hesitate to elect hospice, and how to establish trust among patient populations that have historically experienced structural and systemic racism.

**“Treating patients well will spread by word of mouth around the community, which will encourage more people to come to hospice.” – Interviewed Expert**

However, one expert warned that hospice should not fixate on reaching certain percentages of the community, but rather should make sure that it treats the people they serve with dignity and respect. Cultural organizations can help fill the gaps by educating hospices and providing them a better understanding of cultural differences that can build awareness and knowledge necessary for staff to engage more effectively with diverse patients and families.

Experts described efforts to increase community engagement that go beyond encouraging clinical referrals. This includes developing partnerships with faith-based organizations, fraternities, sororities, and other institutions to educate the community about hospice.

**“Go to the community. Do not wait for the community to contact you. Continue to educate the community while they are still healthy instead of waiting until they are dying” – Interviewed Expert**

Using these partners also provides the hospice an opportunity to hear first-hand what the community members need, rather than assuming what they need. Community partnerships can also help hospices better meet the social needs of their patients.

### **Engaging with the Black Community**

Most work on engaging Black patients in hospice advocated reaching patients through churches. Older adults who belong to African American churches, as well as their families and caregivers, often rely on their spirituality and church community to help them cope with illness (Siler et al., 2016). Churches are

considered trusted spaces for health resources and social supports (Siler et al., 2016), with members being receptive to information about hospice even if the educator does not understand the church's specific religious construct (Townsend et al., 2017). Hospices can partner with African American churches to provide education, for example, by arranging regular information sessions at the church (Townsend et al., 2017). Specific content areas that may help to overcome African American patient barriers to hospice care include reframing hospice care in a way that prioritizes cultural values and practices, creating alternative goals for hospice care, and using information from outside the formal medical system (Dillon and Basu, 2016). Other approaches include counteracting the perception that hospice means giving up on faith, for example, by emphasizing the continued support patients can receive from their spiritual leaders and peers and that prayer can remain powerful in hospice (Rhodes et al., 2017).

A recent position paper from the National Hospice and Palliative Care Organization (NHPCO), which does not specifically reference engaging churches, suggests that organizations can support Black communities at the end-of-life by conducting an analysis of the education system within redlined communities, investing in a community health education campaign, advocating for equitable health laws, being innovative about multi-generational engagement and who can be community health equity stakeholders, identifying implicit biases and reflecting on the impacts of their decisions, having a clear and precise dialogue with both physician and patient about available options, and scheduling time for relationship building (NHPCO, 2020). NHPCO also cautions that organizations should engage minorities in ways “add genuine value to communities rather than investing in ‘Diversity, Inclusion and Equity’ solely for capitalization and incentivization.” Hospice and palliative care providers should also “educate themselves on the psyche of BIPOC that has been shaped by systemic racism, socioeconomic inequities, and disparities in health care education” (NHPCO, 2020).

Regardless of the engagement approach used, hospices that set specific goals to increase the number African American patients they serve engage in their outreach activities more frequently than organizations without specific goals (Johnson et al., 2016). Additionally, evidence suggests that being more clinically inclusive can improve hospice use for both Black patients and white patients. One study found that that less restrictive hospice admission practices, such as being more likely to enroll patients receiving expensive palliative therapies or patients with less robust home support systems, were associated with a greater proportion of both Black Medicare beneficiaries and white Medicare beneficiaries using hospice. Other characteristics associated with increased use of hospice by both African American Medicare beneficiaries and white Medicare beneficiaries include hospices having nonprofit status or larger budgets and being in a service area with a larger proportion of generalists, less market competition, and fewer physicians available for those age 65 years or older (Johnson, 2016).

### ***Engaging with the Hispanic Community***

In addition to some of the strategies already discussed, for Hispanic patients, language plays a role in overcoming barriers. In rural US-Mexico border towns, while most family caregivers of Latino patients were likely to use hospice for their loved ones, they preferred hospice providers that were able to speak their primary language and where they trusted the physician to “make the right decision” (Ko, et al., 2017). Yet, hospice staff volunteers and patients were almost entirely white and rarely spoke Spanish (Reese and Beckwith, 2015). Education about hospice should reflect how cultural values impact hospice placement, and should clearly explain hospice's purpose, function, and benefits (Ko and Fuentes, 2020). However, Rising and colleagues believe that efforts to increase engagement are most effective for those that already have a paternalistic, or deferential, relationship with their physicians, and that “cultural accommodation may do little to mitigate hospice avoidance that is rooted in mistrust” (Rising et al., 2021).

### ***Engaging with the Indigenous American community and the Asian Community***

We identified limited work addressing how to increase enrollment for Indigenous American populations and Asian populations. For Great Plains American Indians, Soltoff and colleagues recommended

increasing the availability of hospice at the reservation or in local Indian Health Service Facilities, helping families navigate the health care system, and improving the “trustworthiness of the system” by giving clinicians access to cultural training and engaging Tribal Nations in health system changes. (Soltoff et al., 2022). Interviews with Elders of the Blackfeet Nation revealed that while many members of the Blackfeet Nation fear death, they would not feel that their beliefs were being violated if a culturally competent provider was caring for them (Colclough et al., 2019). As with all patients, providers should work with Native Americans on an individual level to establish how much care a Native American patient would like to receive (Colclough, 2017). For Asian populations, interviews with Hmong family members, shamans, and funeral officiants found that Hmong patients prefer to die at home and that providing families and patients information about hospice helps families see hospice as a viable care option within their deeply held cultural beliefs (Helsel et al., 2020).

### ***Engaging with the LBGTQ+ community***

For LBGTQ+ populations, a few case studies illuminated the ways hospice care can be more inclusive of these populations. One case study of a male with metastatic breast cancer who was assigned female at birth (Stevens and Abrahm, 2019) and another of a lesbian woman receiving hospice care from Veteran’s Affairs (Hinrichs and Christie, 2019) both advocated for building the trust of the LBGTQ+ community by being overtly welcoming and inclusive. This includes using inclusive language and images in outreach materials. For those in hospice, organizations should update the wording on intakes form to be more inclusive and ask patients who they want to be involved in decision making—then including partners and chosen families in decision making when the patient wishes (Hinrichs and Christie, 2019). LBGT adults often have a “chosen family” over a biological one. Providers should not make assumptions about family dynamics but instead ask questions (Acquaviva, 2017). For transgender patients, additional considerations include recognizing the lack of specific guidelines and standards for transgender patients in hospice settings, understanding patient preferences for discontinuation of hormone therapy, understanding insurance billing guidelines to avoid gender mismatch, and reflecting their SOGI disclosure preferences in their plan of care (Stevens and Abrahm, 2019). Despite the unique considerations applicable caring for the LBGTQ+ community, a small survey found that providers generally felt that LBGT adults do not require different treatment than other adults (Cloyes et al., 2022).

One the most significant barriers to improving patient care in the LBGTQ+ community is insufficient data. A survey of hospice care team members found that most hospices did not collect any SOGI data, and a third of them were unsure whether collecting data was mandatory. Providers generally felt that the patient should disclose SOGI data instead of asking them for it (Cloyes et al., 2022). Because of their unique needs, researchers believe that collection of collection of SOGI data should be mandatory (Candrian and Cloyes, 2021), and providers should ask the patient how they identify rather than assuming. A patient’s assigned gender and the gender they identify with may differ, and the best way to determine both gender identity and sexual orientation is to ask (Acquaviva, 2017). A study by Kemery and colleagues suggested that in some cases available data that might illuminate the LBGTQ+ experience of care can be flawed. The family members they interviewed reported lower quality of life than their non-LBGT counterparts, yet there was no difference between the two groups in responses to the individual [Quality of Death and Dying](#) questions. This suggests the instrument may not be valid in the LBGTQ community (Kemery et al., 2021)

### ***Organizational Efforts to Improve Hospice Care and Engagement***

Organizations may face barriers in their efforts to provide cultural humility. Reese and Beckwith surveyed hospice directors to identify the main barriers hospices face when trying to provide culturally competent care identified barriers at the community, organizational, and health system level. Organizations had difficulty diversifying their staff because they lacked diverse and bilingual volunteers, funding, community outreach programs, and an organizational culture that recognizes and values cultural differences. Hospice directors cited geography, severe poverty, and a lack of diversity within their

communities as community-level barriers to culturally competent care. Finally, health system factors included government regulations that reduce the hospice's ability to meet diverse needs (Reese and Beckwith, 2015). Boucher and Johnson surveyed hospices about the cultural competence trainings, finding 73% of surveyed hospices offering training and larger hospices (i.e., with an average daily census greater than 100) more likely to offer such training. Trainings were typically one hour included content on cross-cultural communication, beliefs about death, spirituality and religion, and health disparities. (Boucher and Johnson, 2021)

### ***Staffing Challenges and Opportunities***

One factor that seems to be essential to providing equitable care in the hospice setting is having staff that understand different cultural preferences and beliefs, as well as staff that is itself diverse. As an American Academy of Hospice and Palliative Medicine piece highlighted recently, there is an enduring lack of diversity in the field of hospice and palliative medicine and more time and effort should be spent gaining an understanding of how underrepresented people who are medical students make their career choices and how they can be influenced to choose hospice (Beresford, 2020). Those who provided comment to CMS' Request for Information (RFI) echoed those concerns, noting things like a limited pool of applicants, and needing additional resources to support recruitment and retention efforts (87 FR 45669).

### ***Challenges to hiring and maintaining diverse staff***

Sometimes staff themselves may be subject to inequitable care by those they care for. For example, male caretakers may discount the professional status of a nurse relative to a physician (Sutherland et al., 2016). Our experts reflected on these challenges for Black patients and LGBTQ+ patients. Providing adequate staff that understand Black cultural values presents different challenges. As one interviewee described it, African American hospice providers often face discrimination from the patients they serve, which, as one expert noted, is making many Black hospice staff consider leaving the industry. For example, patients may say they "don't want the Black nurse" and some organizations, to be patient-centered, will accommodate those requests. Yet, they may not accommodate a Black person's request to be placed with a Black clinician. The LGBTQ+ community also experiences a dearth of culturally competent care. Not only do staff often fail to treat for LGBTQ+ patients with dignity and respect, but hospice itself may attract a workforce more prone to biases against the LGBTQ+ community. Hospice providers may feel a "calling" to end-of-life care that connects to their personal religious beliefs, which can be imposed upon the patients and families. One expert described hearing of nurses and nursing assistants attempting "death bed conversions" with their LGBTQ+ patients. She further noted that hospice patients may be more vulnerable to this kind of behavior than patients in other settings because hospice care is often provided at home, and rarely are there multiple staff members in the home simultaneously. While LGBTQ+ individuals work in hospices, they may not feel comfortable being "out" at work because of the organizational culture.

Different challenges exist for the Chinese-speaking patients. According to our experts, staff who speak Chinese or Chinese interpreters can be difficult to find. Even when interpreters are available, patients may be unable to comprehend what is happening to them because there is often not a direct translation for medical issues. Finding bilingual Chinese-speaking staff is particularly difficult, as cultural taboos about hospice and end-of-life care in the Chinese community limit the number who choose hospice nursing and social work.

### ***Use of non-traditional roles***

Several studies found that hospices employing students or others in the community through non-traditional roles were better equipped to hire diverse staff and serve patients of diverse backgrounds. Two studies looked specifically at community health workers. A Chicago study found that racial and ethnic minorities from low-income neighborhoods who were newly diagnosed with cancer and assigned a community health worker were more likely to use hospice care than those in without a community health worker. Participants felt more comfortable discussing their care goal and advance directives with

members of their community than with health care professionals (Patel et al., 2021). Soltoff and colleagues also suggested engaging community health workers in their work with Great Plains American Indians. Community health workers can help families navigate the health care system, increase the American Indian workforce, and improve cultural understanding (Soltoff et al., 2022).

For Hispanic patients who were provided patient navigators, the results were mixed. One study provided culturally and linguistically tailored materials describing advance care planning, pain management, and hospice care to a control group of Hispanic patients with advanced cancer and their family caregivers. They provided an intervention group with the same materials, as well as home visits by a Hispanic lay navigator who helped patients understand hospice by, for example, addressing misconceptions about hospice care. The navigators successfully facilitated advance care plan discussions, motivated patients to talk with providers about their pain needs, and helped patients and family caregivers learn more about hospice more so than written materials alone (Fink et al., 2020). However, in a prior study of Latino adults being treated for advanced cancer who worked with a culturally tailored patient navigator, the intervention increased advance care planning and improved physical symptoms, but had no effect on pain management, hospice use, or overall quality of life (Fischer, et al., 2018).

An additional study evaluated the effectiveness of hospice placement of student social workers in a rural community. The students helped address several of the organization staffing barriers by providing public information sessions, cultural competence training for staff, and a needs assessment to identify groups not served by the hospice—all services for which the hospice originally lacked resources (Reese et al., 2017).

### ***Diversity in leadership***

Our expert interviewees emphasized the importance of diversifying the hospice workforce at all levels to better reflect the communities they serve, while noting the particular importance of doing so at more senior levels. Some hospices are diversifying their board members, which helps to hold senior leadership accountable. However, board members are typically not involved in day-to-day decision making. Having representation at the organization’s senior leadership levels can have a “trickle-down” effect, by making those who work at those institutions feel more supported. For example, if a patient refuses the services of a Black hospice clinician because of the color of her skin or her sexual orientation, a leader that has lived experience with discrimination may be more willing or able to address the issue in a way that is supportive of the clinician. Further, leadership may be where diversity is lacking. The most diverse staff often are typically at the bedside with patients and families. Preferably, representation would reflect not only the organization’s patient population, but those in the community they aim to reach.

“How would it [more representation] work against you? Diversity helps us to be more creative in our thinking.” – Interviewed Expert

Supporting the findings of our experts, Boucher and Johnson found that of hospices that provided cultural competency training, 90% of the nursing, social work, and chaplain staff participated. 60 to 70% of leaders participated. Only 26% of board members participated (Boucher and Johnson, 2021)

### ***Data Collection Challenges and Opportunities***

Our expert interviews reflected a unanimous concern that the available data are simply insufficient to understand the complexity of inequities that exist in healthcare systems and settings, beyond what we discussed previously with respect to the LGBTQ+ community. For example, hospices often do not collect any SOGI data. Even with data hospices routinely collect, the quality of that data can be poor. Often, hospices will complete forms based on their perception of the patient, rather than a discussion with the patient—if they collect the data at all. As one expert noted, when a patient goes to a primary care physician, the patient completes paperwork that includes

“When collecting this demographic data, clinicians often click the easiest thing in the EMR rather than asking the patient directly.” – Interviewed Expert

demographic information independently. In hospice, the patient often does not complete those forms on their own, and instead depends on whoever is at the bedside. Hospice providers should be trained on how to collect patient data, including why collecting these data is important. One expert opined that hospice providers, who are comfortable asking about bowel movements, should not be worried they will offend a patient by asking questions about their gender identity.

Absent robust data on subpopulations, researchers, policymakers, and hospice providers are limited in their understanding of the quality of care in different subpopulations and how they might differ from each other. Multiple interviewees supported mandating more extensive data collection. For example, requiring the addition of questions about race, ethnicity, sex assigned at birth, gender identity, and sexual orientation in the CAHPS® Hospice Surveys, and requiring hospices to collect race, ethnicity, sex assigned at birth, gender identity, and sexual orientation data. Most interviewees explicitly requested mandatory data collection and reporting, with one interviewee warning that organizations can skew voluntary data collection and reporting, as they often want to demonstrate improvement or “show that they are doing a good job.” Experts noted that using standard question construction and standard validated instruments can support both comparisons of different subpopulations and lend credibility to the results. One interviewee put mandatory data collection in more stark terms, noting: *“The largest barrier to care is [organizational] prioritization. Health equity is currently viewed as a nice-to-have rather than a must-have. There should be a financial disincentive to provide inequitable and non-inclusive care.”* Those who responded to CMS’ RFI also commented on the need for more data, particularly a standardized on sociodemographic and SDOH data (87 FR 45669)

Our experts also suggested data collection beyond patient demographics—specifically, community-level demographic data and patient preferences data. Understanding community level data is a precursor to hospices understanding the subpopulations they may not be engaging in services. One expert advocated for collecting data on end-of-life preferences, such as preferences for invasive treatment, whether the patient or their caregiver stated those preferences, and whether a patient has an advanced care plan. They also recommended that hospice staff ask SDOH questions of all patients, noting that hospice staff cannot make assumptions about a patient’s needs.

All our experts supported qualitative data collection to inform health equity in hospice. Qualitative research offers an opportunity to collect more personalized details about hospice care, including understanding what is most important to patients and the caregivers, and what barriers they may face. However, interviewees warned that such research can be subject to selection bias, particularly if hospices select the participants. Of particular concern is that certain standardized data collection tools have not been validated with people of color. Though standardized research is important, it may need to be balanced with more creative or ethnographic research to accurately reflect the experiences of certain subpopulations.

Two identified studies focused on telehealth illustrate the need for caution with validated instruments. Hughes and Vernon believe that the COVID-19 public health emergency presents an opportunity to increase equity in hospice care. With the expansion of telehealth, hospices have an opportunity to provide their services in a more inclusive way, with approaches that may lead to greater hospice inclusion beyond the public health emergency. For example, health care providers can make their content and health services mobile friendly, work with patients to obtain affordable internet services, and lend electronic devices to patients (Hughes and Vernon, 2021). However, a meta-analysis focused on telehealth in the hospice setting found that validation and utilization of telehealth assessment measures underrepresented adolescents, geriatric populations, non-white or low-income populations, and those without a post-secondary education (Weaver et al., 2021).

## **Measurement Approaches**

A few studies suggested specific approaches to considering for measuring conditions relevant to health equity. Mendola and colleagues suggest introducing the term “social determinants of comfort” to describe structural conditions that influence to what degree hospices offer and patients and their families accept comfort measures. This framework would recognize factors such as safety of the built environment, access to nourishing food, a steady income source, among others as structural conditions that influence the health outcomes of individuals and populations (Mendola et al., 2021). A survey by AbuDagga and colleagues asked home health and hospice agencies about cultural competency training and awareness and found that they could reliably calculate two measure constructs based on their survey questions: 1) whether the hospice provides mandatory cultural competency training, and 2) whether the hospice effectively communicate in culturally competent ways (AbuDagga et al., 2018).

Lastly, CMS requested information on a multi-domain structural composite measure in their FY 2023 proposed hospice rule, which includes domains related to health equity and community engagement in strategic planning; diversity, equity, and inclusion training; and organizational inclusion and capacity to promote health equity (87 FR 45669). Commenters were generally supportive of a health equity structural measure, but noted that having adequate resources and accurate, actionable data related to the measure are important. As this report has suggested, there are several opportunities to improve access to hospice and the experience of care for hospice patients and their caregivers.

In the months following this report, Abt Associates will convene two TEPs that will engage in work to incorporate health equity into quality measure development. The first is a newly recruited TEP of health equity experts in both hospice and home health that will further reflect on the role CMS can play within its quality reporting programs to improve equity in these settings. The second is the existing HQRP TEP (which has provided input for the HQRP since 2019), which will consider this report and reflect upon the available opportunities to promote health equity within the HQRP.



## Other Recent Hospice Literature

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To identify any emerging trends outside of our research questions, we conducted an environmental scan to identify literature related to quality of care in the hospice setting that was published in the last year. Our results fell into three main categories: hospice care for dementia patients, use of new technologies in hospice, and approaches to staffing and services. One additional study explores a Health Days at Home measure.

Two recent studies using National Health and Retirement Study data linked to Medicare claims considered hospice care for patients with dementia. The first considered patients with both primary and co-morbid dementia, which combined represented approximately 45 percent of hospice patients. Patients with either co-morbid or primary dementia had longer lengths of stay and were more likely to disenroll from hospice after six months than those without dementia (Aldridge et al., 2022). The second study considered caregiver experience and found that, for dementia patients enrolled in hospice, proxies were more likely to report excellent care, that the patient's anxiety and sadness was managed, and that the patient changed care settings in the last 3 days of life less frequently than those not enrolled in hospice. For those receiving hospice, proxy ratings did not differ between patients with dementia and those without (Harrison et al., 2022).

Two studies pertained to use of technology at end of life: one focused on telehealth and the other on machine learning. A recent study using both caregiver surveys and hospice leader interviews explored telehealth use. Telehealth reportedly enhanced usual care activities such as addressing patient and family concerns, explaining lab results, and basic diagnostic activities as well as bereavement support; however, perceptions of telehealth for social workers and spiritual counselors were mixed. Some felt social workers and spiritual counselors could reach more people using telehealth and did not have to visit patient homes, but others felt these services “are more difficult to do well without in-person connection.” Providers also expressed continued confusion over telehealth policies and concerns about abuse, such as some hospices doing phone calls instead of true audio-visual visits or family drug diversion becoming more prevalent. From a patient perspective, those with better internet, better access to video, and under 65 were more satisfied with telehealth (Hughes et al., 2022). With respect to machine learning, a recent analysis of therapy sessions for family caregivers of hospice patients found that machine learning techniques that use automated speech-to-text transcription and acoustic features can reasonably indicate improvements in anxiety and quality of life measures in older adults with a reasonable degree of accuracy relative to assessment with a validated instrument. The authors reported this may have implications for the use of chatbots to provide therapy. They further noted that the use of machine learning could minimize the need to repeatedly administer instruments such as the Generalized Anxiety Disorder-7 and the Caregiver Quality of Life Index-Revised, and increases the ability of these instruments to be administered outside of clinical settings. (Demiris et al., 2022)

Two studies addressed hospice staffing and services. The first, an Italian study, analyzed the predictive power of staffing on controlling clinically significant symptoms in residential hospices. They found a ratio of approximately 20% physicians, 20% nurse assistants, and 60% registered nurses was associated with the greatest likelihood of symptom control (including pain, nausea, shortness of breath, feeling sad, feeling nervous), and that physicians and nurses trained in palliative care were associated with improved patient outcomes (Artico et al., 2022). Another study looked at how the provision of inpatient services can impact a hospice's total operating margin (i.e., income/revenue) and their return on assets (i.e., income/assets). Hospices that had staff provide inpatient services had shorter lengths of stay and lower total operating margins than hospices that did not offer inpatient services. Hospices that offered a combination of inpatient services provided by staff and by a third-party arrangement had a lower return on assets than hospices that do not provide inpatient services. The authors conclude that many hospices



increasingly look to provide inpatient services by arrangement to maintain financial sustainability (He et al., 2021).

Lastly, one study used a novel quality measure in the last 180 days of life for cancer patients. The HDAH measure considers the last 180 days of life and subtracts days the patient spends in an acute inpatient setting or emergency department (including observation), skilled nursing facility, inpatient psychiatric setting, inpatient rehabilitation facility, long-term hospital, or inpatient hospice. Days at home with home hospice or home health are considered HDAHs and not subtracted. Skilled nursing facility days and inpatient facility days resulted in the most substantial HDAH reductions, and males and Medicaid patients had fewer HDAH's than their female and male counterpart, respectively. (Lam et al., 2021)

## Conclusion

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Many studies have explored differential use of hospice care over the past seven years, with many focused on race and ethnicity. Historically excluded populations are less likely to use hospice, and often less likely to be aware of hospice care and its benefits. However, there is some evidence that historically excluded populations are not referred to services less. In fact, some evidence suggests that Black patients are more likely referred to hospice more often than their white counterparts. Indigenous American populations face limited access, and Hispanic patients and Asian patients face language barriers. There are also myriad complex cultural values and lived experiences unique to each population that influence willingness to use hospice care. Of those that choose to enroll in hospice, historically excluded races and ethnicities are more likely to enroll early. Though most of the health equity research focuses on race and ethnicity, other influencers of likelihood to receive hospice care include gender, education, income, and location.

Studies consistently reported Asian and LGBTQ+ populations having poorer care experiences. Asian patients seem to face particular cultural and language barriers to receiving high quality hospice care. For LGBTQ+ patients, there are no incentives for hospice providers to discuss SOGI with patients and discounting of chosen family and spouses persists. Pain management, a bedrock of hospice care, also reflects inequities of gender and race.

Addressing equity in hospice involves community engagement, recruiting and retaining diverse staff, and expanded available data. Many studies offered specific approaches to engage communities to increase enrollment, though strategies will vary depending on the specific community. Recruiting and maintaining diverse staff can be a particular challenge for hospice providers, especially when bedside employees may face discrimination from patients. Increasing diversity in senior roles may help staff feel more supported. Use of non-traditional staff and students has also shown promise for both increasing staff diversity and engaging the community. Currently available data are insufficient to effectively understand health equity in hospice care. Additional patient demographic data (e.g., SOGI), community-level demographic information, SDOH data, and qualitative data can all help to better illuminate how equitable hospice care is.

Few studies suggested specific measures or constructs related to health equity, though CMS asked for feedback on a health equity focused structural measure in its FY 2023 Hospice Rule (87 FR 45669). Over the next few months CMS will convene two TEPs focused on health equity to reflect on the role CMS can play within its quality reporting programs to improve equity in these settings.

As for other emerging trends in hospice, in the past year the literature has focused on dementia patients, technology, hospice structures, and the novel HDAH measure. Almost half of hospice patients have dementia and benefit from hospice care. Technology advancements in hospice in telehealth and machine learning have potential to improve care, but telehealth works better for certain medical interventions than for social and spiritual care, and there remains confusion and concern over potential abuse. Structural elements also impact hospice care, with a higher ratio of nurses to physicians associated with better symptom management, and hospice perhaps deciding to offer inpatient services by arrangement rather than their own staff to maintain financial stability. A novel HDAH measure looks at quality of life in the last 180 days of life and can help users understand where patients are going when not at home and who is more likely to have HDAHs.

## Appendix I: Methods

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### **Literature Reviews**

The Information Gathering Team used a stepwise process to identify information relevant to our research questions. Those steps are outlined here.

**Determine search terms.** We determined a specific set of search terms to both identify the hospice setting and to identify work relevant to each specific research question using the following steps:

- Determine MeSH terms using [MeSH on Demand](#),
- Determine additional non-MeSH terms,
- Discuss identified search terms as a group and solicit expert review where needed,
- Finalize search terms.

The following search terms to identify the hospice setting were consistent across all searches:

- MeSH terms included: Hospices, Hospice Care, Hospice and Palliative Care Nursing, Terminal Care.
- Non-MeSH terms included: end-of-life care.

**Determine search parameters and identify articles.** We conducted our literature searches in PubMed, which include MEDLINE indexed journals, journal and manuscripts deposited in PubMed Central, and the National Center for Biotechnology Information Bookshelf. We used the following steps to conduct the search and ensure the most relevant results.

1. Determine Boolean phrase using predetermined search terms (i.e., how terms will connect using and/or)
2. Set results filters to adult, human, and English language results in the past 5 years.
3. Use the Advanced Search option to search in the Title and Abstract fields

If this yielded fewer than ten results, we updated the parameters to search in all Text Word fields. If this still yielded fewer than ten results, we searched in All Fields and reviewed the search terms with subject matter expert to see if the terms should be revised. If a search yielded greater than 500 results, we revised our search terms to narrow the results and consulted with a subject matter expert. We exported all results to an EndNote library.

**Review identified articles.** To facilitate our review, we designated folders within each EndNote Library for relevant articles, somewhat relevant articles, and insufficiently relevant articles that we rejected from our results. We further sorted rejected articles based on how detailed our review of each article was. Some were rejected based on the relevance of their title or abstract. Remaining articles were either kept or rejected based on a review of the full text. Potential reasons for rejection include incorrect setting, incorrect population, or lack of specificity to target questions. If fewer than five articles remained after the review process, we consulted with a subject matter expert and conducted a supplementary Google Scholar search.

**Supplement results using Google Scholar.** For searches with fewer than five relevant articles remaining after review, we conducted a search in Google Scholar using the same search terms and review criteria outlined for our PubMed searches.

**Identify and review grey literature.** The Information Gathering lead identified relevant grey literature by using the hospice search terms identified above in the [Harvard Kennedy School Think Tank](#) site as well as the following individual sites with a focus on healthcare or hospice:

- Center to Advance Palliative Care
- Institute for Healthcare Improvement
- Joint Commission
- Robert Wood Johnson Foundation
- The Commonwealth Fund
- Kaiser Family Foundation
- National Academy of Medicine
- National Coalition for Hospice and Palliative Care (NCHPC) (trade group membership)
- Hospice and Palliative Care Nurses Association
- American Academy of Hospice and Palliative Care
- National Hospice and Palliative Care Organization (NHPCO) (membership required)
- Visiting Nurse Associations of America

The Information Gathering lead reviewed the search results within each site and compiled links relevant to hospice or our topics. The larger Information Gathering team searched these compiled links using the previously determined search terms for each of their research questions. For the Center to Advance Palliative Care site, staff searched the overall site with their research question specific search terms.

Most of the sites did not yield any recent, accessible, and relevant content apart from: Kaiser Family Foundation, NHPCO, the Commonwealth Fund and the American Academy of Hospice and Palliative Care.

**Review additional supplemental information.** We compiled information provided by the TEP, subject matter experts, and other stakeholders over the course of the year. Information Gathering staff reviewed these materials and incorporated findings relevant into their research questions.

### ***Expert Interviews***

We identified nine experts, including representatives of diversity, equity, and inclusion initiatives and provider associations as well as health services researchers with relevant expertise. After CMS approved this list of experts, we emailed each of these experts and invited them to speak with us. Four agreed, one declined, and the remainder did not respond after three outreach attempts. Our four interviewed experts were:

- Kimberly Acquaviva, Betty Norman Norris Endowed Professor at the University of Virginia School of Nursing and end-of-life advocate for the lesbian, gay, bisexual, transgender, gender-non-conforming, queer, and/or questioning (LGBTQ+) community.

- Karen Bullock, former Professor and Head of the School of Social Work at North Carolina State University
- Sandy Chen Stokes, Founder and Executive Director of the Chinese American Coalition for Compassionate Care and Member of NHPCO's Diversity Advisory Council
- Nicole McCann Davis, former Associate Vice President of Health Equity and Access at Seasons Hospice and Palliative Care and Chair of NHPCO's Diversity Advisory Council

We created a brief, semi-structured interview guide to facilitate our discussion that included health equity focused questions on both receipt of and access to hospice care. We probed on topics such as key health equity terms and concepts, use of data, cultural gaps, hospice referral and enrollment, and increasing representative hospice staff.

## Appendix II: Search Results

<b>Social Determinants of Health</b>	
Search Terms	("social determinant*" AND ("hospice" OR "hospice care" OR "end of life care" OR "terminal care" OR "hospice and palliative care nursing")) [All Fields]
Search Date	March 2022
Total Peer-Reviewed Articles	43
Total Google Scholar Results	N/A
Total Grey Literature Articles	0
Title/Abstract Rejection	15
Article Rejections	21
Final Articles	7
<b>Health Equity in the Hospice Setting</b>	
Search Terms	(Hospice OR Hospice Care OR Hospice and Palliative Care Nursing OR terminal care OR end-of-life care) AND (ident* OR disparit* OR equity OR underrepresent* OR inclus* OR cultur* OR diversity OR underserve OR minori*) [Title Abstract = 3,300]  (Hospice OR "terminal care" OR "end-of-life care") AND (identity OR disparit* OR equity OR underrepresent* OR inclus* OR cultur* OR diversity OR underserve OR minori*) [title/Abstract = 1,961]  (Hospice) AND (identity OR disparit* OR equity OR underrepresent* OR inclus* OR cultur* OR diversity OR underserve OR minori*) [title/abstract = 805]  (Hospice) AND (identity OR disparit* OR equity OR underrepresent* OR inclusive OR cultur* OR diversity OR underserve OR minori*) [title/abstract = 619]
Search Date	June 2022
Total Peer-Reviewed Articles	619
Total Google Scholar Results	N/A
Total Grey Literature Articles	5
Title/Abstract Rejection	409
Article Rejections	105
Final Articles	111
<b>Other Recent Hospice Literature</b>	
Search Terms	("hospice") AND ("quality")
Search Date	August 8, 2022
Total Peer-Reviewed Articles	71
Total Google Scholar Results	NA
Total Grey Literature Articles	0
Title/Abstract Rejection	60
Article Rejections	4
Final Articles	7

## Appendix III: Literature Review Tables

### Health Equity and Social Determinants of Health

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
2021 Massachusetts State Hospice Report: 2019 Medicare Information with 2018 Comparisons Using Annual Files. (2021, 02/23/2021). State Hospice Organization.	Massachusetts, Hospice	NA	Hospice utilization data for the country in comparison to the United States	Presentation presents nice data visualizations for county-level variation in hospice utilization as percent of Medicare deaths (slide 7 and 8). This visualization particularly shows inequities of hospice utilization in the West.
Abbas, A., Madison Hyer, J., & Pawlik, T. M. (2021). Race/Ethnicity and County-Level Social Vulnerability Impact Hospice Utilization Among Patients Undergoing Cancer Surgery. <i>Ann Surg Oncol</i> , 28(4), 1918-1926. <a href="https://doi.org/10.1245/s10434-020-09227-6">https://doi.org/10.1245/s10434-020-09227-6</a>	United States	54, 256 patients 65 years of age or older with a diagnosis of lung, esophageal, pancreatic, colon, or rectal cancer who underwent a resection for cancer between 2013 and 2017.	Patients were identified through CMS Standard Analytical Files, which contain de-identified data on Medicare beneficiaries. They used the CDC Social Vulnerability Index to understand the socioeconomic qualities of a patient's area of residence. SVI = higher is more vulnerable.	White patients were more likely to utilize hospice care than minority patients (OR 1.24, 1.17-1.31). As the Social Vulnerability Index (SVI) increases for minority patients, hospice utilization and early hospice initiation decrease (OR 0.97, 0.96-0.99). Ultimately, patients in high SVI areas were less likely to be enroll in hospice, especially if they are not white.
AbuDagga, A., Mara, C. A., Carle, A. C., & Weech-Maldonado, R. (2018). Factor Structure of the Cultural Competence Items in the National Home and Hospice Care Survey. <i>Med Care</i> , 56(4), e21-e25. <a href="https://doi.org/10.1097/mlr.0000000000000714">https://doi.org/10.1097/mlr.0000000000000714</a>	United States	1,036 home health and hospice agencies.	Data were collected from the 2007 National Home and Hospice Care Survey, which consisted of interviews with agency directors and designated staff. The NHHCS asks 9 questions about cultural competency, and all were included in this study. Analysis was then performed to understand what combination of questions can be measured to provide a decent measure of cultural competency.	The study found two constructs that can be measured using the 9 survey questions. The first is mandatory cultural competency training (questions 1-3), and the second is cultural competency communication practices (questions 7-9). These constructs were analyzed with the questions for correlation and found to have a p value of <0.01.
Acquaviva, Kimberly D. <i>LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice</i> . Harrington Park Press, 2017.	United States	Book – guide to practical changes	N/A	Chapter 2: It is important to recognize that gender identity occurs on a spectrum and that assigned sex does not always show what gender a person identifies as. The only way to determine gender identity and sexual orientation is to ask.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
				<p>Chapter 3: To provide LGBT-inclusive care, providers must understand oppression faced by LGBT adults. Furthermore, hospice providers must address barriers (perceptual, financial, and institutional) in both an outward facing (outreach, education) and inward facing (staff education) fashion.</p> <p>Chapter 5: When discussing family dynamics with LGBT patients, do not assume anything about the relationship with their family. Asking questions is the easiest way to understand these dynamics and will help determine who is the legal decisionmaker and who should be excluded from decisions. It should also be noted that LGBT adults often have a “chosen family” over a biological one.</p> <p>Chapter 6: It is important to remember that LGBT adults are more often smokers, so oxygen usually becomes more of an issue at end of life. It's important to understand differences between LGBT and cis/hetero adults when planning care.</p> <p>Chapter 10: Health code of ethics compels a person to advocate for changes to ensure equal treatment of LGBT adults. This can be achieved through four main planks:</p> <p>Plank 1: Nondiscrimination statement  Plank 2: Employee benefits, orientation, and training  Plank 3: Intake forms and processes  Plank 4: Marketing and community engagement</p> <p>For LGBT patients to feel safe, LGBT employees should also feel safe.</p>



Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Bazargan, M., Cobb, S., Assari, S., & Kibe, L. W. (2021). Awareness of Palliative Care, Hospice Care, and Advance Directives in a Racially and Ethnically Diverse Sample of California Adults. <i>Am J Hosp Palliat Care</i> , 38(6), 601-609. <a href="https://doi.org/10.1177/1049909121991522">https://doi.org/10.1177/1049909121991522</a>	California	2,328 people. Hispanic (31%), Black (30%), and non-Hispanic White (39%)	Cross-sectional study from the Survey of California Adults on Serious Illness and End of Life 2019. The goal of the study was to examine socioeconomic, racial, and medical factors to understand the awareness of palliative and hospice care.	Adjusted for socioeconomic and demographic characteristics, as well as chronic conditions, Whites are more likely to be aware of hospice than Black people (OR 0.44) or Hispanics (OR 0.23).  Primary caregivers were more likely to be aware of palliative care (OR 1.71) or advanced care planning (OR 1.48) than hospice care (OR 0.99).  Having a primary care provider was associated with a higher likelihood of being aware of hospice care.
Beltran, S. J. (2018). Hispanic Hospice Patients' Experiences of End-Stage Restlessness. <i>J Soc Work End Life Palliat Care</i> , 14(1), 93-109. <a href="https://doi.org/10.1080/15524256.2018.1437589">https://doi.org/10.1080/15524256.2018.1437589</a>	United States	143 Hispanic patients, 285 non-Hispanic patients who were discharged due to death	Analyzed the patients to understand whether they had restlessness prior to death or present at death (NHHCS question 77). Binary yes/no. Then they performed bivariate analyses to determine the statistical significance of race on this question.	Being Hispanic (OR: 1.67), having trouble breathing (OR: 2.13), pain (OR: 2.38), and sedation (OR: 3.06) were all factors that were significantly associated with end stage restlessness. Furthermore, the odds of experiencing end-stage restlessness were 3.77 times higher for Hispanics experiencing pain ( $p < .01$ ) than for non-Hispanic whites and Hispanics not in pain.
Beltran, S. J. (2022). Latino Families' Decisions to Accept Hospice Care. <i>Am J Hosp Palliat Care</i> , 39(2), 152-159. <a href="https://doi.org/10.1177/10499091211042336">https://doi.org/10.1177/10499091211042336</a>	United States	13 Latinos 65+ age, who are enrolled in hospice (or their proxies) who scored 8+ on the Brief Interview for Mental Status	Descriptive, cross-sectional study that conducted semi-structured interviews in English and Spanish regarding factors that guide decisions regarding end-of-life care.	The interviews shed light on several subjects specific to Latino experiences in hospice care.  Latino people generally do not have a lot of experience with the US healthcare system – reporting a lack of healthcare due to location or finances.  Limited health literacy and language barriers mean that patients often rely on family members for translation and can lose the fundamental understanding of their prognosis during the process. Most patients learned about hospice at the time of referral.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
				In terms of expectations, Latinos expect nursing care and medical supplies from hospice. Often, they are confused about what services can exactly be provided.
Beresford, L. (2020). Programs Have Stepped Up to New Roles--Where They've Had Sufficient Staffing. American Academy of Palliative and Hospice Medicine. <a href="http://aahpm.org/quarterly/fall-20-feature">http://aahpm.org/quarterly/fall-20-feature</a> . Accessed August 26, 2022	American Academy of Hospice and Palliative Medicine Fall Feature 2020	N/A	Reporting on staff experience in care in COVID	"Another important issue raised by the COVID pandemic, with its disproportional impact on people of color, is the enduring lack of diversity in the field of hospice and palliative medicine. "We need to spend more time and effort reaching out to underrepresented people among our medical students and to gain better understanding of how they make their career choices and how to influence them to choose us," [Robert Arnold, MD FACP FAAHPM, chief of the section of palliative care and medical ethics at the University of Pittsburgh Medical Center in Pennsylvania] said."
Booker, S. Q., Herr, K. A., & Wilson Garvan, C. (2020). Racial Differences in Pain Management for Patients Receiving Hospice Care. <i>Oncol Nurs Forum</i> , 47(2), 228-240. <a href="https://doi.org/10.1188/20.Onf.228-240">https://doi.org/10.1188/20.Onf.228-240</a>	Midwestern United States	32 African Americans and 32 Caucasian Americans 65+ age who are receiving hospice care at home for cancer.	Secondary analysis of a completed cluster randomized controlled trial 2007-2010. Patients were measured using the Cancer Pain Practice Index (CPPI)	There was no statistically significant difference in CPPI scores between races.
Boucher, N. A., & Johnson, K. S. (2021). Cultivating Cultural Competence: How Are Hospice Staff Being Educated to Engage Racially and Ethnically Diverse Patients? <i>Am J Hosp Palliat Care</i> , 38(2), 169-174. <a href="https://doi.org/10.1177/1049909120946729">https://doi.org/10.1177/1049909120946729</a>	United States	197 hospices	Data obtained from a cross-sectional national survey of a convenience sample of hospices from 2014-2015. Telephone interview with hospice leaders. Additionally, a web-based survey with questions about CCT.	Hospices with a >100 average daily census were more likely to offer CCT (80% vs. 64%)  73% of surveyed hospices offered cultural competency training, although there was no statistical significance in characteristics between hospices that do and do not offer CCT.  Most of these trainings are 1 hour in length. Of the hospices that participated, 90% of the nursing, social work, and chaplain staff participated. 60-

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
				70% of leaders participated. Only 26% of board members participated.  Main themes covered in CCT include cross-cultural communication, death beliefs, spirituality/religion, and health disparities.
Cagle, J. G., LaMantia, M. A., Williams, S. W., Pek, J., & Edwards, L. J. (2016). Predictors of Preference for Hospice Care Among Diverse Older Adults. <i>Am J Hosp Palliat Care</i> , 33(6), 574-584. <a href="https://doi.org/10.1177/1049909115593936">https://doi.org/10.1177/1049909115593936</a>	United States	2487 people	Analysis of North Carolina AARP End of Life Survey in 2002. Socioeconomic and demographic information was collected, as well as questions regarding attitudes about hospice, dying, and healthcare.	Black Americans are less likely to prefer or request hospice support (63.8% vs. 79.2%, $P < 0.0001$ ). Black Americans were more likely to not know their preference for hospice as well (31.5% vs. 16.8%).  Furthermore, gender, age, income, insurance coverage, importance of physical comfort, religiosity, and importance of being on/off machines to extend life were able to predict hospice preference.  Generally, Black Americans are much more uncertain about receiving hospice than their white counterparts.
Cagle, J. G., Van Dussen, D. J., Culler, K. L., Carrion, I., Hong, S., Guralnik, J., & Zimmerman, S. (2016). Knowledge About Hospice: Exploring Misconceptions, Attitudes, and Preferences for Care. <i>Am J Hosp Palliat Care</i> , 33(1), 27-33. <a href="https://doi.org/10.1177/1049909114546885">https://doi.org/10.1177/1049909114546885</a>	United States	123 adults living in the contiguous US	Telephone numbers were randomly selected, and minority groups were over-sampled. A small telephone survey was conducted to ask questions regarding awareness and knowledge about hospice.	86% of respondents had heard of hospice, and 54% had already had a personal experience with hospice. Greater knowledge of hospice was associated with better attitudes toward hospice.  Respondents who were college-educated, worked in the medical field, or were non-Hispanic white, are more likely to be aware of and be knowledgeable of hospice.
Candrian, C., & Cloyes, K. G. (2021). "She's Dying and I Can't Say We're Married?": End-of-Life Care for LGBT Older Adults. <i>Gerontologist</i> , 61(8), 1197-1201.	United States	31 older lesbian adults	Qualitative interviews conducted with lesbian adults to understand their perspectives about end-of-life care. Interviews lasted 1-2 hours and were conducted in-home or on video.	Hospices do not routinely collect SOGI data. In a 2018 survey, 43% of hospice professionals reported that they had observed directly discriminatory behavior against LGBT people and their spouses.

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Citation	Setting	Population	Design	Main Findings
<a href="https://doi.org/10.1093/geront/gnaa186">https://doi.org/10.1093/geront/gnaa186</a>				<p>The interviews elaborated the fact that LGBT people, even if asked about SOGI, can receive discrimination from hospice staff. One story of a wife dying from leukemia involved a nurse providing less and less care once he realized the patient and the visitor were a couple.</p> <p>As a result, LGBT people are often forced to hide their identities as they receive healthcare to receive the best quality care. However, developing LGBT-approved SOGI guidelines and mandating SOGI collection in hospice can help normalize the process, which may not stop personal discrimination, but can help shift the system towards inclusivity.</p>
<p>Carrion, I. V., Cagle, J. G., Van Dussen, D. J., Culler, K. L., &amp; Hong, S. (2015). Knowledge About Hospice Care and Beliefs About Pain Management: Exploring Differences Between Hispanics and Non-Hispanics. <i>Am J Hosp Palliat Care</i>, 32(6), 647-653.</p> <p><a href="https://doi.org/10.1177/1049909114536023">https://doi.org/10.1177/1049909114536023</a></p>	United States	123 individuals, 13% of whom were Hispanic	Cross-sectional phone survey of adults living in the contiguous US. Phone numbers were randomly selected. Participants were measured on knowledge, attitudes, experiences, and preferences related to hospice and pain management.	<p>Hispanic people generally have less knowledge and understanding of hospice, as well as more difficult views on pain.</p> <p>Hispanic people were less likely to have heard of hospice and more likely to have incorrect information about it (<math>p &lt; 0.001</math>, <math>p = 0.05</math>). 56% of Hispanic respondents thought that hospice was only for people 65+ years old (versus 7% for non-Hispanic respondents).</p> <p>Hispanic people were also more likely to say pain is a sign of weakness and that a good patient does not talk about pain.</p>
<p>Check, D. K., Samuel, C. A., Rosenstein, D. L., &amp; Dusetzina, S. B. (2016). Investigation of Racial Disparities in Early Supportive Medication Use and End-of-Life Care Among Medicare Beneficiaries with Stage IV Breast Cancer. <i>J Clin Oncol</i>, 34(19), 2265-2270.</p>	United States	752 white and 131 Black women who had stage IV breast cancer	SEER-Medicare data collected from 2007 – 2012, analyzed for the relationship between race and hospice admission (among other factors).	Disparity in hospice use: Black women were 14% less likely to be enrolled in hospice than their white counterparts (OR: 0.86).

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<a href="https://doi.org/10.1200/jco.2015.64.8162">https://doi.org/10.1200/jco.2015.64.8162</a>				
Cloyes, K. G., Jones, M., Gettens, C., Wawrzynski, S. E., Bybee, S., Tay, D. L., Reblin, M., & Ellington, L. (2022). Providing home hospice care for LGBTQ+ patients and caregivers: Perceptions and opinions of hospice interdisciplinary care team providers. <i>Palliat Support Care</i> , 1-9. <a href="https://doi.org/10.1017/s1478951522000657">https://doi.org/10.1017/s1478951522000657</a>	United States	48 hospice care team members	Six focus groups from three hospice sites were convened with hospice care team members. HCT members were asked about their knowledge and experience related to EOL care for LGBT adults.	<p>Two sites said they do not collect any SOGI data. The third site believed it was collected but was unsure. In the absence of SOGI, providers used terms like “partner” or “significant other” to indicate an LGBT relationship.</p> <p>Providers felt that it was the patient’s job to disclose their SOGI to the provider. Many providers felt that LGBT people do not need specialized care and used death as the “great equalizer” to justify this. They view equal treatment as a positive as opposed to lacking specialized care for a marginalized group.</p> <p>Only one site had received any competency training on LGBT services.</p> <p>Providers emphasized a need for further education surrounding the needs of transgender patients.</p> <p>The best practice for care and communication with LGBT adults is to establish trust and ensure the patient that they are in a safe space.</p>
Colclough, Y. Y. (2017). Native American Death Taboo: Implications for Health Care Providers. <i>Am J Hosp Palliat Care</i> , 34(6), 584-591. <a href="https://doi.org/10.1177/1049909116638839">https://doi.org/10.1177/1049909116638839</a>	United States	N/A	N/A – paper that discusses Native American beliefs on death, no formal methods section	<p>Native Americans have a different perspective on death. They believe that death is the Creator’s job to determine, and that human control is not required. They believe that silence reduced evil spirits and therefore harm. They also believe that death may trigger more deaths.</p> <p>Healthcare providers must be sensitive to these beliefs, as they can determine how much care a Native American patient wants to receive. Providers should establish comfort level with</p>

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				<p>advanced medication and provide many reassurances to the patient that this care is not against the Creator.</p> <p>Involving family members in the decision is also important, although it may vary family to family.</p>
Colclough, Y. Y., & Brown, G. M. (2019). Moving Toward Openness: Blackfeet Indians' Perception Changes Regarding Talking About End of Life. <i>Am J Hosp Palliat Care</i> , 36(4), 282-289. <a href="https://doi.org/10.1177/1049909118818255">https://doi.org/10.1177/1049909118818255</a>	United States	10 Elders, 102 tribal members. All the Blackfeet Nation.	Interviews conducted with Elders and members of the Blackfeet Nation. Questions were asked based on a modified Duke End of Life Care Survey.	<p>Elders among the Blackfeet people were divided in their beliefs about end-of-life. Some felt that discussing end-of-life care was not against tradition, while others felt that sickness breaks the living spirit and should not be mentioned.</p> <p>Researchers concluded that fear of death primarily drove the Blackfeet to avoid discussing end-of-life. They found that, as long as a culturally comfortable environment is available, the Blackfeet people will not feel that end-of-life care is violating their beliefs.</p>
Dhingra, L., et al. (2022). "Low Hospice Utilization in New York State: Comparisons Using National Data." <i>J Pain Symptom Manage</i> 63(4): 522-529.	All hospices in New York.	All patients in the U.S. insured by traditional Medicare who died in 2018.	Analysis of national data to evaluate the differences between New York State and the rest of the country by exploring associations between patient and state characteristics and a group of hospice utilization outcome variables.	This study identified eight factors that independently accounted for differences in hospice utilization— in enrollment or length of stay, or both outcomes—when comparing New York State to all other states. In addition to the relatively higher socioeconomic status of the New York State population, these factors included the higher number of physicians seen in the last two years of life; the greater number of SNF beds and lower number of for-profit SNF facilities; and the smaller number of hospice agencies (both for-profit and not-for-profit).
Dillon, P. J. and A. Basu (2016). "African Americans and Hospice Care: A Culture-Centered Exploration of Enrollment Disparities." <i>Health Commun</i> 31(11): 1385-1394.	Quest Hospice, a comprehensive hospice organization that serves four counties surrounding a large metropolitan	26 African American hospice patients (n = 10) and lay caregivers (n = 16) receiving hospice or bereavement services from Quest Hospice. Patients'	39 total semi-structured in-depth interviews (with a mean length of 37 minutes) that were conducted in participants' homes (n = 37) and in a private office at the hospice organization's headquarters (n = 2).	Interviewees identified several barriers to hospice enrollment and reported how they were able to overcome these barriers by reframing/prioritizing cultural values and practices, creating alternative

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	area in the southeastern United States. The hospice is part of a larger non-profit, post-acute care system that also provides palliative care and senior services. In 2013, 9.8% of the hospice's patients self-identified as African American.	mean age was 69.8 years, with a range of 29–81 years. The 16 caregivers who took part in the study ranged in age from 34 to 76 years (M = 46).	The research questions were: 1) How do African American patients and lay caregivers overcome potential barriers to hospice enrollment? And 2) How do African American patients and lay caregivers make sense of hospice enrollment disparities?	goals for hospice care, and relying on information obtained outside the formal health system.  Barriers include: 1) inconsistent access and/or active avoidance of medical care leads, which means that some African Americans learn of a terminal diagnosis (relatively) late in the disease trajectory; 2) a history of discrimination and/or mistreatment within the health care system, causing mistrust in hospice; and 3) the perception of hospice policies and procedures to be incongruent with cultural values and practices associated with death.  These interviews demonstrate how disparities are intertwined with structural patterns of financial insecurity, differentiated health care access, and racial prejudice that perpetuate a marginal position for African Americans with the medical system. This perspective shifts the conception of hospice enrollment disparities from a matter of knowledge-based or motivational deficiencies to an issue of equity.
Dressler, G., Cicoello, K., & Anandarajah, G. (2021). "Are They Saying It How I'm Saying It?" A Qualitative Study of Language Barriers and Disparities in Hospice Enrollment. <i>J Pain Symptom Manage</i> , 61(3), 504-512. doi:10.1016/j.jpainsymman.2020.08.019	End-of-life care (EOL) clinicians in the state of Rhode Island, where around 22% of the population speaks a language other than English at home, and 8.6% speak English less than very well. Spanish is the most commonly spoken language after English. About 6.9% of the population	Twenty-two participants included six nurses/certified nursing assistants, five physicians, three administrators, three social workers, three patient caregivers, and two chaplains, self-identifying from a variety of racial/ethnic backgrounds. All participants lived or worked in RI.	A secondary qualitative analysis of semi structured individual interviews that were audio recorded and transcribed verbatim. Data were coded using NVivo 11. Three researchers analyzed all data related to language barriers, first individually, then in group meetings, using a grounded theory approach, until they reached consensus regarding themes. Institutional review board approval was obtained.	Disparities in quality EOL care and hospice enrollment persist for patients with low English proficiency, despite attempts to improve access to trained medical interpreters via implementation of Culturally and Linguistically Appropriate Services standards, increased training for medical interpreters, and access to phone and video interpretation services.  Three themes emerged regarding language barriers: 1) structural barriers inhibit access to interpreters; 2) variability in accuracy of translation of EOL concepts exacerbates language barriers; and 3) interpreters' style and manner influence

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	speaks other Indo-European languages, and 2.3% speaks Asian or Pacific Islander languages.			communication efficacy during complex conversations about prognosis, goals of care, and hospice. The theoretical model derived from the data suggests that Theme 1 is foundational and common to other medical settings. However, Theme 2 and particularly Theme 3 appear especially critical for hospice enrollment and care.
Du, X. L., Parikh, R. C., & Lairson, D. R. (2015). Racial and geographic disparities in the patterns of care and costs at the end of life for patients with lung cancer in 2007-2010 after the 2006 introduction of bevacizumab. <i>Lung Cancer</i> , 90(3), 442-450. doi:10.1016/j.lungcan.2015.09.017	End-of-life care settings in Detroit, Seattle, Atlanta, rural Georgia, California, Connecticut, Iowa, New Mexico, Utah, Hawaii, Kentucky, Louisiana, and New Jersey.	37,393 patients (ages 65+) who were diagnosed with non-small cell lung cancer of all stages in 1991–2009 and died between July 2007 and December 2010.	A retrospective cohort study of The National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) cancer registries and Medicare linked databases.	<p>Overall, Black people or other ethnic populations were significantly less likely to receive hospice care and more likely to be hospitalized in the last 6 months of life. Patients from urban areas were significantly more likely to receive hospice care than those from rural or less urban areas.</p> <p>There are no standard or clear-cut guidelines about what should not be used in the last few months of life for cases with terminal cancer, which is likely leading to substantial variations in choices of types of cancer care by the providers or patients/family members.</p> <p>Additionally, religious and cultural beliefs played a major role in the end-of-life care, which may vary significantly in the same area or same ethnic population. For example, African Americans preferred more aggressive treatment at the end-of-life care than other racial/ethnic populations and desired to provide all possible care to prolong life, whereas the treatment decisions for whites were more likely to withhold treatment before death.</p>
Elting, L. S., Liao, K. P., Giordano, S. H., & Guadagnolo, B. A. (2020). Hospice enrollment among cancer patients in Texas covered by Medicare managed care and	Hospice – Texas.	40,184 elderly Texas Medicare beneficiaries who died from primary breast, colorectal, lung, pancreas, or prostate cancer between	We studied the use of hospice care in the final 30 days of life using statewide Medicare claims linked to the Texas Cancer Registry. Rates of hospice use were computed by	Rates of hospice use increased significantly over time, from 68.9% in 2007 to 76.1% in 2013. By 2013, differences in hospice use rates between MC and FFS plans had been reduced from 10% to < 5%.



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traditional fee-for-service plans: a statewide population-based study. <i>Support Care Cancer</i> , 28(7), 3351-3359. doi:10.1007/s00520-019-05142-z		January 1, 2007, and December 31, 2013.	race/ethnicity and insurance plan (managed care (MC) or fee-for-service (FFS)). We used logistic regression to account for the impact of confounding factors.	However, after accounting for insurance plan and confounding factors, racial/ethnic minority beneficiaries' hospice use was significantly lower than non-Hispanic white beneficiaries' (p < 0.0001). This disparity was observed among both FFS and MC beneficiaries.  In conclusion, hospice use among elderly patients with cancer has increased over time, particularly among dually eligible and fee-for-service beneficiaries. Despite these positive trends, racial/ethnic-based disparities persist.
Fair, T. M. (2021). Lessons on Older LGBTQ Individuals' Sexuality and Spirituality for Hospice and Palliative Care. <i>Am J Hosp Palliat Care</i> , 38(6), 590-595. doi:10.1177/1049909120978742	Colorado Front Range	16 total LGBTQ participants born prior to 1964. The majority (n = 14) were cisgender; of those, women (n = 8) and men (n = 6). There was also a transgender woman (n = 1) and one gender queer transgender participant (n = 1). To qualify as a participant, the individual had to identify as LGBTQ and be born before 1964 (the cut-off year for the Baby Boomer generation).	Semi-structured interviews were conducted following a pre-established interview guide. First, the participant was asked demographic questions. Next, they were asked to share their spiritual or religious background as a child or earliest spiritual memory. When adequate trust and familiarity were established, the researcher asked the central sexuality/ spirituality questions of focus.	Hospice and palliative care are in the beginning stages of providing inclusive care to older lesbian, gay, bisexual, transgender, queer (LGBTQ) patients. This inclusivity is exceedingly more pressing given the growing population of out and aging LGBTQ individuals. Hospice and palliative care literature recognizes that spirituality and religion can be fraught topics for LGBTQ patients. A few resources are available to help providers give more inclusive care. Few in hospice and palliative care, however, explicitly outline the direct connection for LGBTQ elders between their sexuality and their spiritual lives.  All 16 participants responded that there was a connection for them. The participants expanded on this connection using five themes in their answers: the sexual act itself is spiritual; their authentic LGBTQ journey as spiritual; love/attraction is spiritual; spirituality and sexuality are inseparable; and finally, noting the ineffability of the sexuality-spirituality connection.

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Citation	Setting	Population	Design	Main Findings
Fink, R. M., Kline, D. M., Siler, S., & Fischer, S. M. (2020). Apoyo con Cariño: A Qualitative Analysis of a Palliative Care-Focused Lay Patient Navigation Intervention for Hispanics With Advanced Cancer. <i>J Hosp Palliat Nurs</i> , 22(4), 335-346. doi:10.1097/njh.0000000000000666	3 urban and 5 rural cancer center clinics across Colorado.	223 self-identified Hispanic patients, 18 years or older, with stage III/IV advanced cancer. Participants received either a culturally and linguistically tailored educational material packet describing ACP, pain management, and hospice care (control group [n = 111]) or the same educational materials and at least 5 home visits over 3 months from a Hispanic lay patient navigator (intervention group [n = 112]).	As part of a qualitative analysis, research team members analyzed field notes comprising 499 visits to 112 intervention patients and family caregivers (if available).	Part of the navigators' role was raising awareness about hospice by asking patients about their understanding of hospice, if they know anyone who has been under hospice care, addressed misconceptions about hospice care, and confirmed hospice care choice. Findings demonstrate that navigators facilitated ACP discussions, advocated for and motivated patients to talk with their provider about pain needs with the intent to receive optimal pain management, and helped patients/family caregivers learn more about hospice.  Findings helped further understanding of how lay patient navigators may be effective in reducing barriers to palliative care and improving palliative care health literacy for underserved populations.
Fischer, S. M., Kline, D. M., Min, S. J., Okuyama-Sasaki, S., & Fink, R. M. (2018). Effect of Apoyo con Cariño (Support With Caring) Trial of a Patient Navigator Intervention to Improve Palliative Care Outcomes for Latino Adults With Advanced Cancer: A Randomized Clinical Trial. <i>JAMA Oncol</i> , 4(12), 1736-1741. doi:10.1001/jamaoncol.2018.4014	Clinics across the state of Colorado, including an academic National Cancer Institute–designated cancer center, community cancer clinics (urban and rural), and a safety-net cancer center.	Participants were adults who self-identified as Latino and were being treated for advanced cancer. In total, 223 Latino adults enrolled (mean [SD] age, 58.1 [13.6] years; 55.6% female) and were randomized to control (n = 111) or intervention (n = 112) groups.	A randomized clinical trial of a culturally tailored patient navigator intervention was conducted from July 2012 to March 2016. Primary outcome measures included hospice use. Secondary outcome measures included the McGill Quality of Life Questionnaire (MQQL), hospice length of stay, and aggressiveness of care at the end of life. This study used an intent-to-treat design.	The intervention had mixed results. The intervention increased advance care planning and improved physical symptoms; however, it had no effect on pain management and hospice use or overall quality of life. Further research is needed to determine the role and scope of lay navigators in palliative care.  In this overall sample, 81.7% (98 of 120) of the patients enrolled in hospice, which is well above previously reported national averages of a 40% Hispanic enrollment. The National Hospice and Palliative Care Organization reports that, over the past decade, 6% to 8% of hospice patients have been Hispanic. However, the US Hispanic population is young, and accounting for crude death rates among Hispanics, the hospice enrollment rate for Hispanic deaths is 38%.

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Citation	Setting	Population	Design	Main Findings
Foley, R. N., Sexton, D. J., Drawz, P., Ishani, A., & Reule, S. (2018). Race, Ethnicity, and End-of-Life Care in Dialysis Patients in the United States. <i>J Am Soc Nephrol</i> , 29(9), 2387-2399. doi:10.1681/asn.2017121297	End-of-life care, United States.	1,098,384 patients on dialysis dying between 2000 and 2014.	We performed a retrospective national study using United States Renal Data System files to determine whether end-of-life care among patients on dialysis is subject to racial or ethnic disparity. The primary outcome was a composite of discontinuation of dialysis and death in a nonhospital or hospice setting.	<p>Patients of a minority race or ethnicity were likely to discontinue dialysis, less likely to receive hospice care, and more likely to die in hospital than their non-Hispanic white counterparts.</p> <p>Across the breadth of end-of-life outcomes studied here, patterns were broadly similar for patients of non-Hispanic Black and Asian race-ethnicity, and broadly similar for patients of non-Hispanic Native American race ethnicity and Hispanic ethnicity.</p> <p>These disparities could not be explained by differences in age, demography, local income dispersion, urban-rural configuration, dialysis facility type, mode of insurance coverage, and recent illness profiles, and were evident in a wide range of subgroups.</p> <p>These data suggest the existence of substantial, graded, and unexplained racial and ethnic disparities in end-of-life care practices in United States patients on dialysis.</p>
Fornehed, M. L. C., Mixer, S. J., & Lindley, L. C. (2020). Families' Decision Making at End of Life in Rural Appalachia. <i>J Hosp Palliat Nurs</i> , 22(3), 188-195. doi:10.1097/njh.0000000000000642	End-of-life care – east Tennessee region of rural Appalachia.	10 key informants consented to participate in this study. Four were family members with a loved one (spouse or parent) who had already died when their interview took place. Six had a parent hospitalized in an acute care setting with a life-limiting illness and were actively making EOLC decisions.	Unstructured interviews were conducted in homes, hospital rooms, and private conference rooms. Observations before and during the interviews about the environmental context, artifacts, nonverbal informant expressions, interview time and location, and researcher thoughts, feelings, and hunches were recorded in a field journal. The interviews were digitally audiotaped, transcribed verbatim, and deidentified through coding.	<p>Four themes provide insights that could help improve this underserved population's access to palliative and hospice care:</p> <p><i>Rural Appalachians make EOL decisions with family.</i> Rural Appalachian families' awareness of the illness trajectory moves at different rates and influences EOL decision making. Accepting death as a part of life influences Rural Appalachian family decision making (FDM) at EOL.</p> <p><i>Communication Encompassing EOL FDM Is Essential and Complex.</i> Rural Appalachians describe that EOL FDM communication is a burden on someone (either in the family or</p>

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				<p>interdisciplinary team). Interdisciplinary team members plant seeds for families to consider when making decisions at EOL. The concept of “lay it on the line” characterizes effective communication among family and interdisciplinary team members.</p> <p><i>Education and Economics Influence Decision Making at EOL.</i> Rural Appalachian EOL FDM is influenced by a lack of knowledge about the illness trajectory and EOL care. Rural Appalachian FDM at EOL is influenced by economics and the need to choose “the lesser of two evils.”</p> <p><i>Comfort—Living While Dying.</i> Folk care for rural Appalachian families making decisions at EOL meant experiencing “a sense of normalcy.” Some rural Appalachian families felt hospice care was helpful and some did not.</p>
<p>Forst, D., Adams, E., Nipp, R., Martin, A., El-Jawahri, A., Aizer, A., &amp; Jordan, J. T. (2018). Hospice utilization in patients with malignant gliomas. <i>Neuro Oncol</i>, 20(4), 538-545. doi:10.1093/neuonc/nox196</p>	<p>The SEER database includes information about incident cancer cases from 17 affiliated cancer registries, covering approximately 26% of the US population. These data include information for patients between January 1, 1973, and December 31, 2012.</p>	<p>We used the SEER-Medicare database to retrospectively identify patients 18 years of age or older who were diagnosed with malignant glioma (MG) and subsequently passed away between January 1, 2002, and December 31, 2012. We excluded the 13.7% of patients who did not have fee-for-service Medicare insurance, as well as those who were diagnosed with MG after</p>	<p>We extracted sociodemographic and clinical data and used univariate logistic regression analyses to compare characteristics of hospice recipients versus nonrecipients. We performed multivariable logistic regression analyses to examine predictors of hospice enrollment &gt;3 or &gt;7 days prior to death.</p>	<p>We identified important disparities in hospice utilization among patients with malignant glioma, with differences by race, sex, age, level of education, and rural versus urban residence.</p> <p>12,437 eligible patients (46% female), of whom 7849 (63%) were enrolled in hospice before death.</p> <p>On multivariable regression analysis, older age, female sex, higher level of education, white race, and lower median household income predicted hospice enrollment.</p> <p>Of those enrolled in hospice, 6996 (89%) were enrolled for &gt;3 days, and 6047 (77%) were enrolled for &gt;7 days.</p>

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		entering hospice or during autopsy.		<p>Older age, female sex, and urban residence were predictors of longer LOS (3- or 7-day minimum) on multivariable analysis. Median LOS on hospice for all enrolled patients was 21 days.</p> <p>Our study highlights important disparities in hospice utilization among patients with MG. We found differences by race, sex, age, level of education, and rural versus urban residence.</p> <p>We also describe important predictors of a suboptimal short stay in hospice (<math>\leq 3</math> days or <math>\leq 7</math> days), including younger age, male sex, and rural place of residence.</p>
Gerlach, L. B., Kales, H. C., Kim, H. M., Zhang, L., Strominger, J., Covinsky, K., . . . Maust, D. T. (2021). Prevalence of psychotropic and opioid prescribing among hospice beneficiaries in the United States, 2014-2016. <i>J Am Geriatr Soc</i> , 69(6), 1479-1489. doi:10.1111/jgs.17085	Hospice – United States	554,022 older Medicare beneficiaries with an index hospice enrollment period between July 1, 2014, and December 31, 2016. Most hospice enrollees were female (58.3%), non-Hispanic white (87.5%), and the average age was 83.2.	Cross-sectional analysis of a 20% sample of traditional and managed Medicare with Part D enrolled in hospice, 2014–2016.	<p>The prevalence of any psychotropic or opioid medication prescription fill was highest among beneficiaries who were female (76.7%), younger (76.5%), lived in rural areas (76.6%), non-Hispanic white (76.6%), and those with cancer (78.9%). Male beneficiaries were slightly less likely to receive psychotropic and opioid medication prescriptions.</p> <p>Non-Hispanic whites were more likely to receive prescriptions for most medication classes. Compared to non-Hispanic white beneficiaries, non-Hispanic Black beneficiaries were less likely to receive nearly every class of medication, with significantly lower odds of receiving opioids and benzodiazepines.</p> <p>Psychotropic and opioid medications are frequently prescribed in hospice. Observed variations in prescribing across race and ethnicity may reflect disparities in prescribing as well as patient preferences for care. Further work is important to understand factors driving prescribing</p>

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				given limited studies surrounding medication prescribing in hospice.
Haines, K. L., Jung, H. S., Zens, T., Turner, S., Warner-Hillard, C., & Agarwal, S. (2018). Barriers to Hospice Care in Trauma Patients: The Disparities in End-of-Life Care. <i>Am J Hosp Palliat Care</i> , 35(8), 1081-1084. doi:10.1177/1049909117753377	Hospice – United States	Critically ill trauma patients. Sample is trauma patients older than 15 from 2012 to 2015 logged into the National Trauma Databank. N= 2,966,444	Two methodological approaches: (1) For disposition to hospice, chi-square and multivariate logistic regression were used (2) Negative binomial regression was used to explore the length of stay in hospice	<p>“Race and ethnicity are independent predictors of a trauma patient’s transition to hospice care and significantly affect [length of stay]. Our data demonstrate prominent racial and socioeconomic disparities exist, with uninsured and minority patients being less likely to receive hospice services and having a delay in transition to hospice care when compared to their insured Caucasian counterparts.”</p> <p>“Asian, African Americans, and Hispanic patients were less likely to patients (P &lt; .001). than Caucasians (P &lt; .0001).”</p> <p>“Additionally, socioeconomic status affected total hospital LOS. An analysis of 23 612 patients revealed that Medicare patients were transferred to hospice 1.2 days sooner than privately insured patients (P &lt; .001), and uninsured patients remained in the hospital 1.6 days longer than privately insured patients (P &lt; .001).”</p> <p>“When evaluating racial disparities, African American patients who were discharged to hospice stayed in the hospital 3.7 days longer and Hispanic patients stayed 2.4 days longer than Caucasian patients (P &lt; .0001). A secondary analysis for the more severely injured trauma patients (ISS &gt; 15) showed that African Americans stayed inpatient 4.9 days longer and Hispanics 2.3 days longer than their equivalent Caucasians counterparts (P &lt; .0001).”</p> <p>“This analysis shows that despite efforts to promote and improve access for end-of-life referrals, enormous racial disparities are prevalent</p>

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Citation	Setting	Population	Design	Main Findings
				<p>in the trauma system separate from significant socioeconomic inequalities.”</p> <p>“Additionally, this analysis demonstrates that for those uninsured and minority population who do receive hospice care, there is a delay in transfer to hospice when compared to their insured, Caucasian counterparts.”</p> <p>“...a project exploring end-of-life barriers in lower income, African Americans, and Hispanics found that when focus groups were conducted, they were highly receptive to care that would provide relief for patients. This study found that improving awareness of hospice services would increase utilization in minority populations. These analyses combined with the knowledge that minority trauma patients are transferred to hospice less often than Caucasians portend to the success of workgroups developed for minority trauma populations.”</p>
Haines, K. L., Kawano, B. A., & Agarwal, S. K. (2021). Disparities in Asians' Hospice Utilization and Location of Death. <i>Am Surg</i> , 31348211034756. doi:10.1177/00031348211034756	See next row	Disaggregates the Asian category to look at place of death based on ethnicity.	This is a letter to the editor that disaggregates the category of “Asian” based on the below study	<p>“There are differences in place of death among Asian subgroups. Japanese and Korean patients were less likely than Chinese patients to die in a hospital and more likely to die at home (OR = .53, OR = .78/OR = 1.39, OR = 1.18, P &lt; .001).</p> <p>Japanese patients were likewise more likely than Chinese patients to die in a nursing facility/long-term care (OR = 1.24, P &lt; .001) but less likely to die in hospice (OR = .87, P &lt; .001).</p> <p>Koreans were slightly more likely than Chinese patients to die in hospice (OR = 1.09, P &lt; .05).</p> <p>In comparison, Filipinos and Indians were more likely than Chinese patients to die in hospitals or at home (OR = 1.05, P &lt; .001, OR = 1.04, P &lt; .05; OR = 1.21, P &lt; .001; OR = 1.10, P &lt; .001), and</p>

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
				<p>less likely to die to in a nursing facility/long-term care (OR = .62, P &lt; .001; OR = .42, P &lt; .001) or hospice (OR = .78, P &lt; .001; OR=.82, P &lt; .001).</p> <p>Similarly, Vietnamese patients were more likely than Chinese patients to die at home (OR = 1.28, P &lt; .001) and less likely to die in a nursing facility/long-term care (OR = .63, P &lt; .001) or hospice (OR = .90, P &lt; .05).</p> <p>There are clear disparities in hospice utilization and location of death amongst varying [Asian] subgroups.”</p>
Haines, K. L., Nguyen, B. P., Antonescu, I., Freeman, J., Cox, C., Krishnamoorthy, V., . . . Agarwal, S. (2021). Insurance Status and Ethnicity Impact Health Disparities in Rates of Advance Directives in Trauma. <i>Am Surg</i> , 31348211011115. doi:10.1177/00031348211011115	United States, inpatient trauma	Adult trauma patients. Sample is American College of Surgeons Trauma Quality Improvement Program from 2013-2015. N= 44,705	Multivariable logistic regression was used on the data to measure the primary outcome, advance directive (AD) presence. Other outcomes include mortality, length of stay (LOS), mechanical ventilation, ICU admission/LOS, withdrawal of life-sustaining measures, and discharge disposition	<p>Authors are primarily leveraging large-N data and running naïve regressions on them to see what pop up. There are some leaps in logic to get at health equity outcomes in hospice as hospice is not a primary outcome in this study.</p> <p>“Nationally, over one-third of US adults have ADs; however, disparities in AD completion are commonly seen depending on race, ethnicity, and socioeconomic status. African American and Asian patients are less likely to complete ADs.”</p> <p>“Presence of ADs was associated with increased odds of discharge to hospice and a decreased odds of discharge to inpatient rehabilitation, a skilled care facility, or home.”</p>
Hamel, L., Wu, B., & Brodie M. 2017. Views and Experiences with End-of-Life Medical Care in Japan, Italy, the United States, and Brazil: A Cross-Country Survey. KFF. <a href="https://www.kff.org/other/report/views-and-experiences-with-end-of-life-medical-care-in-japan-italy-the-united-">https://www.kff.org/other/report/views-and-experiences-with-end-of-life-medical-care-in-japan-italy-the-united-</a>	end-of-life care in the U.S. and three other nations	Americans’ experiences and opinions about aging and end-of-life care and how this compares with the views and experiences of residents of Italy, Japan and Brazil	The poll was conducted by telephone from March through November 2016 among random digit dial telephone (landline and cell phone) samples of adults in the U.S. (1,006), Italy (1,000), Japan (1,000) and Brazil (1,233). The margin of sampling error for results from each country is plus	<p>When asked to think about their own death, most Americans (54%) say it is “extremely important” to make sure their family is not burdened financially by their care.</p> <p>Large shares also cite other factors as “extremely important,” including having loved ones around</p>



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states-and-brazil-a-cross-country-survey/			or minus 4 percentage points. For results based on subgroups, the margin of sampling error may be higher.	<p>them (48%), being at peace spiritually (46%) and being comfortable and without pain (42%).</p> <p>Fewer (23%) say living as long as possible is “extremely important,” though the share who do is higher among Blacks (45%) and Hispanics (28%) than among whites (18%).</p> <p>Black and Hispanic people are also more likely than whites to say the health care system in the U.S. places too little emphasis on preventing death and extending life as long as possible.</p>
Hart, A. S., Matthews, A. K., Arslanian-Engoren, C., Patil, C. L., Krassa, T. J., & Bonner, G. J. (2022). Experience of African American Surrogate Decision Makers of Patients With Dementia. <i>J Hosp Palliat Nurs</i> , 24(1), 84-94. doi:10.1097/njh.0000000000000822	Surrogate end-of-life decision makers for dementia patients in the United States	African American surrogate decision makers. Sample n=8	African American decisions makers were interviewed about their experiences with the decision-making process	<p>The most important takeaway here is that interview data indicates that African American surrogates often did not utilize hospice to its full extent due to a lack of information and preparedness with this option and they often expressed regret in not prioritizing comfort-focused care like hospice over life-sustaining treatments after the fact.</p> <p>“Surrogates lacked a general understanding of EOL options resulting in underutilization of hospice and palliative care and subsequent regret, and few interventions exist to improve the uptake of EOL care services.”</p> <p>“Of [African American] surrogates who implemented DNR orders, few elected for comfort-focused care. In addition to the limited use of hospice, patients often did not receive the full benefit of hospice services: both patients who used hospice spent less than a week on the service before they died.”</p> <p>“In contrast [to electing for comfort-based solutions like hospice], some [African American] surrogates who opted for life-sustaining</p>

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				treatments experienced regret, perceiving the decision as out of alignment with personal or patient values, preferences, and priorities. These findings may result from unpreparedness in the acceptance phase, reinforcing the need for patient-surrogate-provider discussion about EOL options early in the dementia trajectory."
Helsel, D., Thao, K. S., & Whitney, R. (2020). Their Last Breath: Death and Dying in a Hmong American Community. <i>J Hosp Palliat Nurs</i> , 22(1), 68-74. doi:10.1097/njh.0000000000000616	End-of-life care decision making in the United States	Hmong Americans. Sample is 15 family care and 5 shamans and Hmong funeral officiants.	Semi-structured interviews with sample to explore the beliefs that ultimately determine end-of-life care goals and strategies for Hmong patients.	Providing information to Hmong patients and families about hospice helps to inform strategies that incorporate hospice as a viable care option.  "All of the caregiver-respondents explained that Hmong people would rather die in their homes, although most acknowledged an awareness of circumstances in which that is not possible. One respondent noted, "They would be homesick and uncomfortable anywhere else. In their own home they can see their family. And if they die in their home, they leave their family a good life; they leave good luck for you. The person who sees your last breath gets your leftover luck. You want that to be your family.""
Her-Xiong, Y., & Schroepfer, T. (2018). Walking in Two Worlds: Hmong End of Life Beliefs & Rituals. <i>J Soc Work End Life Palliat Care</i> , 14(4), 291-314. doi:10.1080/15524256.2018.1522288	End of life beliefs and care in the United States	Hmong American immigrants. Sample is 12 Animist and 8 Christian Hmong elders born in Southeast Asia	In-depth face-to-face interviews	Both Animists and Christians strongly felt that family should provide care at end of life vs. hospice/palliative care. Both samples felt that out-of-home care facilities could not meet their spiritual and cultural needs which they see as centrally integral to end-of-life care and thus generally prefer at-home care if at all possible.
Hinrichs, K. L. and K. M. Christie (2019). "Focus on the family: A case example of end-of-life care for an older LGBT veteran." <i>Clin Gerontol</i> 42(2): 204-211.	Veterans Affairs hospice unit	Older LGBT veterans and their families. Case study of an older, Caucasian, lesbian veteran and her Caucasian wife	In-depth exploration into how the research team could care for the veteran and meet the wife's emotional and psychological needs in the process.	The case study provides specific interventions that are helpful in terms of thinking through inequities LGBT patients face in hospice and how they can be overcome.  "In order to effectively work with Diane, the hospice team had to take a two-pronged approach

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				<p>to address both the emotional and financial needs of the wife as the veteran medically declined. To support her emotionally, the entire hospice team was encouraged to stop by and check in on Diane when she was visiting. This helped her feel less alone and decreased her feelings of dread while sitting with her dying wife. The mental health provider recommended referral to an LGBT Bereavement group and other LGBT-specific support services, but Diane was not open to this idea since she had never been connected with the larger LGBT community before.”</p> <p>“Throughout their time on the unit, the hospice team was able to identify several areas of need and assist Diane with some of her psychosocial and financial concerns. After building trust with the team Diane was able to accept information about social services and government programs to help with paying taxes, applying for disability, etc. She allowed the team to help her apply for supplemental nutrition assistance and fuel assistance to heat her home. The hospice social worker was able to partner with community agencies to arrange a funeral for Susan free of charge so Diane would not have to worry about this.”</p> <p>“After Susan’s death, the hospice team reached out to Diane a few times to provide bereavement support and case management.”</p> <p>“Health care institutions that provide end-of-life care must be more overtly inclusive and welcoming to build the trust of LGBT older adults. This can be accomplished by altering the wording on intake forms, updating policies, and assessing</p>

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				<p>outreach materials for inclusive language and images.”</p> <p>“Inclusion of partners and families of choice is essential to the provision of patient-centered end-of-life care for marginalized populations. This is best accomplished by encouraging LGBT patients to engage in advance care planning (e.g., completing advance directives and DPOAs), and by simply asking patients who they would like to be involved in their decision-making at end-of-life and documenting the conversations.”</p> <p>“Mental health providers should familiarize themselves with Affirmative Therapy approaches, which are used to validate and advocate for the needs of sexual and gender minority patients.”</p> <p>“All health care professions should consider formally adopting and disseminating competencies for practice with this diverse population.”</p>
Holland, J. M., Keene, J. R., Kirkendall, A., & Luna, N. (2015). Family evaluation of hospice care: Examining direct and indirect associations with overall satisfaction and caregiver confidence. <i>Palliat Support Care</i> , 13(4), 901-908. doi:10.1017/s1478951514000595	Hospice in the United States	Primary caregiver or health representative for hospice patients. Sample is taken between 2008 to 2013 “at a large hospice in an urban area of the Southwest United States” n=3226.	Participants were asked to complete the Family Experience of Hospice Care (FEHC) survey. Survey responses were then used to measure the impact of a broad suite of variables on two major outcomes: (1) overall satisfaction and (2) caregiver confidence using structural equation modeling	<p>“Our results suggest that the most important factors that influence caregivers’ perceptions of hospice care are patient race, patient symptoms, and their appraisal of the timing of hospice referral. Specifically, caregivers of racial minority patients, patients with a more complex symptom profile, and patients perceived to be referred too late or too early tended to express less contentment with the information/education and patient care received from the hospice staff.”</p> <p>“Racial minority status and late/early referral were also associated with less positive perceptions of caregiver/family emotional and spiritual support.”</p>

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				<p>“As can be seen from Figure 1, participants completing the FEHC with regard to a racial minority patient were more likely to report lower levels of contentment with the information/education received, provision of care to the patient, and caregiver/family support. Patient race did not show statistically significant direct effects on overall satisfaction or caregiver confidence. However, patient race was indirectly associated with lower levels of caregiver confidence through education/information (see Table 3). Stated differently, participants reporting on a racial minority patient were more likely to express some discontent with the education/information they received, which in turn put them at greater risk for feeling less confident as a caregiver.”</p> <p>“This pattern of results suggests that efforts directed toward informing/educating patients’ family members may be most potent in terms of promoting a sense of self-efficacy and confidence.”</p>
Hostetter, M., Klein, S., & McCarthy, D. (2018). Supporting Patients Through Serious Illness and the End of Life: Sutter Health’s AIM Model. <a href="https://www.commonwealthfund.org/publications/case-study/2018/jan/supporting-patients-through-serious-illness-and-end-life-sutter">https://www.commonwealthfund.org/publications/case-study/2018/jan/supporting-patients-through-serious-illness-and-end-life-sutter</a> . Accessed August 29, 2022	Palliative care in the US	AIM program	Case study of an Advanced Illness Management program (AIM)	An examination of how AIM can improve end-of-life care via planning. It also discusses how AIM increases transitions to hospice and the length of hospice stays which reduce costs.
Hughes, M. C. and E. Vernon (2019). “Closing the Gap in Hospice Utilization for the Minority Medicare	Hospice in all 50 states and	Medicare hospices in all 50 states and Washington,	Quantitative analysis (multivariate logistic regression) of CMS’s Chronic Conditions Data Warehouse (CCW), US Census data, and data from the	Multivariate logistic regression found a positive association between the prevalence of for-profit hospices in a state and hospice utilization by

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Citation	Setting	Population	Design	Main Findings
Population." Gerontol Geriatr Med 5: 2333721419855667.	Washington, D.C., United States	D.C. (N = 51) and Medicare beneficiaries	Pew Research Center, the Bureau of Economic Analysis, the Kaiser Family Foundation, and Hospice Analytics	<p>racial/ethnic minorities, <math>\chi^2 (6, N = 51) = 17.76, p = .007</math>.</p> <p>There was no significant association between hospice utilization by racial/ethnic minorities and religiosity, racial/ethnic diversity, income, or education.</p> <p>The economic analysis found if racial/ethnic minority Medicare hospice utilization were to equal that of the white Medicare users, it would result in an estimated savings of nearly \$270 million per year.</p> <p>To increase equity in hospice utilization, authors recommend hospices conduct community outreach to both racial/ethnic minorities and low-income communities, offer short bouts of increased emotional and physical support for the patient and/or caregiver(s) during times of crisis, create materials that comply with the NIH's Clear Communication initiative, and develop materials in multiple languages and employ bilingual staff.</p>
Hughes, M. C. and E. Vernon (2020). "We Are Here to Assist All Individuals Who Need Hospice Services": Hospices' Perspectives on Improving Access and Inclusion for Racial/Ethnic Minorities." Gerontol Geriatr Med 6: 2333721420920414.	Hospice across the United States	Administrators at 41 unique hospices (n = 41)	Qualitative surveys were conducted. Survey data was analyzed through content analysis including theme and quote identification.	<p>This study surveyed hospice employees to determine outreach strategies to improve minority hospice utilization.</p> <p>Commonly reported barriers to hospice care for racial/ethnic minorities included culture/beliefs (mentioned by 46% of respondents) that hospice is "giving up" or that families are responsible for care, mistrust of the medical system (20%), and language barriers (25%).</p> <p>A major theme pertaining to successful minority hospice enrollment was an inclusive culture that provided language services (mentioned by 70% of</p>

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				<p>survey respondents), staff cultural training (33%), and a diverse staff (33%).</p> <p>Another major theme was the importance of community outreach activities (over 60%) that extended beyond the medical community and forming relationships with churches, racial/ethnic minority community leaders, and Native American reservations.</p> <p>Over 30% of hospices indicated inclusionary policies, though most did not mention formal committees/policies.</p>
Hughes, M. C. and E. Vernon (2021). "Hospice Response to COVID-19: Promoting Sustainable Inclusion Strategies for Racial and Ethnic Minorities." <i>J Gerontol Soc Work</i> 64(2): 101-105.	Hospice in the United States	Hospice patients in the US during the COVID-19 pandemic	Letter to the editor	The author indicates that the COVID-19 crisis disproportionately affects racial/ethnic minorities in the US but presents an opportunity to increase equity in hospice care. Inclusion strategies include supporting advanced care planning through information-sharing in multiple languages by hospices, social workers, community groups, and religious institutions; the expansion of telehealth services and content, including technical support and broadband access; and expansion of hospice services/staff such as hiring from diverse backgrounds.
Hughes, M. C., Vernon, E., Kowalczyk, M., & Basco-Rodillas, M. (2021). US hospices' approach to racial/ethnic minority inclusion: a qualitative study. <i>BMJ Support Palliat Care</i> . doi:10.1136/bmjspcare-2020-002680 <sup>10</sup>	Hospice in the United States	Hospice leaders in the US (n = 22)	Qualitative in-depth, semi structured interviews	Interviews with hospice leaders found racial/ethnic minority inclusion strategies for hospices include language translation services (22 interviewees mentioned), cultural competence training (21), outreach beyond the medical community, and diversity, equity, and inclusion committees (7).

<sup>10</sup> Abt Staff identified this article in both the SDOH and Health Equity literature reviews.

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				The authors found that tailoring strategies to the local population and helping the community meet needs that extend beyond end-of-life care may be especially effective approaches in establishing trust. Another key finding of the study was that hospices were not that focused on the costs of inclusionary strategies and usually believed the benefits resulting from these strategies outweighed the costs.
Johnson, J., Hayden, T., True, J., Simkin, D., Colbert, L., Thompson, B., . . . Martin, L. (2016). The Impact of Faith Beliefs on Perceptions of End-of-Life Care and Decision Making among African American Church Members. <i>J Palliat Med</i> , 19(2), 143-148. doi:10.1089/jpm.2015.0238	Hospice/palliative care in the United States	51 churchgoers at 2 African American churches, including 27 deacons or deaconesses, 17 members of health or bereavement ministries, and 7 other congregation members	Qualitative focus groups (7 focus groups) to understand perceptions, beliefs, and attitudes about: (1) the relation between faith beliefs and EOL care; (2) emotional and family influences on EOL decision making; (3) palliative care and hospice resources; and (4) opportunities to improve communication among lay persons and health professionals and within families	<p>The study found that faith beliefs of African Americans can support discussions about palliative care and hospice.</p> <p>Participants perceived that many of their congregants harbor beliefs, perceptions, and feelings about death and dying that were often not communicated to family members or to health providers.</p> <p>Participants also voiced a consensus that patients, caregivers, and family members of their churches need more knowledge about EOL care – many were unsure what hospice meant and unfamiliar with the term palliative care.</p> <p>Supportive views about hospice were often expressed by persons with prior experience with hospice, but participants expressed uncertainty as to how to approach health care providers and what questions to ask.</p>
Johnson, K. S., Payne, R., & Kuchibhatla, M. N. (2016). What are Hospice Providers in the Carolinas Doing to Reach African Americans in Their Service Area? <i>J Palliat Med</i> , 19(2), 183-189. doi:10.1089/jpm.2015.0438	Hospice in North and South Carolina, United States	Staff (including directors, social workers, chief medical officers, clinical managers, and administrators) at hospices in North and South Carolina	Qualitative cross-sectional surveys used scales to measure the frequency of community outreach, marketing efforts, efforts to recruit African American staff, cultural sensitivity training, and goals to increase service for African Americans, and	A cross sectional survey completed by 79 hospices in the Carolinas found that over 80% were at least somewhat concerned about the low proportion of African Americans they served, and 78.5% had set goals to increase service to African Americans.



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		operating for at least 3 years (n = 79)	nonparametric Wilcoxon tests compared mean scored on these scales	<p>Most were engaged in community education/outreach, with 92.4% reporting outreach to churches, 76.0% to social services organizations, 40.5% to businesses, 35.4% to civic groups, and over half to health care providers; 48.0% reported directed marketing via newspaper and 40.5% via radio.</p> <p>The vast majority reported efforts to recruit African American staff, most often registered nurses (63.75%). Nearly 90% offered cultural sensitivity training to staff.</p> <p>The frequency of strategies to increase service to African Americans did not vary by hospice characteristics, such as profit status, size, or vertical integration, but was greater among hospices that had set goals to increase service to African Americans.</p>
Johnson, K. S., Payne, R., Kuchibhatla, M. N., & Tulsy, J. A. (2016). Are Hospice Admission Practices Associated With Hospice Enrollment for Older African Americans and Whites? <i>J Pain Symptom Manage</i> , 51(4), 697-705. doi:10.1016/j.jpainsymman.2015.11.010	Hospice in North and South Carolina, United States	61 hospices in North and South Carolina (n = 61)	Cross-sectional study that developed a hospice admission practices scale to rate the restrictiveness of admissions and conducted multivariate analyses to assess the association between admission practices and proportion of decedents in the hospice service area by racial group	<p>This study explored the relationship of hospice admission practices (e.g., restriction of patients who desire high-cost palliative therapies or without a primary caregiver) and the use of hospice by older African Americans.</p> <p>In the bivariate analyses, less restrictive admission practices were associated with a greater proportion of both African American (r=0.44, P&lt;0.0001) and white Medicare beneficiaries (r=0.47, P&lt;0.0001) served by a hospice in the service areas.</p> <p>Other characteristics associated with serving a larger proportion of decedents in both racial groups include, nonprofit status, larger budgets, larger proportion of generalists in the service areas, less market competition, and fewer</p>

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				physicians per population of those age 65 years or older.
Johnson, T., Walton, S., Jr., Levine, S., Fister, E., Baron, A., & O'Mahony, S. (2020). Racial and ethnic disparity in palliative care and hospice use. <i>Am J Manag Care</i> , 26(2), e36-e40. doi:10.37765/ajmc.2020.42399	Hospital in the Chicago metropolitan area, United States	5613 patients who were discharged to hospice or died during their hospital stay between 2012 and 2014 in 4 urban hospitals with an inpatient palliative care service	Retrospective, cross-sectional study	<p>After adjusting for patient characteristics and hospital site, race/ethnicity was not significantly associated with receipt of inpatient palliative care consultation.</p> <p>A larger proportion of African American patients received an inpatient palliative care consultation than white or Hispanic patients, but there was no significant association between race/ethnicity and receipt of inpatient palliative consultation when hospital site was included in the model, and there was no significant difference in location of death by race/ethnicity.</p> <p>Hispanic race/ethnicity was associated with a higher likelihood of discharge to hospice (odds ratio, 1.22; P = .036), and inpatient palliative care consultation was associated with 4 times higher likelihood of discharge to hospice (P &lt;.001). Hospital site was also associated with both receipt of inpatient palliative care consultation and discharge to hospice.</p>
Jones, R. C., Creutzfeldt, C. J., Cox, C. E., Haines, K. L., Hough, C. L., Vavilala, M. S., . . . Krishnamoorthy, V. (2021). Racial and Ethnic Differences in Health Care Utilization Following Severe Acute Brain Injury in the United States. <i>J Intensive Care Med</i> , 36(11), 1258-1263. doi:10.1177/0885066620945911	Hospital/Hospice across the United States	Adult patients with a primary diagnosis of severe acute brain injury (stroke, traumatic brain injury, or post-cardiac arrest) who received greater than 96 hours of mechanical ventilation between 2002 and 2012 (n = 86 246)	Retrospective cohort study of including multivariable analysis of data from the National Inpatient Sample	<p>Minority race (Black, Hispanic, Asian, and other) was associated with decreased hospice utilization compared to white race among patients with severe acute brain injury. In multivariable analysis, compared to white patients,</p> <p>Black patients had a 25% decreased risk of hospice discharge (RR: 0.75, 95% CI: 0.67-0.85, P &lt; .001), Hispanic patients had a 20% decreased risk (RR: 0.80, 95% CI: 0.69-0.94, P &lt; .01), and Asian patients had a 47% decreased risk (RR: 0.53, 95% CI: 0.39-0.73, P &lt; .001).</p>

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Kemery, S. A. (2021). "Family perceptions of quality of end of life in LGBTQ+ individuals: a comparative study." <i>Palliat Care Soc Pract</i> 15: 2632352421997153.	Hospice in the United States	122 family members of individuals who have died while under hospice care in the past 5 years. n=56 family members of LGBTQ and n =66 family members of non-LGBTQ individuals.	Quantitative comparative descriptive design using the Quality of Dying and Death Version 3.2a Family Member/Friend After-Death Self-Administered Questionnaire	Comparison of the experiences of the lesbian, gay, bisexual, transgender, and queer (LGBTQ) cohort (n = 56) and non-LGBTQ cohort (n = 66) yielded varying results, with the LGBTQ cohort experiencing lower quality end of life in some Quality of Dying and Death measures and no statistically significant difference from the non-LGBTQ cohort in others.
Khosla, N., Washington, K. T., & Regunath, H. (2016). Perspectives of Health Care Providers on US South Asians' Attitudes Toward Pain Management at End of Life. <i>Am J Hosp Palliat Care</i> , 33(9), 849-857. doi:10.1177/1049909115593063	End-of-life care in the United States	57 healthcare and end-of-life care providers in the US	Qualitative descriptive study of interviews (23) and focus groups (35 participants) with thematic analysis of interview and focus group data	<p>Thematic analysis of interviews and focus group discussions with 57 health care providers indicated that providers perceive South Asian patients and families to be generally reluctant to use medications to treat pain experienced at end of life.</p> <p>Patient-related factors contributing to the reluctance include: reluctance to report pain (participants explained that this stoicism may be rooted in a desire to avoid burdening others, fear of embarrassment and showing weakness); concerns about pain medications (including side effects such as drowsiness and confusion and the potential for addiction); spiritual beliefs (particularly those rooted in Hinduism, Buddhism, and Islam); and lack of awareness of medication benefits.</p> <p>Factors Related to the Culture of Health Care in South Asia include minimalistic attitude towards medication (including doctors not routinely asking about pain, less prescribing and lower doses of pain medications, and non-medication alternatives); and limited access to pain medications</p>

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Citation	Setting	Population	Design	Main Findings
Kim, H., Anhang Price, R., Bunker, J. N., Bradley, M., Schlang, D., Bandini, J. I., & Teno, J. M. (2021). Racial Differences in End-of-Life Care Quality between Asian Americans and Non-Hispanic Whites in San Francisco Bay Area. <i>Journal of palliative medicine</i> , 24(8), 1147–1153. <a href="https://doi.org/10.1089/jpm.2020.0627">https://doi.org/10.1089/jpm.2020.0627</a>	San Francisco, Hospice	108 Asian and 414 non-Hispanic white bereaved family members	A San Francisco mortality survey based on the CAHPS® Hospice Survey that asked about how their family member was treated by hospice care staff members during end-of-life found that, compared with their white counterparts and adjusted for cause of death, site of death, type of health insurance, respondent's relationship to decedent, decedent age, and respondent education	<p>Asian decedents more often experienced:</p> <p>Lack of respect for their cultural traditions (Adjusted Odds Ratio [AOR] 3.59; 95% Confidence Interval [CI] 1.88 – 6.86)</p> <p>Lack of respect for their religious and spiritual beliefs (AOR 2.85; CI 1.45 – 5.62)</p> <p>Not receiving as much information as they had wanted about what to expect during the last months of life (AOR 2.15; CI 1.10 – 4.19)</p> <p>Not receiving the right amount of emotional support after the decedent's passing (AOR 2.39; CI 1.23-4.63)</p>
Ko, E. and D. Fuentes (2020). "End-of-Life Communication Between Providers and Family Caregivers of Home Hospice Patients in a Rural US-Mexico Border Community: Caregivers' Retrospective Perspectives." <i>Am J Hosp Palliat Care</i> 37(5): 329-335.	US, Southwest US/Mexico border towns, Home Hospice	Informal caregivers of Latino patients who are enrolled in home hospice in US/Mexico border towns (n = 28)	In-depth interviews using qualitative methods were conducted and thematic analysis was used	<p>Thematic analysis revealed themes including (1) lack of/insufficient EOL communication and (2) informational needs, including (a) signs of symptom changes, (b) EOL treatment options and goals of care, and (c) hospice care and its benefits.</p> <p>Limited caregiver-provider EOL communication was observed, in which most of the caregivers (n = 22, 78.6%) were informed of the patient's terminal condition, but only half (n = 15, 53.6%) had a discussion with the providers about hospice care.</p> <p>Authors recommend timely EOL communication between caregivers and the providers. Providers need to be aware of the caregivers' informational needs relating to patient symptoms and health condition as well as hospice care.</p>

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				It is important to be aware of the impact of cultural values on hospice care placement. A clear explanation about the purpose and functions of hospice care and its benefit can better guide the family caregivers in making hospice care decisions.
Ko, E., Lee, J., Ramirez, C., Lopez, D., & Martinez, S. (2018). Patient-family EoL communication and its predictors: Reports from caregivers of Latino patients in the rural U.S.-Mexico border region. <i>Palliat Support Care</i> , 16(5), 520-527. doi:10.1017/s147895151700092x	US, Southwest rural US/Mexico border towns, Home Health	Caregivers of Latino patients enrolled in a home health agency (n = 189)	Data analysis (data from a hospice needs assessment collected from family caregivers of Latino patients) included Bivariate tests and logistic regression	<p>About half of the family caregivers of Latino patients at a home health agency (n = 96, 50.8%) reported to have ever engaged in EoL discussion with patients.</p> <p>Significant predictors of EoL discussion included life-sustaining treatment preference (odds ratio [OR] = 0.44, p &lt; 0.05); knowledge of an advance directive (AD) (OR = 5.50, p &lt; 0.01); and distrust of physicians (OR = 0.29, p &lt; 0.01).</p> <p>Caregivers who preferred extending the life of their loved one even if he/she had to rely on life supports were less likely to engage in EoL communication.</p> <p>Also, caregivers who worried that physicians might want to stop treatments (i.e., "pull the plug") too soon were less likely to do so.</p> <p>Conversely, caregivers who had knowledge about ADs were more likely to engage in EoL communication.</p>
Ko, E., Lee, J., Ramirez, C., Martinez, S., & Lopez, D. (2017). Willingness to use hospice care among caregivers of Latino patients in the United States-Mexico border region. <i>Palliat Support Care</i> , 15(3), 279-287. doi:10.1017/s1478951516000687	Southern California US/Mexico border towns, Home Hospice	Caregivers of Latino patients enrolled in a home health agency (n = 189)	Data analysis (secondary data from a home health agency and primary data from caregiver interviews) included Bivariate tests and logistic regression	<p>The majority (83%) of family caregivers of Latino patients were willing to use hospice services for their loved ones.</p> <p>The factors impacting willingness to use hospice services included the primary language of the caregiver (OR = 6.30, CI 95% = 1.68, 23.58); trust in doctors to make the right decisions (OR = 3.77,</p>

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				<p>CI 95% = 1.05, 13.57); and the belief that using hospice care means giving up on life (OR = 0.52, CI 95% = 0.30; 0.88).</p> <p>Caregivers who trusted doctors to make the best decisions for their loved ones and English-speaking caregivers were more willing to utilize hospice services, while caregivers who held a strong belief that hospice care means giving up on life were less likely to consider using hospice care for their loved ones.</p>
Koroukian, S. M., Schiltz, N. K., Warner, D. F., Given, C. W., Schluchter, M., Owusu, C., & Berger, N. A. (2017). Social determinants, multimorbidity, and patterns of end-of-life care in older adults dying from cancer. <i>J Geriatr Oncol</i> , 8(2), 117-124. doi:10.1016/j.jgo.2016.10.001	Home, hospice, hospital	Cancer patients, U.S., N=835	Post-mortem multivariable logistic regression (of linked data from 1991-2008 Health and Retirement Study, Medicare, and National Death Index)	<p>The majority (61.2%) of patients enrolled in hospice, but non-Hispanic Black patients and patients with lower incomes were significantly less likely to enroll in hospice.</p> <p>There was a non-linear relationship between income and in-hospital death (U-shaped), and income and cancer-directed treatment (J-shaped).</p> <p>Non- Hispanic Black patients were less likely to enroll in hospice than white patients (p &lt; 0.05)</p> <p>Patients with less than a high school education were less likely to enroll in hospice than patients with a high diploma or some college (p &lt; 0.05)</p> <p>Patients in the lowest income quartile were less likely to enroll in hospice than patients with higher incomes (p &lt; 0.05)</p>
Lee, J. and J. G. Cagle (2017). "Factors Associated with Opinions About Hospice Among Older Adults: Race, Familiarity with Hospice, and	US, Florida, Hospice	2,714 older adults	Analysis of survey data from the American Association of Retired Persons in Florida	<p>Results showed race of the respondent was the strongest predictor of one's opinion about hospice.</p> <p>Predictors of positive opinions of hospice included being of Caucasian race and non-Hispanic</p>

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Attitudes Matter." J Palliat Care 32(3-4): 101-107.				ethnicity, in addition to better health, greater familiarity with hospice, a high importance of pain control, the importance of fulfilling personal goals, a desire to have health-care professionals involved in one's care and having engaged in advance care planning.
Lin, P. J., Zhu, Y., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., . . . Freund, K. M. (2022). Racial and Ethnic Differences in Hospice Use and Hospitalizations at End-of-Life Among Medicare Beneficiaries With Dementia. <i>JAMA Netw Open</i> , 5(6), e2216260. doi:10.1001/jamanetworkopen.2022.16260	Hospice/hospital across the United States	Medicare fee-for-service beneficiaries (continuously enrolled for at least 6 months prior to death) aged 65 years or older diagnosed with dementia who died between 2000 and 2016 (n = 5058)	Cohort study (data from national surveys from the Health and Retirement Study linked with Medicare and Medicaid claims) using 2-part models (logistic regression and generalized linear model)	<p>This cohort study found that non-Hispanic Black and Hispanic decedents with dementia used less hospice but more emergency department and inpatient services and incurred roughly 60% higher Medicare inpatient expenditures at the end of life, compared with non-Hispanic white decedents.</p> <p>A higher proportion of Black and Hispanic than white beneficiaries with dementia who were enrolled in hospice were subsequently admitted to the ED.</p> <p>The proportion of dementia beneficiaries completing advance care planning was significantly lower among non-Hispanic Black and Hispanic decedents compared with non-Hispanic white decedents, and a higher proportion of Black and Hispanic decedents with dementia had written instructions choosing all care possible to prolong life.</p> <p>Predictors of hospice use include older age, female gender, higher education levels, more severe cognitive impairment, and more instrumental activities of daily living impairment.</p>
Mehanna, E. K., Catalano, P. J., Cagney, D. N., Haas-Kogan, D. A., Alexander, B. M., Tulskey, J. A., & Aizer, A. A. (2020). Hospice Utilization in Elderly Patients with		Medicare patients (n=50,148) aged 66 years and older diagnosed with brain metastasis.	Retrospective cohort study using data from the Surveillance, Epidemiology and End Results (SEER)– Medicare database for the period 2005-2016.	The overall incidence of hospice enrollment among elderly patients with brain metastases between 2005 and 2016 was 71.4%, with a sustained increase in incidence over the study

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Brain Metastases. J Natl Cancer Inst, 112(12), 1251-1258.				<p>period. This suggests underutilization of hospice in a high-need group (28.6% do not enroll).</p> <p>The investigators identified statistically significant racial and ethnic disparities in hospice utilization with lower rates of hospice enrollment among Asian, Black, and Hispanic patients, as compared to white.</p> <p>The mechanisms for these disparities cannot be identified through this study, but the authors assert that they may include structural inequality in access to hospice care, cultural and religious preferences, lack of knowledge about the benefits of palliative care and hospice services, and stigma against hospice use or beliefs that palliative services hasten death.</p> <p>This study also identified that male patients and patients with greater comorbidities had lower odds of enrolling in hospice.</p> <p>Lastly, patients living in areas with higher household income were also found to be less likely to enroll in hospice, however this was not a clinically significant finding.</p>
Mendieta, M., & Miller, A. (2018). Sociodemographic Characteristics and Lengths of Stay Associated with Acute Palliative Care: A 10-Year National Perspective. Am J Hosp Palliat Care, 35(12), 1512-1517.	Home-based and facility-based hospice care and acute palliative care settings across the U.S.	Medicare beneficiaries in hospice care, accessing and deceased while in acute palliative care (n=94,557).	Retrospective cohort study using data from the University of Michigan Institute for Healthcare Policy and Innovation (contains data from private insurers and CMS and is nationally representative sample of Medicare population) for the period 2006-2014. The study is designed to examine how various patient characteristics were associated with length of stay in acute palliative care.	<p>Lengths of stay in hospice and acute palliative care are recommended to be longer to allow for patient-provider relationship building and for patients to take full advantage of services.</p> <p>African American and Hispanic patients were more likely to receive home-based hospice care services (12.2% and 8.8%, respectively), as compared to facility-based hospice (10.2% and 6.6%, respectively).</p>



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				<p>In contrast, there was no observed difference in proportion of Asian patients between home-based and facility-based hospice (1.5% and 1.3%, respectively).</p> <p>White patients comprised a greater proportion of facility-based hospice patients (73%) as compared to home-based hospice patients (69%).</p> <p>Nevertheless, this study did not find that home-based hospice was associated with shorter length of stay in acute palliative care across groups.</p> <p>Despite being more likely to use home-based hospice care, African American patients had longer lengths of stay in acute palliative care (10 days), compared to white and Asian patients (9 days).</p> <p>Hispanic patients, who were also more likely to use home-based care, had the shortest lengths of stay (8 days).</p>
Mendola, A., Naumann, W. C., Mooney-Doyle, K., & Lindley, L. C. (2021). Social Determinants of Comfort: A New Term for End-of-Life Care. <i>J Palliat Med</i> , 24(8), 1130-1131. doi:10.1089/jpm.2021.0209	US, end-of-life care	Not applicable	Letter to the editor	<p>This letter to the editor proposes the term “social determinants of comfort” to describe structural conditions that influence to what degree comfort measures are offered to and accepted by patients and their families.</p> <p>Social determinants of comfort include structural conditions that influence the health outcomes of individuals and populations, such as safety of the built environment, access to nourishing food, and steady income source.</p>
Mullins, M. A., Ruterbusch, J. J., Clarke, P., Uppal, S., Wallner, L. P., & Cote, M. L. (2021). Trends and racial disparities in aggressive end-of-life		Medicaid beneficiaries aged >66 years diagnosed with ovarian cancer in the between 2000 and 2015	Retrospective cohort study designed to assess trends in the aggressiveness of end-of-life care for women with ovarian cancer and	The proportion of women who do not enroll in hospice declined over time since 2007 ( $P < .01$ );

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
care for a national sample of women with ovarian cancer. Cancer, 127(13), 2229-2237.		and who died between 2007 and 2016 (n=7,756)	evaluate whether racial disparities in aggressive end-of-life care exist at a national level.	<p>but the proportion enrolling late did not improved over the study period (P = .17).</p> <p>Compared with non-Hispanic white (NHW) women, approximately 10% more non-NHW women did not enroll in hospice (P &lt; .01). Compared with NHW women: Non-Hispanic Black (NHB) women had 38% greater odds of no hospice enrollment, Hispanic women had 36% greater odds of no hospice enrollment, and women in the other races group had 76% greater odds of no hospice enrollment.</p> <p>There were no statistically significant differences in late enrollment in hospice by race/ethnicity.</p>
NHPCO. (2020). Position Paper: COVID-19 and Supporting Black Communities at the End of Life. 1-11. Retrieved from <a href="https://www.nhpc.org/dac-position-paper/">https://www.nhpc.org/dac-position-paper/</a> . Accessed: August 29, 2022	National Hospice and Palliative Care Organization' Diversity Advisory Council	Ethnic communities	<p>The Diversity Advisory Council in this Position Paper endeavors to help communities at all levels better understand the situation, with emphasis on building trust with the diverse populations</p> <p>relative to patient care and the pain, misery, grief and sorrow caused by this horrible virus.</p>	<p>"Ultimately, organizations should entertain innovative minority engagement initiatives that add genuine value to communities rather than investing in "Diversity, Inclusion and Equity" solely for capitalization and incentivization. Hospice and palliative care providers would do well to educate themselves on the psyche of Black, Indigenous, and People of Color (BIPOC) that has been shaped by systemic racism, socioeconomic inequities, and disparities in health care education." Organizations can overcome these barriers and build trust by:</p> <ul style="list-style-type: none"> <li>• Having a health and health care advocate, someone who is in a neutral place but has the influence and authority to see things through.</li> <li>• Building a framework around treatment and quality of life for elders.</li> <li>• Identifying implicit biases and reflect on the impact they have on decisions made related to patient care.</li> </ul>

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				<ul style="list-style-type: none"> <li>• Having a clear and precise plan of care and dialog with physician and patient about all options.</li> <li>• Scheduling time for relationship building. If there are patients who are traditionally underserved, plan to spend more time discussing options, providing education, and building trust. Doing this on the front end will prove to be beneficial to both the patient and clinician later.</li> <li>• Advocating for equitable laws related to health care. The Hospice Action Network and NHPCO advocate annually for policies that impact the Medicare Hospice Benefit and all are welcome to join.”</li> </ul> <p>Hospice and palliative care providers are encouraged to position themselves in the gap between these redlined delivery systems by addressing disparities in health care education.</p> <p>Organizations can conduct an analysis of the education system within redlined communities, identify age group(s) that may benefit from early chronic disease education, consider investing in a community health education campaign, be innovative about multi-generational engagement, and collaborate with unlikely community health equity stakeholders</p>
Nicholson, B. L., Flynn, L., Savage, B., Zha, P., & Kozlov, E. (2022). Hospice Referral in Advanced Cancer in New Jersey. J Hosp Palliat Nurs, 24(3), 167-174.	Inpatient hospital facilities in New Jersey	Patients hospitalized with metastatic cancer in New Jersey in 2018 (n=28,697)	Retrospective cohort study using Health Care Utilization Project (HCUP) New Jersey state inpatient database to examine the relationship	<p>This study revealed racial disparities in hospice referral (either home hospice or hospice facility) patterns in New Jersey.</p> <p>After adjusting for pain and depression, Black patients were 15% less likely and Hispanic patients were 16% less likely to receive hospice</p>

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			among demographics, symptoms of pain and depression, and hospice referral.	referrals in New Jersey hospitals compared with whites.  Patients with a primary language other than English, there were 15% less likely to receive a hospice referral as compared to those with English a primary language.
Noh, H., Kim, J., Sims, O. T., Ji, S., & Sawyer, P. (2018). Racial Differences in Associations of Perceived Health and Social and Physical Activities with Advance Care Planning, End-of-Life Concerns, and Hospice Knowledge. <i>Am J Hosp Palliat Care</i> , 35(1), 34-40.	Alabama communities	Community-dwelling older adults (aged 55+ years) in Alabama (n= 1,044)	Cross-sectional study using survey data from the Comprehensive Center for Healthy Aging at the University of Alabama at Birmingham	Adjusting for sex, age marital status, education, and income, whites were more likely than Black people to have knowledge of hospice care (P < .01).  Both whites and Black people with better perceived health (P < .05; P < .05) and a higher level of social activity (P < .001; P < .05) were likely to have more accurate knowledge of hospice than those with poorer perceived health and a lower social activity level.  However, Black older adults generally reported poorer general perceived health. Higher levels of physical activity were associated with higher levels of knowledge of hospice for Black people (P < .05) but not for whites.
Noh, H., Lee, H. Y., Lee, L. H., & Luo, Y. (2021). Awareness of Hospice Care Among Rural African-Americans: Findings From Social Determinants of Health Framework. <i>Am J Hosp Palliat Care</i> , 10499091211057847. doi:10.1177/10499091211057847	US, Alabama's "black belt," hospice	179 African Americans living in Alabama's "black belt" region	A US cross-sectional survey that examined the association between social determinants of health (operationalized as financial resource strain, food insecurity, housing instability, education/health literacy, social isolation, and threats to interpersonal safety) and hospice awareness and use  They also performed binary logistic regression that estimated the	82.1% of participants had heard of hospice care  Participants over 50 were more likely to report awareness of hospice care (Odds Ratio [OR] = 7.29; CI 1.21 – 43.08)  Participants with higher health literacy were more likely to report awareness of hospice care (OR =2.59; CI 1.27 = 5.31)  Participants reporting worries about stable housing and higher social isolation were less likely

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			association between SDOH and hospice awareness	to have heard of hospice care. (OR= 0.05; CI 0.004 – 0.76)  More socially isolated participants were less likely to be aware of hospice (OR 0.53; CI 0.31 – 0.90)
Núñez, A., Holland, J. M., Beckman, L., Kirkendall, A., & Luna, N. (2019). A qualitative study of the emotional and spiritual needs of Hispanic families in hospice. <i>Palliat Support Care</i> , 17(2), 150-158.	Hospices in Southwestern United States	Hispanic family members (aged <18 years) of former patients at large and well-established hospices in the Southwestern U.S. (n=29)	Qualitative semi-structured key informant interviews to examine the emotional and spiritual needs of Hispanic patients' families while in hospice.	<p>This study revealed five overarching themes that reflect the experiences of Hispanic family members when receiving hospice-based emotional and spiritual support services.</p> <ul style="list-style-type: none"> <li>• The influence of Hispanic cultures in the hospice care relationship, which included ways in which Hispanic cultural norms and values influenced the interactions between patients' families and hospice care providers.</li> <li>• Types of social support (i.e., instrumental, informational) from hospice, which captured helpful types of social support participants received from hospice care providers.</li> <li>• Barriers to receiving support, which included both psychological and practical impediments to receiving support.</li> <li>• Lack of health literacy regarding hospice care, which consisted of participant responses describing difficulties they had in understanding hospice care information and a desire for education for caregivers.</li> <li>• Cultural preferences for religious/spiritual support in hospice, which included participants' responses that pertained to religious/spiritual support and the extent to which it fit with their cultural values.</li> </ul> <p>The authors assert that their findings highlight the need for hospice staff training in culturally sensitivity, integrating members of the Hispanic community into the healthcare team to provide</p>

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				health education, and provision of care that is consistent with the religious/spiritual beliefs of patient families - or at least not contradictory.
Ornstein, K. A., Aldridge, M. D., Mair, C. A., Gorges, R., Siu, A. L., & Kelley, A. S. (2016). Spousal Characteristics and Older Adults' Hospice Use: Understanding Disparities in End-of-Life Care. <i>J Palliat Med</i> , 19(5), 509-515.	United States	Adults over the age of 55 who died between 2000 and 2011, participated in fee-for-service Medicare for at least 6 months, married/partnered, and with at least one chronic condition	Prospective cohort study using Health and Retirement Study and linked Medicare claims data to determine association between spousal characteristics and hospice use.	<p>Bivariate analyses revealed that hospice users were more likely than those who did not use hospice to have a high school degree or higher (70.3% versus 65.1%, <math>p = 0.03</math>) and be white (85.7% versus 79.1%, <math>p = 0.003</math>).</p> <p>Additionally, the spouse having lower educational attainment than the decedent was associated with no hospice use (<math>p = 0.015</math>).</p> <p>After controlling for patient and regional factors associated with hospice use, the spouse having lower educational attainment than the decedent resulted in 42% decreased odds of using hospice (OR = 0.58; 95% CI = 0.40–0.82).</p> <p>The authors assert that the association found between educational attainment discordance of spouse and hospice use may be reflective of socioeconomic status, health literacy, realistic expectations about death, or knowledge about hospice.</p> <p>They suggest that a better understanding of barriers to hospice enrollment, such as the concerns of the patient's spouse or partner, is needed.</p>
Ornstein, K. A., Roth, D. L., Huang, J., Levitan, E. B., Rhodes, J. D., Fabius, C. D., Safford, M. M., & Sheehan, O. C. (2020). Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the	United States	Adults 45 years or older who died between 2013 and 2015	Prospective cohort study using Reasons for Geographic and Racial Differences in Stroke and linked Medicare claims data	Authors point out that extant research has shown that use of hospice care is on the rise in the United State in the last decade and that the fastest-growing segment of the population receiving hospice care includes individuals with noncancer diagnoses.

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REGARDS Cohort. JAMA Netw Open, 3(8), e2014639.				<p>Despite the recent increase in the use of hospice care, this study revealed that racial disparities in the use of hospice remain, especially for noncancer deaths.</p> <p>The investigators found that Black decedents were less likely than white decedents to use hospice for 3 or more days (34.9% vs 46.2%; <math>P &lt; .001</math>).</p> <p>After stratification by cause of death, racial differences in hospice use were found among persons who died of other deaths not attributed to cancer, dementia, or CVD cardiovascular disease.</p>
Osakwe, Z. T., Arora, B. K., Peterson, M. L., Obioha, C. U., & Fleur-Calixte, R. S. (2021). Factors Associated with Home-Hospice Utilization. Home Healthc Now, 39(1), 39-47.	Medicare-certified hospices across the U.S. including home-based hospice providers and institutional settings (i.e., assisted living, skilled nursing facility, inpatient hospice, inpatient hospital hospice, long-term care or non-skilled nursing facility, and other facility hospice).	Medicare-certified hospice providers in 2016 (n=2,148)	Cross-sectional study using Medicare Provider Utilization and Payment Data: Hospice Public Use File (2016) and American Community Survey data linked by hospice provider ZIP code to identify which characteristics are associated with home-hospice use (as compared to institutional hospice use).	<p>The authors point out that home hospice is recognized as an important patient-centered goal in EoL care.</p> <p>Provision of home-hospice was reduced by 2% for each percentage increase in proportion of female patients of the hospice (OR = 0.97, 95% CI = 0.97–0.98).</p> <p>Among community-level factors, hospice location in a ZIP-code with higher proportion of Black residents was not significantly associated with home-hospice provision (OR = 1.00, 95% CI = 1.00–1.01). For each unit increase in the proportion of Hispanic residents in a hospice ZIP-code, there was a decrease in the odds of providing home hospice (OR = 1.00, 95% CI = 0.99–0.99).</p> <p>Hospices with a proportion of dually enrolled beneficiaries in the lower 80th percentile had 42% increased odds of providing home hospice as compared with their counterparts in the upper 20th percentile. The authors suggest that this</p>

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
				<p>finding may reflect higher care needs of the dually enrolled population that may be more easily met in institutional settings.</p> <p>Hospices in the Midwest were 36% less likely to provide home-hospice compared with those in the Northeast (the reference group; OR = 0.64, 95% CI = 0.56–0.72).</p>
Oud, L. (2017). Predictors of Transition to Hospice Care Among Hospitalized Older Adults with a Diagnosis of Dementia in Texas: A Population-Based Study. <i>J Clin Med Res</i> , 9(1), 23-29.	Inpatient hospital settings in Texas	Hospitalized adults aged 65 years and older with a diagnosis of dementia in Texas between 2001 and 2010 (n=889,008).	Retrospective cohort study using the Texas Inpatient Public Use Data file to identify factors associated with hospice utilization in the inpatient setting, and to quantify temporal patterns of escalation of care to ICU setting preceding discharge to hospice.	<p>Discharge to hospice was reported in 40,669 (4.6%) hospitalizations.</p> <p>Dementia hospitalizations discharged to hospice increased from 908 (1.5%) in 2001 to 7,398 (6.3%) in 2010. Insurance other than commercial predicted lower transition to hospice care, being lowest among hospitalizations with Medicaid insurance (aOR (95% CI): 0.41 (0.37 - 0.46); P &lt; 0.0001).</p> <p>Non-white race groups had lower odds of hospice utilization, being lowest among Black patients (aOR (95% CI): 0.67 (0.65 - 0.70); P &lt; 0.0001).</p> <p>This contrasts with other studies which have revealed higher odds of hospice use among non-white patients with dementia, though the authors point out that this may be due to the population sampled in this study which is more likely to be experiencing severe disease as they have already been hospitalized.</p> <p>Discharge to hospice was reported in 16,111 (5.8%) hospitalizations among ICU admissions during study period; this proportion increased significantly from 1.7% in 2001 to 7.7% in 2010, accounting for nearly one in two hospice discharges by the end of the decade.</p>



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				<p>This finding suggests that increasing proportion of key discussions by clinicians about goals of care and options of palliative care likely took place following admission to ICU and possibly after institution of invasive life support interventions.</p> <p>This underscores the need to effectively incorporate discussions on ICU admission and related interventions vs. alternative care options (such as hospice) earlier in the hospital course.</p>
Paredes, A. Z., Hyer, J. M., Palmer, E., Lustberg, M. B., & Pawlik, T. M. (2021). Racial/Ethnic Disparities in Hospice Utilization Among Medicare Beneficiaries Dying from Pancreatic Cancer. <i>J Gastrointest Surg</i> , 25(1), 155-161.	United States, various settings (inpatient, outpatient)	Medicare beneficiaries older than 65 years of age with pancreatic cancer who underwent a pancreatectomy between 2013-2017 and lived at least 30 days following surgery	Retrospective cohort study using CMS Inpatient, Outpatient, and Hospice Standard Analytic files designed to define the incidence and characterize the timing of hospice utilization among racial/ethnic minority patients following pancreatectomy for pancreatic cancer.	<p>Although there were no significant racial/ethnic disparities in mortality rate following pancreatectomy nor in time until death, racial/ethnic minorities (Black or Hispanic) were more likely to have experienced a complication after surgery and to have had a longer length of stay, and less likely to have used hospice services at time of death, compared to their white counterparts.</p> <p>Even after controlling for relevant clinical covariates, racial/ethnic minorities were 22% less likely to use hospice services as compared to white patients.</p> <p>Although hospice utilization among pancreatic patients declined overall between 2013 and 2017, the decrease is more pronounced among racial/ethnic minorities (-11.1% vs. -5.6% among white patients).</p> <p>There was no significant difference between white and minority patients in odds of late hospice use, however.</p>
Park, N. S., Jang, Y., Ko, J. E., & Chiriboga, D. A. (2016). Factors Affecting Willingness to Use Hospice	Florida, community setting	Floridian adults aged 65 years or older cognitively capable in understanding	Retrospective cohort study using Survey of Older Floridians administered between 2004-2005 and	Among non-Hispanic white participants, younger individuals were more willing to use hospice (odds

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Citation	Setting	Population	Design	Main Findings
in Racially/Ethnically Diverse Older Men and Women. Am J Hosp Palliat Care, 33(8), 770-776.		and answering survey questions (n=1,433)	designed to explore the predictors of the willingness to use hospice services in racially/ethnically diverse older men and women.	<p>ratio [OR]=0.93, 95% confidence interval [CI]: 0.87-0.98).</p> <p>Among African American participants, an increasing number of functional disabilities was associated with decreased willingness to use hospice (OR= 0.77, 95% CI: 0.62-0.95).</p> <p>A similar trend was observed in Cuban Americans and non-Cuban Hispanics, though not statistically significant.</p> <p>No observed factor was significantly associated with willingness to use hospice services among Cuban Americans.</p> <p>In the non-Cuban Hispanic sample, English proficiency increased the willingness by 3.1 times (95% CI: 1.26-7.58).</p> <p>Notably this was not the case for Cuban American participants and authors suggest that this is due to unique geographic clustering of this community with significant access to information and services in their native language.</p> <p>These results support the notion that willingness to use hospice may be influenced by different sets of factors that vary by race/ethnicity.</p>
Patel, M. I., Khateeb, S., & Coker, T. (2021). Association of a Lay Health Worker-Led Intervention on Goals of Care, Quality of Life, and Clinical Trial Participation Among Low-Income and Minority Adults with Cancer. JCO Oncol Pract, 17(11), e1753-e1762.	Chicago, community setting	Racial and ethnic minority union members >18 years old from low-income households newly diagnosed with cancer	Prospective cohort evaluation, comparison with historical cohort designed to assess a community health worker-led supportive cancer care intervention impact on variety of outcomes (including hospice use) among racial/ethnic minorities,	<p>Union members (all low-income and racial/ethnic minorities) in the community health worker intervention group were more likely to receive hospice care, as compared with the control group (44% v 7%; P &lt; .001).</p> <p>This study suggests there are associated benefits of using lay health workers to connect low-income</p>

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Citation	Setting	Population	Design	Main Findings
			including hospice use. (n=66, vs n=72 in historical control group)	<p>and minority hourly wage workers with cancer to hospice care in an urban setting.</p> <p>In focus groups with the participants, many acknowledged that they felt more comfortable openly discussing their concerns about their goals of care and advance directives with peers from their community than with health care professionals such lay workers would more readily enable trust in health systems.</p> <p>The authors therefore suggest it is possible that the interpersonal relationships between the lay health workers and participants might have promoted the high uptake of these important cancer care services, such as hospice use.</p>
Phongtankuel, V., Johnson, P., Reid, M. C., Adelman, R. D., Grinspan, Z., Unruh, M. A., & Abramson, E. (2017). Risk Factors for Hospitalization of Home Hospice Enrollees Development and Validation of a Predictive Tool. <i>Am J Hosp Palliat Care</i> , 34(9), 806-813.	Home-based hospices in the United States	Medicare beneficiaries enrolled in home hospice between April and June 2012 (n=384,484)	Retrospective cohort study using Medicare fee-for-service claims from CMS designed to analyze pre-hospice admission risk factors associated with hospitalization to develop and validate a predictive tool aimed at identifying home hospice patients at risk for hospitalization.	<p>Non-Black minorities (OR = 1.40; 95% CI: 1.21-1.62), and Black individuals (OR = 2.68; 95% CI: 2.45-2.92) were associated with greater odds of hospitalization compared to whites (Table 2).</p> <p>These associations persisted even after adjusting for other patient and hospice level factors (Black: OR=2.13; 95% CI: 1.93-2.34; non-Black: OR=1.41; 95% CI: 1.22-1.65).</p>
Price, R. A., Parast, L., Haas, A., Teno, J. M., & Elliott, M. N. (2017). Black And Hispanic Patients Receive Hospice Care Similar to That of White Patients When in The Same Hospices. <i>Health Aff (Millwood)</i> , 36(7), 1283-1290.	Hospice settings across the United States	Hospice primary caregivers (n= 292,516) whose family member or friend died in the period of April 2015 – March 2016	Retrospective cohort study using Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey data. The study was designed to assess whether caregivers' reports of hospice care experiences differ by patients' race/ethnicity and to what degree are observed differences due to racial/ethnic minorities' concentration in certain hospices versus differences	<p>The study revealed that racial/ethnic differences are mostly attributed to between-hospice differences.</p> <p>For all seven CAHPS® Hospice Survey quality measures, Black and Hispanic patients were found to be more likely than white patients to receive care from hospices that offered significantly poorer care experiences (the between-hospice differences).</p>

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Citation	Setting	Population	Design	Main Findings
			in care delivered to racial/ethnic subgroups within the same hospice.	<p>Within a given hospice, however caregivers of Black and Hispanic hospice patients reported significantly better within-hospice care experiences than did caregivers of white patients on five of seven outcomes.</p> <p>The two exceptions to this were that within a given hospice, 1) caregivers of Black patients were less likely to recommend hospice compared to caregivers of white patients, and 2) Hispanic patients were less likely to report receiving the right amount of emotional and religious support (notably, they are more likely to receive “too much” support) as compared to caregivers of white patients.</p> <p>The results of this study highlight that to address racial/ethnic inequities in hospice experience, it will be critical to improve awareness of and access to high quality hospices that currently serve Black and Hispanic patients and their families.</p>
Reese, D. J., & Beckwith, S. K. (2015). Organizational Barriers to Cultural Competence in Hospice. <i>Am J Hosp Palliat Care</i> , 32(7), 685-694.	U.S. hospices	Hospice directors (n=207)	Mixed-methods study utilizing web-based cross-sectional survey including closed (quantitative) and open-ended (qualitative) items	<p>Results from quantitative data indicated that hospice staff, volunteers, and patients across these hospices were almost entirely white and very rarely spoke Spanish. Qualitative results identified organizational, community, healthcare system, and other barriers to cultural competence in hospice settings, as well as organizational strengths that promote cultural competence.</p> <p>Organizational barriers included lack of diverse or bilingual job applicants and volunteers, knowledge barriers. In this case, staff were unaware of any barriers or that anyone was underserved, lack of knowledge about how to access resources, including written materials and videos for patients,</p>

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				<p>lack of funding (e.g., DEI or cultural sensitivity training, interpretation services, additional staff for community outreach), lack of a focused, concentrated community outreach program (e.g., community referral network, collaborations), organizational culture that does not recognize or want to recognize cultural differences, staff unconcerned or uncomfortable with diversity</p> <p>Community barriers included lack of diversity in the community (e.g., rural communities), geographic barriers, and severe poverty. Healthcare system issues included government regulations that reduce ability to meet diverse needs.</p> <p>Other issues with diverse populations included preferences to associate with their own cultural group, in some cases return to their own country, perception of hospice as divergent to their cultural and religious beliefs or thinking.</p> <p>Organizational strengths identified were staff diversity, hiring of interpreters and provision of funding for cultural competence training, access to tools needed for serving diverse populations, community outreach (e.g., speaking at local churches and functions, collaborations with local university), organizational culture in which staff are excited to learn about the culture and providing best possible care, knowledge of underserved populations and inequity.</p>
Reese, D. J., Buila, S., Cox, S., Davis, J., Olsen, M., & Jurkowski, E. (2017). University-Community-Hospice Partnership to Address Organizational Barriers to Cultural	Hospice in a rural community	Staff and patients at one rurally located hospice	Participatory action research project using mixed methods designed to evaluate the effectiveness of a social work student field placement intervention in one rural hospice.	Through the intervention social work students completed clinical field work by providing services and 3 public information sessions and cultural competence training for staff at no cost to the hospice, addressing a reported lack of funding for

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Competence. Am J Hosp Palliat Care, 34(1), 64-78.				<p>community outreach and training needs and a lack of knowledge about diverse cultures.</p> <p>The intervention addressed lack of applications from cultural backgrounds by having a social worker hired from the intervention, as well as increasing the number of Black volunteers.</p> <p>The social work students also conducted a needs assessment of the community to identify groups not being served which addressed the reported barrier of lacking awareness of which cultural groups are not being served.</p>
Rhodes, R. L., Elwood, B., Lee, S. C., Tiro, J. A., Halm, E. A., & Skinner, C. S. (2017). The Desires of Their Hearts: The Multidisciplinary Perspectives of African Americans on End-of-Life Care in the African American Community. Am J Hosp Palliat Care, 34(6), 510-517.	Various/Unclear	African American hospice providers, caregivers, and patients	Qualitative study using semi-structured interviews and focus groups with African American hospice and palliative care providers, ministers, caregivers, patients	<p>Respondents reported hospice was beneficial to patients and family (e.g., helpful, comforting). Perceived barriers among African Americans included cultural differences, conflicts with spirituality and religious preferences, overall lack of knowledge about what hospice entails, and mistrust in the medical system.</p> <p>Strategies to overcome perceived barriers included counteracting the believe that hospice means giving up on faith (e.g., emphasizing the power of prayer in hospice, continuation of support and comfort from spiritual leaders/peers in the community and in hospice, integrating religious and cultural beliefs into individual care plan) more provision of education about the purpose of hospice, taking time to build rapport and respecting and meeting people where they are in the EOL decision-making process, learning about each individual patient (i.e., patient-centered care).</p>
Rice, D. R., Hyer, J. M., Diaz, A., & Pawlik, T. M. (2021). End-of-Life Hospice Use and Medicare	United States, various settings	Medicare beneficiaries with hepatocellular carcinoma	Retrospective cohort study using Surveillance, Epidemiology,	Whereas hospice use was not associated with sex, racial/ethnic minority patients less often used hospice services during the last year of life

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Citation	Setting	Population	Design	Main Findings
Expenditures Among Patients Dying of Hepatocellular Carcinoma. Ann Surg Oncol, 28(9), 5414-5422.		(HCC) diagnosed between 2004 and 2016 (n= 14,369)	and End Results (SEER)-Medicare-linked database and designed to define health care expenditures and hospice use among patients with HCC.	<p>compared with white patients (no hospice [44.3 %] vs. hospice [31.1 %]; P&lt;0.001).</p> <p>Social vulnerability of the patient's county of residence was also associated with hospice use; in specific, the probability of hospice use declined as social vulnerability increased (P&lt;0.001).</p> <p>Among patients who did use hospice, both race and SVI of county were associated with early vs. late hospice use. Notably, white patients were less likely than minority patients to initiate hospice use early (OR, 0.76; 95 % CI, 0.60–0.96), this held true even when holding SVI constant.</p> <p>Furthermore, as SVI of an area increased, the adjusted probability of early hospice use increased among minority patients yet decreased among white patients.</p> <p>These findings suggest that although minority patients may have less access to hospice services, when hospice is available, Black and Latino patients may be referred or decide to enroll earlier.</p> <p>Hospice use was associated with an approximate \$10,000 decrease in inpatient expenditures (hospice, US \$7900 vs. no hospice, US \$18,000; P&lt;0.001) and a \$1,300 decrease in outpatient expenditures (hospice, US \$900 vs. non-hospice, US \$2200; P&lt;0.001) compared with expenditures of patients who did not use hospice.</p> <p>This suggests that, in addition to benefiting patient care, hospice use may reduce overall health care costs, and reduce risk of financial detriment for patients and their families.</p>

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Citation	Setting	Population	Design	Main Findings
Riggs, A., Breuer, B., Dhingra, L., Chen, J., Hiney, B., McCarthy, M., Portenoy, R. K., & Knotkova, H. (2016). Hospice Enrollment After Referral to Community-Based, Specialist-Level Palliative Care: Incidence, Timing, and Predictors. <i>J Pain Symptom Manage</i> , 52(2), 170-177.	MJHS Hospice and Palliative Care is a not-for-profit company that maintains a certified hospice agency and a multifaceted palliative care program and provides care in all the boroughs of New York (except Staten Island) and Nassau County.	Patients who received community-based specialist-level palliative care services in a large program in New York (n=1,505)	Retrospective cohort study using data from electronic medical records and designed to evaluate the incidence, timing, and predictors of hospice enrollment after referral to a community-based palliative care program.	<p>Bivariate analyses revealed that white patients were more likely to receive hospice after palliative care, whereas Black and Hispanic patients were less likely to receive hospice after palliative care. (Asian patients were also more likely to receive hospice, however the numbers were very small).</p> <p>Poverty status was also associated with hospice use among the palliative care cohort, with patients from zip codes with a smaller share of residents living in poverty being more likely to enroll in hospice.</p> <p>Patients whose primary language was not English were less likely to enroll in hospice.</p> <p>Multivariate analyses indicated that poverty status of neighborhood continued to be significantly associated with hospice use and demonstrated that as the length of palliative care stay increased, the odds of hospice admission decreased.</p> <p>Among the patients who did enroll in hospice, mean length of palliative care stay was greater among Black and Hispanic patients as compared to white and Asian patients, and greater among patients whose primary language was Spanish as compared to English speakers.</p> <p>The findings highlight the need for ensuring access to hospice for those in economically and medically underserved communities.</p>
Rising, M. L., Hassounah, D., Berry, P., & Lutz, K. (2021). Mistrust Reported by US Mexicans With Cancer at End of Life and Hospice	United States, various settings	US Mexican family members exposed to hospice (n=26)	Qualitative study using critical grounded in a postcolonial theory framework and semi structured interviews to develop a grounded	This study revealed that hospice avoidance among US Mexicans is driven more so by patients' mistrust of the healthcare system and providers rather than cultural barriers. This



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Citation	Setting	Population	Design	Main Findings
Enrollment. ANS Adv Nurs Sci, 44(1), E14-e31.			theory of hospice decision-making in U.S. Mexicans with terminal cancer	<p>mistrust was found to result in a perception of referral to hospice as coercive in nature.</p> <p>Among those US Mexicans who did enroll in hospice, they were US Mexicans who demonstrated a sense of belonging in the Eurocentric health care system, thereby precluding feelings of mistrust. Other instances of US Mexican use of and satisfaction with enrollment resulted from paternalistic relationship with the Eurocentric health care and provider.</p> <p>Among some older US Mexicans, there was a preference for traditional Mexican paternalistic relationship with physicians and among these patients, a sense of a belonging through identification with Eurocentric views and through trusting their physicians.</p> <p>The authors conclude that these findings suggest that cultural accommodation may do little to mitigate hospice avoidance that is rooted in mistrust.</p>
Rizzuto, J., & Aldridge, M. D. (2018). Racial Disparities in Hospice Outcomes: A Race or Hospice-Level Effect? J Am Geriatr Soc, 66(2), 407-413.	U.S. hospices, various types	Medicare beneficiaries in hospice who died between 2009-2010.	Longitudinal cohort study designed to determine whether there is racial variation in hospice enrollees' rates of hospitalization and hospice disenrollment	<p>In unadjusted models, Black hospice enrollees were significantly more likely than white enrollees to be admitted to the hospital (14.9% vs 8.7%, respectively), visit the ED (19.8% vs 13.5%, respectively), and disenroll from hospice (18.1% vs 13.0%, respectively).</p> <p>These results remained after accounting for participant clinical and demographic covariates and hospice-level random effects. In adjusted models, Black people were at higher risk of hospital admission (OR = 1.75, 95% CI = 1.64–1.86), ED visits (OR = 1.61, 95% CI = 1.52–1.70),</p>

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				<p>and hospice disenrollment (OR = 1.54, 95% CI = 1.45–1.63).</p> <p>This indicates holding clinical and demographic characteristics constant and within the same hospice – Black enrollees have greater odds of poor hospice outcomes as compared to their white counterparts.</p> <p>The authors suggest that these differences in outcomes may be due to Black patients tending to prefer life-sustaining therapies and spiritual beliefs that conflict with goals of hospice – a preference that is rooted in distrust in healthcare system based on the history of racism in medical research and persistent health disparities.</p> <p>They also suggest that racial differences in outcomes may reflect differences in the patterns of communications between providers and patients of different races.</p>
Russell, D., Diamond, E. L., Lauder, B., Dignam, R. R., Dowding, D. W., Peng, T. R., Prigerson, H. G., & Bowles, K. H. (2017). Frequency and Risk Factors for Live Discharge from Hospice. <i>J Am Geriatr Soc</i> , 65(8), 1726-1732.	New York City, large non-profit hospice agency; focus on home hospice service for this study	Home hospice patients who received care from a large urban not-for-profit hospice agency in New York City during a 3-year period between 2013 and 2015 (n = 9,190).	Retrospective cohort study using electronic medical records of hospice patients designed to calculate frequencies and identify associated risk factors for 4 distinct causes of live discharge from hospice.	<p>The risk for acute hospitalization was higher among racial/ethnic minorities (Hispanic AOR = 2.23 [CI = 1.82–2.73] P &lt; .001; African American AOR = 2.46 [CI = 2.00–3.03] P &lt; .001; Asian/other AOR = 1.63 [CI = 1.25–2.11] P &lt; .001) and for patients with Medicaid (AOR =1.53; CI =1.20 -2.25) and Managed Medicaid (AOR=1.54; CI= 1.06–2.25).</p> <p>Odds of acute hospitalization were also higher for patients with primary diagnosis of dementia, (AOR=1.48; CI=1.07-2.05), heart failure (AOR=2.42, CI=1.84-3.20), pulmonary disease (AOR=1.97; CI=1.34-2.90), or any other non-cancerous disease (AOR=1.45; CI-1.13-1.85), as compared to those with cancer diagnosis.</p>

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Citation	Setting	Population	Design	Main Findings
				<p>Supplemental interviews with caregivers of home hospice revealed that decisions to pursue hospitalization were influenced by medical events, uncontrolled symptoms, imminent death, or inability to provide care safely at home.</p> <p>Asians/Others had greater odds of elective revocation (AOR = 1.43; CI = 1.01–2.00), as compared to white non-Hispanic patients.</p> <p>The odds of disqualification were higher among women compared to men (AOR = 1.34; CI = 1.03–1.87). Additionally, patients with non-cancerous primary diagnoses had greater odds of disqualification, as compared to those with cancer as a primary diagnosis.</p> <p>The odds of transferring to another hospice setting or moving out of the area were greater among Hispanics compared to white non-Hispanic patients (AOR = 1.56; CI = 1.45–2.34).</p>
Russell, D., Luth, E. A., Ryvicker, M., Bowles, K. H., & Prigerson, H. G. (2020). Live Discharge from Hospice Due to Acute Hospitalization: The Role of Neighborhood Socioeconomic Characteristics and Race/Ethnicity. <i>Med Care</i> , 58(4), 320-328.	Nonprofit hospice agency in New York City (NYC) between 2013 and 2017	Hospice patients (N=17,290) in NYC between 2013 and 2017	Retrospective cohort study using electronic medical records of hospice patients (N=17,290) linked with neighborhood-level socioeconomic data (N=55 neighborhoods) designed to examine associations between neighborhood socioeconomic characteristics and risk for live discharge from hospice because of acute hospitalization	<p>Notable differences were observed in sociodemographic, clinical, and neighborhood characteristics between patients who died in hospice versus those who experienced live discharge.</p> <p>Greater percentages of Black and Hispanic hospice patients experienced live discharge compared with white patients.</p> <p>Despite Black and Hispanic patients representing 17.3% and 20.1% of the study population, these groups represented 27.4% and 28.4% of hospice patients who were discharged alive because of hospitalization, respectively.</p>

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Citation	Setting	Population	Design	Main Findings
				<p>Patients who experienced live discharge also tended to have Medicaid insurance.</p> <p>Compared with patients who died in hospice, patients who experienced live discharge lived in neighborhoods with greater proportions of residents that lacked a high school diploma, fewer residents that held a college degree, greater proportions of residents that lived below the poverty line, and where median household incomes were lower.</p> <p>In adjusted models, factors associated with higher odds of live discharge included patients from underrepresented racial/ethnic groups, patients with Medicaid insurance, patients residing in neighborhood with lower proportion of college graduates, and patients living in neighborhoods with lower median household incomes.</p> <p>Interaction models demonstrated that disparity between Hispanic and non-Hispanic white patients in odds of live discharge was greatest in most affluent neighborhoods rather than more economically disadvantaged neighborhoods; notably there was no such differential effect of neighborhood characteristics on odds of live discharge among Black patients.</p>
Samuel-Ryals, C. A., Mbah, O. M., Hinton, S. P., Cross, S. H., Reeve, B. B., & Dusetzina, S. B. (2021). Evaluating the Contribution of Patient-Provider Communication and Cancer Diagnosis to Racial Disparities in End-of-Life Care Among Medicare Beneficiaries. <i>J Gen Intern Med</i> , 36(11), 3311-3320.	United States, various settings	Black and white Medicare beneficiaries 65 years or older with cancer (N=2000) and without cancer (N=11,524).	Retrospective cohort study using the population-based SEER-CAHPS linked dataset, which combines Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient experience surveys (2001–2005, 2007–2015), Medicare enrollment and claims data (2003–2015), and Surveillance,	<p>Black beneficiaries were 26% less likely than their white counterparts to enroll in hospice (ARR: 0.74, 95%CI: 0.66–0.83).</p> <p>Notably these racial disparities in enrollment use varied by primary diagnosis. Among beneficiaries without cancer, Black beneficiaries had a 32% lower likelihood of enrolling in hospice (ARR: 0.68, 95%CI: 0.59–0.79); however, there was no</p>

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Citation	Setting	Population	Design	Main Findings
			Epidemiology, and End Results (SEER) cancer registry data (2003–2015). This study was designed to examine racial disparities in hospice use overall and by disease group (cancer vs. non-cancer) and to assess whether racial differences in patient-provider communication accounted for observed disparities.	<p>significant difference in hospice enrollment between Black and white patients with cancer.</p> <p>This indicates that overall hospice use disparities between Black and white patients are largely driven by non-cancer patients.</p> <p>Patient-provider communication did not explain racial disparities in hospice use.</p> <p>Condition-specific differences in palliative care integration at the end-of-life may partly account for variations in hospice use disparities across disease groups.</p>
Sharma, R. K., Cameron, K. A., Chmiel, J. S., Von Roenn, J. H., Szmuiłowicz, E., Prigerson, H. G., & Penedo, F. J. (2015). Racial/Ethnic Differences in Inpatient Palliative Care Consultation for Patients with Advanced Cancer. <i>J Clin Oncol</i> , 33(32), 3802-3808. doi:10.1200/jco.2015.61.6458	US, Chicago, inpatient hospital	6,288 Patients with advanced cancer admitted to a Chicago hospital	Retrospective medical record review that evaluated the association between race/ethnicity and rates of inpatient palliative care consultation (IPCC).	<p>African Americans were more likely than whites to be referred to hospice (15.9 v 11.0 p &lt; 0.001).</p> <p>There was no difference between Hispanics and whites, or Hispanics and African Americans.</p> <p>Of those who received IPCC, there was no difference in referrals to hospice.</p>
Shenker, R. F., Elizabeth McLaughlin, M., Chino, F., & Chino, J. (2022). Disparities in place of death for patients with primary brain tumors and brain metastases in the USA. <i>Support Care Cancer</i> , 30(8), 6795-6805. doi:10.1007/s00520-022-07120-4	US, multiple	7,255,693 patients who died between 2003 and 2016 and has solid cancer (primary brain, brain metastases, or solid non-brain tumors) as their primary cause of death.	Retrospective cohort study using WONDER death certificate data to examine place of death.	<p>For all solid cancers, multivariate analysis:</p> <p>Black patients were less likely to die at home or in hospice than white patients (OR 0.71; CI 0.70, 0.71; P &lt; 0.001)</p> <p>Native American patients were less likely to die at home or in hospice than white patients (OR 0.85; CI 0.82, 0.87; P &lt; 0.001)</p> <p>Asian/Pacific Islander patients were less likely than whites to die at home in a hospice facility (OR 0.66; 0.64, 0.65; p &lt; 0.001)</p>

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Citation	Setting	Population	Design	Main Findings
Shepard, V., Al Snih, S., Burke, R., Downer, B., Kuo, Y. F., Malagaris, I., & Raji, M. (2022). Characteristics Associated with Mexican American Hospice Use: Retrospective Cohort Study Using the Hispanic Established Population for the Epidemiologic Study of the Elderly (H-EPESE). <i>Am J Hosp Palliat Care</i> , 10499091221110125. doi:10.1177/10499091221110125	US, Southwest, Hospice	Cohort 1: 970 Mexican Americans who died between 2004 and 2016  Cohort 2: 403 decedents of Cohort 1	Retrospective cohort study using the Hispanic Estimate Population for the Epidemiological Study of the Elderly (H-EPESE) and CMS data.  A second cohort added H-EPESE Survey data.	Mexican American are more likely to use hospice in 2016 than in 2008 (OR 1.88; 1.19=2.97; p<0.001)  38% of patients died within the first week of hospice care.  In the second cohort, no significant relationship was found between hospice use, marital status, high depressive symptoms, ADL disability, church attendance or seeing a doctor in the last year.  They concluded that health system factors were most likely driving the variation in hospice use and referral.
Sheu, J., Palileo, A., Chen, M. Y., Hoepner, L., Abulafia, O., Kanis, M. J., & Lee, Y. C. (2019). Hospice utilization in advanced cervical malignancies: An analysis of the National Inpatient Sample. <i>Gynecol Oncol</i> , 152(3), 594-598. doi:10.1016/j.ygyno.2018.12.016	US, Hospital	2073 admissions with a cervical cancer diagnosis that were discharged to hospice or died the hospital	Retrospective cohort study	Asian/Pacific Islander were more likely to die in the hospital than white patients (OR 2.24; 1.11-4.49; p 0.02)  There is no difference in place of death any other race (Black, Hispanic, Native American, Other) in likelihood of dying in the hospital rather than in hospice.  There are also regional differences in hospice use.  Rural patients are more like to die in the hospital than urban patients (OR 1.62; 1.12-2.36; p = 0.01)
Shin, J. A., Parkes, A., El-Jawahri, A., Traeger, L., Knight, H., Gallagher, E. R., & Temel, J. S. (2016). Retrospective evaluation of palliative care and hospice utilization in hospitalized patients with metastatic breast cancer. <i>Palliat Med</i> , 30(9),	US, Boston, inpatient hospital	123 patients hospitalized for the first time with a diagnosis of metastatic breast cancer at one tertiary care center.	Retrospective chart review	Less than one-third of patients (29%) were referred to hospice after their last hospitalization.

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Citation	Setting	Population	Design	Main Findings
854-861. doi:10.1177/0269216316637238				
Shiovitz, S., Bansal, A., Burnett-Hartman, A. N., Karnopp, A., Adams, S. V., Warren-Mears, V., & Ramsey, S. D. (2015). Cancer-Directed Therapy and Hospice Care for Metastatic Cancer in American Indians and Alaska Natives. <i>Cancer Epidemiol Biomarkers Prev</i> , 24(7), 1138-1143. doi:10.1158/1055-9965.Epi-15-0251	US, non-specific	388 American Indian/Alaska Native (AI/AN) and 85,871 non-Hispanic whites (NHW) metastatic cancer cases that were identified in Medicare enrollment files or Indian Health Service Care System records and linked to SEER Medicare data	Retrospective cohort study that used regression model to estimate odds ratios and hazard ratios for receipt of care.	Of those who died within two years, AI/ANs were less likely to enroll in hospice before death (OR 0.78; 95% CI; 0.61 – 0.99; P = 0.04) than NHWs. AN/AIs showed less hospice use across cancer types. Late hospice utilization was not significantly lower for AI/ANs than NHWs.
Shirsat, N., Hoe, D., & Enguidanos, S. (2021). Understanding Asian Indian Americans' Knowledge and Attitudes Toward Hospice Care. <i>Am J Hosp Palliat Care</i> , 38(6), 566-571. doi:10.1177/1049909120969128	US, Northern California, Hospice	82 Indian Americans aged 60 and over recruited from Indian cultural centers	Cross-sectional survey assessing attitudes towards hospice care and advance care planning.	10% of respondents know someone in hospice care.  10.4% answered 4 to 5 knowledge questions.  After being educated about hospice 69.6% of participants agreed that if a family member was extremely ill, they would consider enrolling them in hospice.  44% would not want strangers in their home, even if the stranger was with hospice.
Siler, S., Arora, K., Doyon, K., & Fischer, S. M. (2021). Spirituality and the Illness Experience: Perspectives of African American Older Adults. <i>Am J Hosp Palliat Care</i> , 38(6), 618-625. doi:10.1177/1049909120988280	US, Colorado, non-specific	Church members who identified as African Americans living with at least one chronic condition, and their family caregivers.	Qualitative analysis of 5 churches with African American older adults living with chronic health conditions.	Participants relied on their spirituality and church community to help them cope with illness.  Social struggles include mistrust of the health system and not being connected to adequate resources.  Churches were referred to as a trusted space for health resources as well as spiritual and social supports.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Soltoff, A., Purvis, S., Ravicz, M., Isaacson, M. J., Duran, T., Johnson, G., . . . Daubman, B. R. (2022). Factors Influencing Palliative Care Access and Delivery for Great Plains American Indians. <i>J Pain Symptom Manage</i> . doi:10.1016/j.jpainsymman.2022.05.011	US, Great Plains reservation land, end-of-life care	21 specialty and 17 primary care clinicians caring for American Indians in the Great Plains.	Qualitative analysis of interview data that identified themes associated with palliative care delivery and access	Themes identified were health care system operations (e.g., insufficient availability of hospice), geography (e.g., travel distances), workforce elements (e.g., cultural familiarity), and historical trauma and racism  The authors suggest increasing availability of hospice that can be provided on the reservation or in local Indian Health Service facilities; engaging community health workers to help families navigate the health care system, visit the home, increase AI/AN workforce, and improve cultural understanding; improving the “trustworthiness of the system” by investing in the workforce and giving clinicians access to cultural training and engaging Tribal Nations in health system changes.
Starr, L. T., Bullock, K., Washington, K., Aryal, S., Parker Oliver, D., & Demiris, G. (2022). Anxiety, Depression, Quality of Life, Caregiver Burden, and Perceptions of Caregiver-Centered Communication among Black and White Hospice Family Caregivers. <i>J Palliat Med</i> , 25(4), 596-605. doi:10.1089/jpm.2021.0302	US, Northeast and Midwest, hospice	722 Black and white hospice family caregivers that were over 18	Secondary analysis of baseline data from two randomized clinical trials to compare caregiver experience between Black and white caregivers	There were demographic and socioeconomic differences between the Black and white caregivers, but they experience similarly high levels of anxiety, depression, burden, and perception of hospice communication.
Starr, L. T., Ulrich, C. M., Junker, P., Appel, S. M., O'Connor, N. R., & Meghani, S. H. (2020). Goals-of-Care Consultation Associated with Increased Hospice Enrollment Among Propensity-Matched Cohorts of Seriously Ill African American and White Patients. <i>J Pain Symptom Manage</i> , 60(4), 801-810.	US, Northeast, Hospital	11,158 African American or 23,994 white propensity-score matched patients over 18 not admitted for conditions other than childbirth or rehabilitation, who weren't hospitalized at the end of the study, and	Secondary analysis of a retrospective cohort study that used stratified propensity-score matching to compare enrollment in hospice at discharge between African American and white patients with and without palliative care consultations (PCCs)	Both whites and African Americans who received a PCC were more likely to be discharged to hospice.  African Americans were 15% more likely (2.4% vs 36%; p < 0.0001) and whites were 14% more likely (3.0% v 42.7%, p < 0.0001)



Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
doi:10.1016/j.jpainsymman.2020.05.020		who did not die during index hospitalization.		
Starr, L. T., Ulrich, C. M., Perez, G. A., Aryal, S., Junker, P., O'Connor, N. R., & Meghani, S. H. (2021). Hospice Enrollment, Future Hospitalization, and Future Costs Among Racially and Ethnically Diverse Patients Who Received Palliative Care Consultation. <i>Am J Hosp Palliat Care</i> , 39(6), 619-632. doi:10.1177/10499091211034383 <sup>11</sup>	US, Northeast, Hospital	1,306 patients who received a palliative care consultation at an academic hospital	Secondary analysis of a retrospective cohort study	Medicaid patients were 42% less likely to than non-Medicaid patients to be discharged to hospice (AOR=0.59 95% CI 0.37 -0.90; P=0.02).  Race and ethnicity did not predict hospice enrollment among patients who received a palliative care consultation.
Stein, G. L., Berkman, C., O'Mahony, S., Godfrey, D., Javier, N. M., & Maingi, S. (2020). Experiences of Lesbian, Gay, Bisexual, and Transgender Patients and Families in Hospice and Palliative Care: Perspectives of the Palliative Care Team. <i>J Palliat Med</i> , 23(6), 817-824. doi:10.1089/jpm.2019.0542	US, multiple	865 hospice and palliative care providers.	Mixed-methods Cross-sectional study with data collected via an online survey	53.6% of respondents believed that lesbian, gay, or bisexual (LGB) patients were more likely than non-LGB patients to experience discrimination.  23.7% observed discriminatory care.  64.3% believed transgender patients were more likely than non-transgender patients to experience discrimination.  21.3% observed discrimination to transgender patients.  15% observed the spouse/partner of LGBT patients have their treatment decisions disregarded or minimized, be denied or have limited access to the patient, and be denied private time.  14.3% observed the spouse or partner being treated disrespectfully.

<sup>11</sup> Abt Staff identified this article in both the SDOH and Health Equity literature reviews.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Stephens, S. J., Chino, F., Williamson, H., Niedzwiecki, D., Chino, J., & Mowery, Y. M. (2020). Evaluating for disparities in place of death for head and neck cancer patients in the United States utilizing the CDC WONDER database. <i>Oral Oncol</i> , 102, 104555. doi:10.1016/j.oraloncology.2019.104555	US, non-specific	101,963 patients who died of head and neck cancers	Retrospective study using CDC WONDER Underlying Cause of Death database with using sample proportions and multivariate logistic regression.	Caucasian patients were more likely to die at home or in hospice than patients of other races [59.5% v 50.8%; mean difference 8.7%; 95% CI 6.3%, 11.0%)  African Americans and Asian/Pacific Islander were less likely to die at home or in hospice than Caucasians. [African Americans OR 0.73; CI 0.65 – 0.82; Asian/Pacific Islander OR 0.66; CI 0.54-0.81)
Stevens, E. E., & Abrahm, J. L. (2019). Adding Silver to the Rainbow: Palliative and End-of-Life Care for the Geriatric LGBTQ Patient. <i>J Palliat Med</i> , 22(5), 602-606. doi:10.1089/jpm.2018.0382	US, Hospice and Palliative Care	67-year-old male with metastatic ovarian cancer who was assigned female at birth.	Case study	The patient did not want to disclose his gender identity to friends or family.  His spouse and he were legally married, but the current state of residence did not recognize the marriage, and his spouse was unable to take FMLA.  Medical teams were vigilant in using inclusive language and his preferred terms. The cancer was referred to as a “germ cell tumor”  Home hospice care was not possible due to insurance barriers (he did not have Medicare coverage) and his spouse inability to take FMLA he was unable to received hospice.  They compiled a list of clinical recommendations for sexual and gender minorities in the hospice and palliative care settings (see Table 1)
Sutherland, N., Ward-Griffin, C., McWilliam, C., & Stajduhar, K. (2016). Gendered Processes in Hospice Palliative Home Care for Seniors With Cancer and Their Family Caregivers.	US, home hospice	25 patients with terminal cancer	A qualitative study with in-depth interviews, 9 observed agency home visits, and 12 institutional documents qualitative study comprised of 25 in-depth interviews, 9 observed agency home visits, and 12 institutional documents found that gendered	They found that gendered power dynamics are present among patients, caregivers, and providers. For example,  in some cases, nurses in resource-constrained settings shifted care responsibilities to female (but not male) caretakers and pushed back more

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
<p><i>Qual Health Res</i>, 26(7), 907-920. doi:10.1177/1049732315609571</p>			<p>power dynamics are present among patients, caregivers, and providers. For example:</p>	<p>against female caretakers' boundaries than male caretakers.</p> <p>Male caretakers discounted the professional status of nurses as compared to physicians.</p> <p>Female nurses and caregivers focused care efforts on female over male clients.</p> <p>To promote equity, the authors suggest providers and policymakers recognize gender as a prevalent social determinant of health.</p>
<p>Taylor, J. S., Brown, A. J., Prescott, L. S., Sun, C. C., Ramondetta, L. M., &amp; Bodurka, D. C. (2016). Dying well: How equal is end of life care among gynecologic oncology patients? <i>Gynecol Oncol</i>, 140(2), 295-300. doi:10.1016/j.ygyno.2015.12.012</p>	US, Texas, hospital	189 gynecologic oncology patients	Retrospective analysis of medical records using	<p>Non-white race increased the odds of dying without hospice (OR 3.07, 95% CI 1.27,2.46).</p> <p>Non-white patients who did enroll, did so earlier than white patients (42 vs 47 days before death, p=0.054).</p> <p>Most patients, regardless of race, preferred to die at home (74% of white patients; 61% of Black patients; 61% of Hispanic patients, 57% of Asian patients).</p> <p>Black patients had the highest percentage of inpatient hospice deaths (23%) and Asian patients and had the highest percentage of hospital deaths (29%).</p> <p>There were no racial differences in other medical outcomes (admissions, receipt of chemo, ER visits, aggressive medical care, use of supportive care).</p> <p>Non-white patients were less likely to have medical power of attorney or living will documentation (24% v 76%, p=0.09) even if enrolled in hospice (12% v 31%; p=0.07)</p>

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Taylor, J. S., Rajan, S. S., Zhang, N., Meyer, L. A., Ramondetta, L. M., Bodurka, D. C., . . . Giordano, S. H. (2017). End-of-Life Racial and Ethnic Disparities Among Patients with Ovarian Cancer. <i>J Clin Oncol</i> , 35(16), 1829-1835. doi:10.1200/jco.2016.70.2894	US, Texas, hospital	3,666 patients with ovarian cancer	Retrospective study using the Cancer Texas Registry-Medicare data	Those of Hispanic ethnicity were less likely to enroll in hospice than white people (OR 0.78; CI 0.62, 0.97).  Those of Black race were less likely to enroll in hospice than white patients (OR 0.74; CI 0.55, 0.98).  No racial or ethnic groups were more likely to have multiple hospice enrollments. Those who did not die while enrolled in hospice were similar in terms on race/ethnicity.
Taylor, J. S., Zhang, N., Rajan, S. S., Chavez-MacGregor, M., Zhao, H., Niu, J., . . . Giordano, S. H. (2019). How we use hospice: Hospice enrollment patterns and costs in elderly ovarian cancer patients. <i>Gynecol Oncol</i> , 152(3), 452-458. doi:10.1016/j.ygyno.2018.10.041	US, Texas, Hospital	2,331 patients with ovarian cancer	Retrospective study using the Cancer Texas Registry-Medicare data	Black patients were more likely to unenroll from hospice prior to death than white patients (OR 2.07; CI 1.15-3.73; p=0.02).  There was no difference in disenrollment for other racial/ethnic groups and whites.
Townsend, A., March, A. L., & Kimball, J. (2017). Can Faith and Hospice Coexist: Is the African American Church the Key to Increased Hospice Utilization for African Americans? <i>J Transcult Nurs</i> , 28(1), 32-39. doi:10.1177/1043659615600764	US, hospice	34 members of African American churches	Focus group to elicit beliefs about hospice care	Lack of knowledge of hospice services and spiritual beliefs were the top two contributing factors to underutilization of hospice care.  Findings support partnerships between hospices and African American churches to provide hospice education to the African America community.  Participants either believed that the hospice provider needed to understand and support their spiritual beliefs, or that it was necessary for their hospice provider to share their specific religious beliefs.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
				<p>While some participants felt cultural competence was necessary, others felt it was unrelated to the delivery of hospice care.</p> <p>Participants would be receptive to information about hospice even if the educator did not understand African American based religious constructs.</p> <p>The authors recommend that local hospices arrange regular information sessions at African American churches.</p>
Turkman, Y. E., Williams, C. P., Jackson, B. E., Dionne-Odom, J. N., Taylor, R., Ejem, D., . . . Rocque, G. B. (2019). Disparities in Hospice Utilization for Older Cancer Patients Living in the Deep South. <i>J Pain Symptom Manage</i> , 58(1), 86-91. doi:10.1016/j.jpainsymman.2019.04.006	US, Deep South, Cancer Hospital	12,725 University of Alabama Cancer Center Network who were Medicare decedents	Retrospective cohort study	<p>Non-white patients had a 24% increased risk of no hospice utilization compared to whites (Unadjusted Relative Risk [URR] 1.24; 95% CI 1.17 – 1.32).</p> <p>Males has a 15% increased risk of no hospital utilization compared to females (URR 1.1595% CI 1.09 – 1.21).</p> <p>Patients seen at hospitals with inpatient palliative care beds has a 15% increased risk for no hospice utilization compared to those without (URR 1.15; 95% CI 1.10 – 1.21).</p> <p>Non-white patients had a 16% decreased risk of receiving late hospice compared to white patients (URR 0.84; 95% CI 0.73 – 0.97).</p>
Wallace, C. L. (2017). Examining hospice enrollment through a novel lens: Decision time. <i>Palliat Support Care</i> , 15(2), 168-175. doi:10.1017/s1478951516000493	US, South, hospice	90 hospice patients or their primary decision maker	Cross-sectional study exploring the time between initial referral to hospice and enrollment in hospice	<p>White patients took longer to enroll in hospice than nonwhites (60 days vs 8 days (t -2.75; df 88; p = 0.01).</p> <p>Those with higher incomes (&gt; \$50,000) took longer to enroll in hospice than those with lower</p>

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Citation	Setting	Population	Design	Main Findings
				<p>incomes (114 days vs 25 days; <math>t = -283</math>; <math>df = 85</math>; <math>p = 0.007</math>).</p> <p>Those receiving treatment took longer to enroll than those not in treatment (166 days vs 23 days).</p> <p>Those who were referred by a family member took longer to enroll than those referred by a physician (89 days vs 39 days; <math>t = -2.39</math>; <math>df = 88</math>; <math>p = 0.019</math>).</p>
<p>Wang, H., Qiu, F., Boilesen, E., Nayar, P., Lander, L., Watkins, K., &amp; Watanabe-Galloway, S. (2016). Rural-Urban Differences in Costs of End-of-Life Care for Elderly Cancer Patients in the United States. <i>J Rural Health, 32</i>(4), 353-362. doi:10.1111/jrh.12160</p>	US, multiple end-of-life	175,181 elderly adults with lung, colorectal, breast, or prostate cancer who died in 2008	Retrospective cohort study using Medicare claims data	Rural cancer patients were less likely to use hospice for all cancer types (coefficient range 0.1 to 0.08; $p \leq 0.01$ ).
<p>Wang, S. Y., Aldridge, M. D., Canavan, M., Cherlin, E., &amp; Bradley, E. (2016). Continuous Home Care Reduces Hospice Disenrollment and Hospitalization After Hospice Enrollment. <i>J Pain Symptom Manage, 52</i>(6), 813-821. doi:10.1016/j.jpainsymman.2016.05.031</p>	US, hospice	All fee-for-service Medicare beneficiaries older than 66 who died in 2011; 3592 hospices	Retrospective cohort analysis	<p>White patients are much more likely to receive continuous home care (CHC) than other races/ethnicities (85.4% vs 6.1% [Black], 6.7% [Hispanic], 1.8% [other]; <math>p &lt; 0.001</math>).</p> <p>CHC care use was associated with a decreased likelihood of hospice disenrollment (CHC 10.6% vs 3.7% <math>p &lt; 0.001</math>).</p>
<p>Washington, K. T., Oliver, D. P., Smith, J. B., Kruse, R. L., Meghani, S. H., &amp; Demiris, G. (2019). A Comparison of Rural and Urban Hospice Family Caregivers' Cancer Pain Knowledge and Experience. <i>J Pain Symptom Manage, 58</i>(4), 685-689.</p>	US, Midwest, hospice	196 Adult Family Caregivers (FCGs) from one of 6 hospices	Substudy of an ongoing National Cancer Institute cluster randomized crossover pragmatic trial. Substudy compares rural and urban hospice FCGs cancer pain knowledge and experience using the Family Pain Questionnaire	Rural FCGs knowledge of pain management principles was worse than their urban counterparts (Multiple Regression Model [MRM] estimate -4.95; CI -8.91 – 1.01; $p = 0.01$ ) however rural FCGs experiences when managing cancer pain were not statistically significantly different.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
doi:10.1016/j.jpainsymman.2019.07.010				
Wasp, G. T., Alam, S. S., Brooks, G. A., Khayal, I. S., Kapadia, N. S., Carmichael, D. Q., . . . Barnato, A. E. (2020). End-of-life quality metrics among Medicare decedents at minority-serving cancer centers: A retrospective study. <i>Cancer Med</i> , 9(5), 1911-1921. doi:10.1002/cam4.2752	US, cancer centers	110,119 Medicare beneficiaries who received treatment at one of 54 cancer centers and had poor prognosis cancers	Retrospective study cohort study	Minority patients were more likely to receive no referral to hospice (39.5% v 37%; CI 0.03) when looking across hospitals. Within hospitals, there was no significant differences within hospitals.
Weaver, M. S., Lukowski, J., Wichman, B., Navaneethan, H., Fisher, A. L., & Neumann, M. L. (2021). Human Connection and Technology Connectivity: A Systematic Review of Available Telehealth Survey Instruments. <i>J Pain Symptom Manage</i> , 61(5), 1042-1051.e1042. doi:10.1016/j.jpainsymman.2020.10.010	US, hospice	3,100 articles focused on available survey instruments that assess telehealth interactions, the constructs covered, and the patient populations surveyed.	Meta-analysis conforming to PRISMA guidelines	Studies focused on validation and utilization of telehealth assessment measures found that they underrepresented adolescents, geriatric populations, non-white or low-income populations, and those without a postsecondary education.
Wilkie, D. J., Ezenwa, M. O., Yao, Y., Gill, A., Hipp, T., Shea, R., . . . Wang, Z. W. (2017). Pain Intensity and Misconceptions Among Hospice Patients with Cancer and Their Caregivers: Status After 2 Decades. <i>Am J Hosp Palliat Care</i> , 34(4), 318-324. doi:10.1177/1049909116639612	US, Chicago, home hospice	161 patients who received home hospice, had cancer, had their worst pain in the past 24 hours ( $\geq 3$ out of 10), were 18 or older, were English or Spanish literate, had caregiver willing to participate, and had a Palliative performance scale $> = 30$ .	Cross-sectional study using baseline data from an ongoing RCT or patient and lay caregiver dyads receiving hospice care.	Hispanic patients had higher scores on the Barrier Questionnaire 13, which determines perceived barriers to pain management, than non-Hispanic patients (mean score on 3.09 v 2.56) $p=0.05$ . For caregivers, there was no difference.  Minority caregivers scored higher on the BQ 13 than their non-Hispanic white counterparts (2.86 v 2.55; $p = 0.03$ ). For patients, there was no difference.  There was no difference between Caucasians and African Americans, or males and females.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Worster, B., Bell, D. K., Roy, V., Cunningham, A., LaNoue, M., & Parks, S. (2018). Race as a Predictor of Palliative Care Referral Time, Hospice Utilization, and Hospital Length of Stay: A Retrospective Noncomparative Analysis. <i>Am J Hosp Palliat Care</i> , 35(1), 110-116. doi:10.1177/1049909116686733	US, Philadelphia,	3207 patients from referred to the palliative care service inpatient team between 2006 and 2015 a single, large, urban medical center.	Retrospective non-comparative analysis assessing if race predicts time to palliative care consult, hospice, or overall length of hospital stay for inpatient palliative care patients using archival data	Race was not significantly associated with hospice enrollment. They analyzed Black and Asian patients relative to white patients and Hispanic patients relative to white patients.
Yaqoob, Z. J., Al-Kindi, S. G., & Zein, J. G. (2017). Trends and Disparities in Hospice Use Among Patients Dying of COPD in the United States. <i>Chest</i> , 151(5), 1183-1184. doi:10.1016/j.chest.2017.02.030	US, hospice	1,242,350 patients who died of COPD, were aged 50 or older, and were in the US mortality files	Retrospective cohort study	Female patients are more likely to die in hospice (6.1% v 5.7%; p < 0.001).  Whites were more likely to die in hospice than were African American (6.1% v 4.2%; p < 0.001).  Dying in hospice had regional variation: Northeast 4.1%, Midwest 4.7%, South 8.1%, West 4.7% (p < 0.001).



## Other Recent Hospice Literature

Other Recent Hospice Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Aldridge, M. D., Hunt, L., Husain, M., Li, L., & Kelley, A. (2022). Impact of Comorbid Dementia on Patterns of Hospice Use. <i>J Palliat Med</i> , 25(3), 396-404. doi:10.1089/jpm.2021.0055	US, hospice, unspecified	3,123 Medicare beneficiaries who died in hospice	Pooled cross-section analysis of Health and Retirement Study data linked with Medicare claims	Approximately 45% of hospice patients have primary or co-morbid dementia. Co-morbid dementia was associated with hospice stays longer than 6 months (AOR 1.52; 95% CI 1.11 – 2.09) and hospice disenrollment after 6 months (AOR 2.55; 95% CI 1.43 – 4.55)
Artico, M., Piredda, M., D'Angelo, D., Di Nitto, M., Giannarelli, D., Marchetti, A., . . . De Marinis, M. G. (2022). Palliative care organization and staffing models in residential hospices: Which makes the difference? <i>Int J Nurs Stud</i> , 126, 104135. doi:10.1016/j.ijnurstu.2021.104135	Italy, residential hospice	Adult patients enrolled in one of 13 residential hospices.	Secondary analysis of a multicenter prospective longitudinal observational study to analyze the predictive power of staffing, structure, and process indicators on optimal control of clinically significant symptoms	A staffing ratio of 19% physicians, 23% nurse assistants, and 58% registered nurses was most likely to control patient symptoms (pain, nausea, shortness of breath, feeling sad, feel nervous, and overall feeling).  Physicians and nurses with palliative care qualifications were associated with improved patient outcomes.
Demiris, G., Oliver, D. P., Washington, K. T., Chadwick, C., Voigt, J. D., Brotherton, S., & Naylor, M. D. (2022). Examining spoken words and acoustic features of therapy sessions to understand family caregivers' anxiety and quality of life. <i>Int J Med Inform</i> , 160, 104716. doi:10.1016/j.ijmedinf.2022.104716	US, hospice	124 audio files of discussion between family caregivers of hospice patients	Assessment of how well a machine learning algorithm using an automated speech recognition system and trained to use both spoken word and acoustic features correlates to anxiety and quality of life assessed by validated instruments.	Machine learning that uses automated speech-to-text transcription and acoustic features improved accuracy. Incorporating acoustic features in machine learning improved precision (86% to 92%) accuracy (81% - 89%), and recall (78% - 88%).  Machine learning techniques can indicate improvements in anxiety and quality of life measures with a reasonable degree of accuracy and can be used to inform the design of tailored therapy chatbots.

Other Recent Hospice Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Harrison, K. L., Cenzer, I., Ankuda, C. K., Hunt, L. J., & Aldridge, M. D. (2022). Hospice Improves Care Quality for Older Adults with Dementia in Their Last Month of Life. <i>Health Aff (Millwood)</i> , 41(6), 821-830. doi:10.1377/hlthaff.2021.01985	US, hospice	2,059 National Health and Aging Trends (NHATS) participants aged 70 or older	NHATS study and Medicare claims to determine the impact of hospice enrollment on caregiver on proxy perceptions of care quality in the last month of life using predicted probability.	Proxies of people with dementia enrolled in hospice (compared to proxies of patients with dementia not enrolled in hospice) were more likely to report the care to be excellent (predicted probability 52% v 41.4%; p=0.012), more often reported having anxiety and sadness managed (67% v 46%), and less often reported changes in care settings in the last 3 days of life (10% v 25%).  There we no differences between proxy ratings for hospice for patients with and without dementia.
He, M., O'Connor, S. J., Qu, H., Menachemi, N., & Shewchuk, R. M. (2021). Hospice inpatient services provision, utilization, and financial performance. <i>Health Care Manage Rev</i> , 46(4), E68-e76. doi:10.1097/hmr.0000000000000303	US, inpatient hospice	9,929 hospices (537 did not provide inpatient services, 1,197 offered inpatient services by staff, 7,811 offered inpatient services by arrangement	Longitudinal retrospective analysis of CMS hospice cost reports, provider of service files, and areas resource health files to explore the relationship between inpatient hospice, hospice use, and financial performance.	Hospice with staff offering inpatient services had shorter lengths of staff and lower total operating margins (TOM) (b = -0.063, p < 0.05; b = -0.022, p < 0.05).  Hospices that offer inpatient services both by staff and under arrangement had a lower return on assets (ROA) than hospices that don't offer inpatient services (b = -0.073; p < 0.05).

Other Recent Hospice Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Hughes, M. C., Vernon, E., Kowalczyk, M., & Zhou, H. (2022). Experiences of caregivers and hospice leaders with telehealth for palliative care: a mixed methods study. <i>Ann Palliat Med</i> , 11(7), 2302-2313. doi:10.21037/apm-21-3899	US, Hospice unspecified	595 caregivers of seriously ill patients and 25 hospice leaders	Cross-sectional survey (caregivers) and interviews (hospice leaders)	<p>Those with good internet, better access to video, and under 65 were more satisfied with their telehealth. The general outlook from hospice leaders is that telehealth is positive and hopeful</p> <p>Patients mentioned that having training or instructions helped, as did having a family member present and customer service available.</p> <p>There is still confusion over telehealth policies and concern about abuse. For example, a hospice may only do telephone calls instead of true audio-visual telehealth visits, or family drug diversion may become more prevalent if informal caregivers are given more control over medication.</p> <p>Telehealth was reported to have enhanced usual care for activities such as addressing patient/family concerns, explaining lab results, and basic diagnostic activities. Interviewees also reported positive experiences with bereavement support, enhancing connections with out-of-town family members.</p> <p>Thoughts on virtual social workers or spiritual counselor services was more mixed, with some noting they could reach more patients and fewer people would need to visit the patient's home, but other felt these areas are difficult to do well within an in-person connection.</p>

Other Recent Hospice Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Lam, M. B., Riley, K. E., Zheng, J., Orav, E. J., Jha, A. K., & Burke, L. G. (2021). Healthy days at home: A population-based quality measure for cancer patients at the end of life. <i>Cancer</i> , 127(22), 4249-4257. doi:10.1002/cncr.33817	US, multiple	284,751 Medicare patients with who died of cancer	Calculation and analysis of a novel population-based measure called Health Days at Home	<p>The measure calculates Healthy Days at Home (HDAH) in the last 180 days before death. It subtracts days spent in inpatient or outpatient emergency departments (including observations stays), skilled nursing facilities, inpatient psychiatry, inpatient rehabilitation, long-term hospitals, and inpatient hospice.</p> <p>Days on home hospice and home health were considered HDAH.</p> <p>Time spent in inpatient and at skilled nursing facilities resulted in the most substantial HDAH reductions.</p> <p>Males had fewer HDAHs than females (153 v 156; <math>p &lt; 0.001</math>), Medicaid patients had fewer HDAH than non-Medicaid (152 v 155; <math>p &lt; 0.001</math>).</p>

## Appendix IV: References

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- 2021 Massachusetts State Hospice Report: 2019 Medicare Information with 2018 Comparisons Using Annual Files. (2021, 02/23/2021). State Hospice Organization.
- Abbas, A., Madison Hyer, J., & Pawlik, T. M. (2021). Race/Ethnicity and County-Level Social Vulnerability Impact Hospice Utilization Among Patients Undergoing Cancer Surgery. *Ann Surg Oncol*, 28(4), 1918-1926. <https://doi.org/10.1245/s10434-020-09227-6>
- AbuDagga, A., Mara, C. A., Carle, A. C., & Weech-Maldonado, R. (2018). Factor Structure of the Cultural Competence Items in the National Home and Hospice Care Survey. *Med Care*, 56(4), e21-e25. <https://doi.org/10.1097/mlr.0000000000000714>
- Acquaviva, Kimberly D. *LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice*. Harrington Park Press, 2017.
- Aldridge, M. D., Hunt, L., Husain, M., Li, L., & Kelley, A. (2022). Impact of Comorbid Dementia on Patterns of Hospice Use. *J Palliat Med*, 25(3), 396-404. doi:10.1089/jpm.2021.0055
- Artico, M., Piredda, M., D'Angelo, D., Di Nitto, M., Giannarelli, D., Marchetti, A., . . . De Marinis, M. G. (2022). Palliative care organization and staffing models in residential hospices: Which makes the difference? *Int J Nurs Stud*, 126, 104135. doi:10.1016/j.ijnurstu.2021.104135
- Bazargan, M., Cobb, S., Assari, S., & Kibe, L. W. (2021). Awareness of Palliative Care, Hospice Care, and Advance Directives in a Racially and Ethnically Diverse Sample of California Adults. *Am J Hosp Palliat Care*, 38(6), 601-609. <https://doi.org/10.1177/1049909121991522>
- Beltran, S. J. (2018). Hispanic Hospice Patients' Experiences of End-Stage Restlessness. *J Soc Work End Life Palliat Care*, 14(1), 93-109. <https://doi.org/10.1080/15524256.2018.1437589>
- Beltran, S. J. (2022). Latino Families' Decisions to Accept Hospice Care. *Am J Hosp Palliat Care*, 39(2), 152-159. <https://doi.org/10.1177/10499091211042336>
- Beresford, L. (2020). Programs Have Stepped Up to New Roles--Where They've Had Sufficient Staffing. *American Academy of Palliative and Hospice Medicine*. <http://aahpm.org/quarterly/fall-20-feature>. Accessed August 26, 2022
- Booker, S. Q., Herr, K. A., & Wilson Garvan, C. (2020). Racial Differences in Pain Management for Patients Receiving Hospice Care. *Oncol Nurs Forum*, 47(2), 228-240. <https://doi.org/10.1188/20.Onf.228-240>

- Boucher, N. A., & Johnson, K. S. (2021). Cultivating Cultural Competence: How Are Hospice Staff Being Educated to Engage Racially and Ethnically Diverse Patients? *Am J Hosp Palliat Care*, 38(2), 169-174. <https://doi.org/10.1177/1049909120946729>
- Cagle, J. G., LaMantia, M. A., Williams, S. W., Pek, J., & Edwards, L. J. (2016). Predictors of Preference for Hospice Care Among Diverse Older Adults. *Am J Hosp Palliat Care*, 33(6), 574-584. <https://doi.org/10.1177/1049909115593936>
- Cagle, J. G., Van Dussen, D. J., Culler, K. L., Carrion, I., Hong, S., Guralnik, J., & Zimmerman, S. (2016). Knowledge About Hospice: Exploring Misconceptions, Attitudes, and Preferences for Care. *Am J Hosp Palliat Care*, 33(1), 27-33. <https://doi.org/10.1177/1049909114546885>
- Candrian, C., & Cloyes, K. G. (2021). "She's Dying and I Can't Say We're Married?": End-of-Life Care for LGBT Older Adults. *Gerontologist*, 61(8), 1197-1201. <https://doi.org/10.1093/geront/gnaa186>
- Carrion, I. V., Cagle, J. G., Van Dussen, D. J., Culler, K. L., & Hong, S. (2015). Knowledge About Hospice Care and Beliefs About Pain Management: Exploring Differences Between Hispanics and Non-Hispanics. *Am J Hosp Palliat Care*, 32(6), 647-653. <https://doi.org/10.1177/1049909114536023>
- Check, D. K., Samuel, C. A., Rosenstein, D. L., & Dusetzina, S. B. (2016). Investigation of Racial Disparities in Early Supportive Medication Use and End-of-Life Care Among Medicare Beneficiaries with Stage IV Breast Cancer. *J Clin Oncol*, 34(19), 2265-2270. <https://doi.org/10.1200/jco.2015.64.8162>
- Cloyes, K. G., Jones, M., Gettens, C., Wawrzynski, S. E., Bybee, S., Tay, D. L., Reblin, M., & Ellington, L. (2022). Providing home hospice care for LGBTQ+ patients and caregivers: Perceptions and opinions of hospice interdisciplinary care team providers. *Palliat Support Care*, 1-9. <https://doi.org/10.1017/s1478951522000657>
- Colclough, Y. Y. (2017). Native American Death Taboo: Implications for Health Care Providers. *Am J Hosp Palliat Care*, 34(6), 584-591. <https://doi.org/10.1177/1049909116638839>
- Colclough, Y. Y., & Brown, G. M. (2019). Moving Toward Openness: Blackfeet Indians' Perception Changes Regarding Talking About End of Life. *Am J Hosp Palliat Care*, 36(4), 282-289. <https://doi.org/10.1177/1049909118818255>
- Demiris, G., Oliver, D. P., Washington, K. T., Chadwick, C., Voigt, J. D., Brotherton, S., & Naylor, M. D. (2022). Examining spoken words and acoustic features of therapy sessions to understand family caregivers' anxiety and quality of life. *Int J Med Inform*, 160, 104716. doi:10.1016/j.ijmedinf.2022.104716
- Dhingra, L., et al. (2022). "Low Hospice Utilization in New York State: Comparisons Using National Data." *J Pain Symptom Manage* 63(4): 522-529.

- Dillon, P. J. and A. Basu (2016). "African Americans and Hospice Care: A Culture-Centered Exploration of Enrollment Disparities." *Health Commun* 31(11): 1385-1394.
- Dressler, G., Cicolello, K., & Anandarajah, G. (2021). "Are They Saying It How I'm Saying It?" A Qualitative Study of Language Barriers and Disparities in Hospice Enrollment. *J Pain Symptom Manage*, 61(3), 504-512. doi:10.1016/j.jpainsymman.2020.08.019
- Du, X. L., Parikh, R. C., & Lairson, D. R. (2015). Racial and geographic disparities in the patterns of care and costs at the end of life for patients with lung cancer in 2007-2010 after the 2006 introduction of bevacizumab. *Lung Cancer*, 90(3), 442-450. doi:10.1016/j.lungcan.2015.09.017
- Elting, L. S., Liao, K. P., Giordano, S. H., & Guadagnolo, B. A. (2020). Hospice enrollment among cancer patients in Texas covered by Medicare managed care and traditional fee-for-service plans: a statewide population-based study. *Support Care Cancer*, 28(7), 3351-3359. doi:10.1007/s00520-019-05142-z
- Fair, T. M. (2021). Lessons on Older LGBTQ Individuals' Sexuality and Spirituality for Hospice and Palliative Care. *Am J Hosp Palliat Care*, 38(6), 590-595. doi:10.1177/1049909120978742
- Fink, R. M., Kline, D. M., Siler, S., & Fischer, S. M. (2020). Apoyo con Cariño: A Qualitative Analysis of a Palliative Care-Focused Lay Patient Navigation Intervention for Hispanics With Advanced Cancer. *J Hosp Palliat Nurs*, 22(4), 335-346. doi:10.1097/njh.0000000000000666
- Fischer, S. M., Kline, D. M., Min, S. J., Okuyama-Sasaki, S., & Fink, R. M. (2018). Effect of Apoyo con Cariño (Support With Caring) Trial of a Patient Navigator Intervention to Improve Palliative Care Outcomes for Latino Adults With Advanced Cancer: A Randomized Clinical Trial. *JAMA Oncol*, 4(12), 1736-1741. doi:10.1001/jamaoncol.2018.4014
- Foley, R. N., Sexton, D. J., Drawz, P., Ishani, A., & Reule, S. (2018). Race, Ethnicity, and End-of-Life Care in Dialysis Patients in the United States. *J Am Soc Nephrol*, 29(9), 2387-2399. doi:10.1681/asn.2017121297
- Fornhed, M. L. C., et al. (2020). "Families' Decision Making at End of Life in Rural Appalachia." *J Hosp Palliat Nurs* 22(3): 188-195.
- Forst, D., Adams, E., Nipp, R., Martin, A., El-Jawahri, A., Aizer, A., & Jordan, J. T. (2018). Hospice utilization in patients with malignant gliomas. *Neuro Oncol*, 20(4), 538-545. doi:10.1093/neuonc/nox196
- Gerlach, L. B., Kales, H. C., Kim, H. M., Zhang, L., Strominger, J., Covinsky, K., . . . Maust, D. T. (2021). Prevalence of psychotropic and opioid prescribing among hospice beneficiaries in the United States, 2014-2016. *J Am Geriatr Soc*, 69(6), 1479-1489. doi:10.1111/jgs.17085

- Haines, K. L., Jung, H. S., Zens, T., Turner, S., Warner-Hillard, C., & Agarwal, S. (2018). Barriers to Hospice Care in Trauma Patients: The Disparities in End-of-Life Care. *Am J Hosp Palliat Care*, 35(8), 1081-1084. doi:10.1177/1049909117753377
- Haines, K. L., Kawano, B. A., & Agarwal, S. K. (2021). Disparities in Asians' Hospice Utilization and Location of Death. *Am Surg*, 31348211034756. doi:10.1177/00031348211034756
- Haines, K. L., Nguyen, B. P., Antonescu, I., Freeman, J., Cox, C., Krishnamoorthy, V., . . . Agarwal, S. (2021). Insurance Status and Ethnicity Impact Health Disparities in Rates of Advance Directives in Trauma. *Am Surg*, 31348211011115. doi:10.1177/00031348211011115
- Hamel, L., Wu, B., & Brodie M. 2017. Views and Experiences with End-of-Life Medical Care in Japan, Italy, the United States, and Brazil: A Cross-Country Survey. KFF. <https://www.kff.org/other/report/views-and-experiences-with-end-of-life-medical-care-in-japan-italy-the-united-states-and-brazil-a-cross-country-survey/>
- Harrison, K. L., Cenzer, I., Ankuda, C. K., Hunt, L. J., & Aldridge, M. D. (2022). Hospice Improves Care Quality for Older Adults with Dementia in Their Last Month of Life. *Health Aff (Millwood)*, 41(6), 821-830. doi:10.1377/hlthaff.2021.01985
- Hart, A. S., Matthews, A. K., Arslanian-Engoren, C., Patil, C. L., Krassa, T. J., & Bonner, G. J. (2022). Experience of African American Surrogate Decision Makers of Patients With Dementia. *J Hosp Palliat Nurs*, 24(1), 84-94. doi:10.1097/njh.0000000000000822
- He, M., O'Connor, S. J., Qu, H., Menachemi, N., & Shewchuk, R. M. (2021). Hospice inpatient services provision, utilization, and financial performance. *Health Care Manage Rev*, 46(4), E68-e76. doi:10.1097/hmr.0000000000000303
- Helsel, D., Thao, K. S., & Whitney, R. (2020). Their Last Breath: Death and Dying in a Hmong American Community. *J Hosp Palliat Nurs*, 22(1), 68-74. doi:10.1097/njh.0000000000000616
- Her-Xiong, Y., & Schroepfer, T. (2018). Walking in Two Worlds: Hmong End of Life Beliefs & Rituals. *J Soc Work End Life Palliat Care*, 14(4), 291-314. doi:10.1080/15524256.2018.1522288
- Hinrichs, K. L. and K. M. Christie (2019). "Focus on the family: A case example of end-of-life care for an older LGBT veteran." *Clin Gerontol* 42(2): 204-211.
- Holland, J. M., Keene, J. R., Kirkendall, A., & Luna, N. (2015). Family evaluation of hospice care: Examining direct and indirect associations with overall satisfaction and caregiver confidence. *Palliat Support Care*, 13(4), 901-908. doi:10.1017/s1478951514000595
- Hostetter, M., Klein, S., & McCarthy, D. (2018). Supporting Patients Through Serious Illness and the End of Life: Sutter Health's AIM Model. <https://www.commonwealthfund.org/publications/case->



study/2018/jan/supporting-patients-through-serious-illness-and-end-life-sutter. Accessed August 29, 2022

- Hughes, M. C. and E. Vernon (2019). "Closing the Gap in Hospice Utilization for the Minority Medicare Population." *Gerontol Geriatr Med* 5: 2333721419855667.
- Hughes, M. C. and E. Vernon (2020). "'We Are Here to Assist All Individuals Who Need Hospice Services': Hospices' Perspectives on Improving Access and Inclusion for Racial/Ethnic Minorities." *Gerontol Geriatr Med* 6: 2333721420920414.
- Hughes, M. C. and E. Vernon (2021). "Hospice Response to COVID-19: Promoting Sustainable Inclusion Strategies for Racial and Ethnic Minorities." *J Gerontol Soc Work* 64(2): 101-105.
- Hughes, M. C., Vernon, E., Kowalczyk, M., & Basco-Rodillas, M. (2021). US hospices' approach to racial/ethnic minority inclusion: a qualitative study. *BMJ Support Palliat Care*. doi:10.1136/bmjspcare-2020-002680
- Hughes, M. C., Vernon, E., Kowalczyk, M., & Zhou, H. (2022). Experiences of caregivers and hospice leaders with telehealth for palliative care: a mixed methods study. *Ann Palliat Med*, 11(7), 2302-2313. doi:10.21037/apm-21-3899
- Johnson, J., Hayden, T., True, J., Simkin, D., Colbert, L., Thompson, B., . . . Martin, L. (2016). The Impact of Faith Beliefs on Perceptions of End-of-Life Care and Decision Making among African American Church Members. *J Palliat Med*, 19(2), 143-148. doi:10.1089/jpm.2015.0238
- Johnson, K. S., Payne, R., & Kuchibhatla, M. N. (2016). What are Hospice Providers in the Carolinas Doing to Reach African Americans in Their Service Area? *J Palliat Med*, 19(2), 183-189. doi:10.1089/jpm.2015.0438
- Johnson, K. S., Payne, R., Kuchibhatla, M. N., & Tulsky, J. A. (2016). Are Hospice Admission Practices Associated With Hospice Enrollment for Older African Americans and Whites? *J Pain Symptom Manage*, 51(4), 697-705. doi:10.1016/j.jpainsymman.2015.11.010
- Johnson, T., Walton, S., Jr., Levine, S., Fister, E., Baron, A., & O'Mahony, S. (2020). Racial and ethnic disparity in palliative care and hospice use. *Am J Manag Care*, 26(2), e36-e40. doi:10.37765/ajmc.2020.42399
- Jones, R. C., Creutzfeldt, C. J., Cox, C. E., Haines, K. L., Hough, C. L., Vavilala, M. S., . . . Krishnamoorthy, V. (2021). Racial and Ethnic Differences in Health Care Utilization Following Severe Acute Brain Injury in the United States. *J Intensive Care Med*, 36(11), 1258-1263. doi:10.1177/0885066620945911

- Kemery, S. A. (2021). "Family perceptions of quality of end of life in LGBTQ+ individuals: a comparative study." *Palliat Care Soc Pract* 15: 2632352421997153.
- Khosla, N., Washington, K. T., & Regunath, H. (2016). Perspectives of Health Care Providers on US South Asians' Attitudes Toward Pain Management at End of Life. *Am J Hosp Palliat Care*, 33(9), 849-857. doi:10.1177/1049909115593063
- Kim, H., Anhang Price, R., Bunker, J. N., Bradley, M., Schlang, D., Bandini, J. I., & Teno, J. M. (2021). Racial Differences in End-of-Life Care Quality between Asian Americans and Non-Hispanic Whites in San Francisco Bay Area. *Journal of palliative medicine*, 24(8), 1147–1153. <https://doi.org/10.1089/jpm.2020.0627>
- Ko, E. and D. Fuentes (2020). "End-of-Life Communication Between Providers and Family Caregivers of Home Hospice Patients in a Rural US-Mexico Border Community: Caregivers' Retrospective Perspectives." *Am J Hosp Palliat Care* 37(5): 329-335.
- Ko, E., Lee, J., Ramirez, C., Lopez, D., & Martinez, S. (2018). Patient-family EoL communication and its predictors: Reports from caregivers of Latino patients in the rural U.S.-Mexico border region. *Palliat Support Care*, 16(5), 520-527. doi:10.1017/s147895151700092x
- Ko, E., Lee, J., Ramirez, C., Martinez, S., & Lopez, D. (2017). Willingness to use hospice care among caregivers of Latino patients in the United States-Mexico border region. *Palliat Support Care*, 15(3), 279-287. doi:10.1017/s1478951516000687
- Koroukian, S. M., Schiltz, N. K., Warner, D. F., Given, C. W., Schluchter, M., Owusu, C., & Berger, N. A. (2017). Social determinants, multimorbidity, and patterns of end-of-life care in older adults dying from cancer. *J Geriatr Oncol*, 8(2), 117-124. doi:10.1016/j.jgo.2016.10.001
- Lam, M. B., Riley, K. E., Zheng, J., Orav, E. J., Jha, A. K., & Burke, L. G. (2021). Healthy days at home: A population-based quality measure for cancer patients at the end of life. *Cancer*, 127(22), 4249-4257. doi:10.1002/cncr.33817
- Lee, J. and J. G. Cagle (2017). "Factors Associated with Opinions About Hospice Among Older Adults: Race, Familiarity with Hospice, and Attitudes Matter." *J Palliat Care* 32(3-4): 101-107.
- Lin, P. J., Zhu, Y., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., . . . Freund, K. M. (2022). Racial and Ethnic Differences in Hospice Use and Hospitalizations at End-of-Life Among Medicare Beneficiaries With Dementia. *JAMA Netw Open*, 5(6), e2216260. doi:10.1001/jamanetworkopen.2022.16260
- Medicare Payment Advisory Commission. 2021. *March 2021 Report to the Congress: Medicare Payment Policy*. Washington, DC: MedPAC

- Mehanna, E. K., Catalano, P. J., Cagney, D. N., Haas-Kogan, D. A., Alexander, B. M., Tulskey, J. A., & Aizer, A. A. (2020). Hospice Utilization in Elderly Patients with Brain Metastases. *J Natl Cancer Inst*, 112(12), 1251-1258.
- Mendieta, M., & Miller, A. (2018). Sociodemographic Characteristics and Lengths of Stay Associated with Acute Palliative Care: A 10-Year National Perspective. *Am J Hosp Palliat Care*, 35(12), 1512-1517.
- Mendola, A., Naumann, W. C., Mooney-Doyle, K., & Lindley, L. C. (2021). Social Determinants of Comfort: A New Term for End-of-Life Care. *J Palliat Med*, 24(8), 1130-1131. doi:10.1089/jpm.2021.0209
- Mullins, M. A., Ruterbusch, J. J., Clarke, P., Uppal, S., Wallner, L. P., & Cote, M. L. (2021). Trends and racial disparities in aggressive end-of-life care for a national sample of women with ovarian cancer. *Cancer*, 127(13), 2229-2237.
- NHPCO. (2020). Position Paper: COVID-19 and Supporting Black Communities at the End of Life. 1-11. Retrieved from <https://www.nhpc.org/dac-position-paper/>. Accessed: August 29, 2022
- Nicholson, B. L., Flynn, L., Savage, B., Zha, P., & Kozlov, E. (2022). Hospice Referral in Advanced Cancer in New Jersey. *J Hosp Palliat Nurs*, 24(3), 167-174.
- Noh, H., Kim, J., Sims, O. T., Ji, S., & Sawyer, P. (2018). Racial Differences in Associations of Perceived Health and Social and Physical Activities with Advance Care Planning, End-of-Life Concerns, and Hospice Knowledge. *Am J Hosp Palliat Care*, 35(1), 34-40.
- Noh, H., Lee, H. Y., Lee, L. H., & Luo, Y. (2021). Awareness of Hospice Care Among Rural African-Americans: Findings From Social Determinants of Health Framework. *Am J Hosp Palliat Care*, 10499091211057847. doi:10.1177/10499091211057847
- Nuñez, A., Holland, J. M., Beckman, L., Kirkendall, A., & Luna, N. (2019). A qualitative study of the emotional and spiritual needs of Hispanic families in hospice. *Palliat Support Care*, 17(2), 150-158.
- Ornstein, K. A., Aldridge, M. D., Mair, C. A., Gorges, R., Siu, A. L., & Kelley, A. S. (2016). Spousal Characteristics and Older Adults' Hospice Use: Understanding Disparities in End-of-Life Care. *J Palliat Med*, 19(5), 509-515.
- Ornstein, K. A., Roth, D. L., Huang, J., Levitan, E. B., Rhodes, J. D., Fabius, C. D., Safford, M. M., & Sheehan, O. C. (2020). Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort. *JAMA Netw Open*, 3(8), e2014639.

- Osakwe, Z. T., Arora, B. K., Peterson, M. L., Obioha, C. U., & Fleur-Calixte, R. S. (2021). Factors Associated with Home-Hospice Utilization. *Home Healthc Now*, 39(1), 39-47.
- Oud, L. (2017). Predictors of Transition to Hospice Care Among Hospitalized Older Adults with a Diagnosis of Dementia in Texas: A Population-Based Study. *J Clin Med Res*, 9(1), 23-29.
- Paredes, A. Z., Hyer, J. M., Palmer, E., Lustberg, M. B., & Pawlik, T. M. (2021). Racial/Ethnic Disparities in Hospice Utilization Among Medicare Beneficiaries Dying from Pancreatic Cancer. *J Gastrointest Surg*, 25(1), 155-161.
- Park, N. S., Jang, Y., Ko, J. E., & Chiriboga, D. A. (2016). Factors Affecting Willingness to Use Hospice in Racially/Ethnically Diverse Older Men and Women. *Am J Hosp Palliat Care*, 33(8), 770-776.
- Patel, M. I., Khateeb, S., & Coker, T. (2021). Association of a Lay Health Worker-Led Intervention on Goals of Care, Quality of Life, and Clinical Trial Participation Among Low-Income and Minority Adults with Cancer. *JCO Oncol Pract*, 17(11), e1753-e1762.
- Phongtankuel, V., Johnson, P., Reid, M. C., Adelman, R. D., Grinspan, Z., Unruh, M. A., & Abramson, E. (2017). Risk Factors for Hospitalization of Home Hospice Enrollees Development and Validation of a Predictive Tool. *Am J Hosp Palliat Care*, 34(9), 806-813.
- Price, R. A., Parast, L., Haas, A., Teno, J. M., & Elliott, M. N. (2017). Black And Hispanic Patients Receive Hospice Care Similar to That of White Patients When in The Same Hospices. *Health Aff (Millwood)*, 36(7), 1283-1290.
- Reese, D. J., & Beckwith, S. K. (2015). Organizational Barriers to Cultural Competence in Hospice. *Am J Hosp Palliat Care*, 32(7), 685-694.
- Reese, D. J., Buila, S., Cox, S., Davis, J., Olsen, M., & Jurkowski, E. (2017). University-Community-Hospice Partnership to Address Organizational Barriers to Cultural Competence. *Am J Hosp Palliat Care*, 34(1), 64-78.
- Rhodes, R. L., Elwood, B., Lee, S. C., Tiro, J. A., Halm, E. A., & Skinner, C. S. (2017). The Desires of Their Hearts: The Multidisciplinary Perspectives of African Americans on End-of-Life Care in the African American Community. *Am J Hosp Palliat Care*, 34(6), 510-517.
- Rice, D. R., Hyer, J. M., Diaz, A., & Pawlik, T. M. (2021). End-of-Life Hospice Use and Medicare Expenditures Among Patients Dying of Hepatocellular Carcinoma. *Ann Surg Oncol*, 28(9), 5414-5422.
- Riggs, A., Breuer, B., Dhingra, L., Chen, J., Hiney, B., McCarthy, M., Portenoy, R. K., & Knotkova, H. (2016). Hospice Enrollment After Referral to Community-Based, Specialist-Level Palliative Care: Incidence, Timing, and Predictors. *J Pain Symptom Manage*, 52(2), 170-177.

- Rising, M. L., Hassouneh, D., Berry, P., & Lutz, K. (2021). Mistrust Reported by US Mexicans With Cancer at End of Life and Hospice Enrollment. *ANS Adv Nurs Sci*, 44(1), E14-e31.
- Rizzuto, J., & Aldridge, M. D. (2018). Racial Disparities in Hospice Outcomes: A Race or Hospice-Level Effect? *J Am Geriatr Soc*, 66(2), 407-413.
- Russell, D., Diamond, E. L., Lauder, B., Dignam, R. R., Dowding, D. W., Peng, T. R., Prigerson, H. G., & Bowles, K. H. (2017). Frequency and Risk Factors for Live Discharge from Hospice. *J Am Geriatr Soc*, 65(8), 1726-1732.
- Russell, D., Luth, E. A., Ryvicker, M., Bowles, K. H., & Prigerson, H. G. (2020). Live Discharge from Hospice Due to Acute Hospitalization: The Role of Neighborhood Socioeconomic Characteristics and Race/Ethnicity. *Med Care*, 58(4), 320-328.
- Samuel-Ryals, C. A., Mbah, O. M., Hinton, S. P., Cross, S. H., Reeve, B. B., & Dusetzina, S. B. (2021). Evaluating the Contribution of Patient-Provider Communication and Cancer Diagnosis to Racial Disparities in End-of-Life Care Among Medicare Beneficiaries. *J Gen Intern Med*, 36(11), 3311-3320.
- Sharma, R. K., Cameron, K. A., Chmiel, J. S., Von Roenn, J. H., Szmuiłowicz, E., Prigerson, H. G., & Penedo, F. J. (2015). Racial/Ethnic Differences in Inpatient Palliative Care Consultation for Patients with Advanced Cancer. *J Clin Oncol*, 33(32), 3802-3808. doi:10.1200/jco.2015.61.6458
- Shenker, R. F., Elizabeth McLaughlin, M., Chino, F., & Chino, J. (2022). Disparities in place of death for patients with primary brain tumors and brain metastases in the USA. *Support Care Cancer*, 30(8), 6795-6805. doi:10.1007/s00520-022-07120-4
- Shepard, V., Al Snih, S., Burke, R., Downer, B., Kuo, Y. F., Malagaris, I., & Raji, M. (2022). Characteristics Associated with Mexican American Hospice Use: Retrospective Cohort Study Using the Hispanic Established Population for the Epidemiologic Study of the Elderly (H-EPESE). *Am J Hosp Palliat Care*, 10499091221110125. doi:10.1177/10499091221110125
- Sheu, J., Palileo, A., Chen, M. Y., Hoepner, L., Abulafia, O., Kanis, M. J., & Lee, Y. C. (2019). Hospice utilization in advanced cervical malignancies: An analysis of the National Inpatient Sample. *Gynecol Oncol*, 152(3), 594-598. doi:10.1016/j.ygyno.2018.12.016
- Shin, J. A., Parkes, A., El-Jawahri, A., Traeger, L., Knight, H., Gallagher, E. R., & Temel, J. S. (2016). Retrospective evaluation of palliative care and hospice utilization in hospitalized patients with metastatic breast cancer. *Palliat Med*, 30(9), 854-861. doi:10.1177/0269216316637238
- Shiovitz, S., Bansal, A., Burnett-Hartman, A. N., Karnopp, A., Adams, S. V., Warren-Mears, V., & Ramsey, S. D. (2015). Cancer-Directed Therapy and Hospice Care for Metastatic Cancer in American Indians and Alaska Natives. *Cancer Epidemiol Biomarkers Prev*, 24(7), 1138-1143. doi:10.1158/1055-9965.Epi-15-0251

- Shirsat, N., Hoe, D., & Enguidanos, S. (2021). Understanding Asian Indian Americans' Knowledge and Attitudes Toward Hospice Care. *Am J Hosp Palliat Care*, 38(6), 566-571. doi:10.1177/1049909120969128
- Siler, S., Arora, K., Doyon, K., & Fischer, S. M. (2021). Spirituality and the Illness Experience: Perspectives of African American Older Adults. *Am J Hosp Palliat Care*, 38(6), 618-625. doi:10.1177/1049909120988280
- Soltoff, A., Purvis, S., Ravicz, M., Isaacson, M. J., Duran, T., Johnson, G., . . . Daubman, B. R. (2022). Factors Influencing Palliative Care Access and Delivery for Great Plains American Indians. *J Pain Symptom Manage*. doi:10.1016/j.jpainsymman.2022.05.011
- Starr, L. T., Bullock, K., Washington, K., Aryal, S., Parker Oliver, D., & Demiris, G. (2022). Anxiety, Depression, Quality of Life, Caregiver Burden, and Perceptions of Caregiver-Centered Communication among Black and White Hospice Family Caregivers. *J Palliat Med*, 25(4), 596-605. doi:10.1089/jpm.2021.0302
- Starr, L. T., Ulrich, C. M., Junker, P., Appel, S. M., O'Connor, N. R., & Meghani, S. H. (2020). Goals-of-Care Consultation Associated with Increased Hospice Enrollment Among Propensity-Matched Cohorts of Seriously Ill African American and White Patients. *J Pain Symptom Manage*, 60(4), 801-810. doi:10.1016/j.jpainsymman.2020.05.020
- Starr, L. T., Ulrich, C. M., Perez, G. A., Aryal, S., Junker, P., O'Connor, N. R., & Meghani, S. H. (2022). Hospice Enrollment, Future Hospitalization, and Future Costs Among Racially and Ethnically Diverse Patients Who Received Palliative Care Consultation. *Am J Hosp Palliat Care*, 39(6), 619-632. doi:10.1177/10499091211034383
- Stein, G. L., Berkman, C., O'Mahony, S., Godfrey, D., Javier, N. M., & Maingi, S. (2020). Experiences of Lesbian, Gay, Bisexual, and Transgender Patients and Families in Hospice and Palliative Care: Perspectives of the Palliative Care Team. *J Palliat Med*, 23(6), 817-824. doi:10.1089/jpm.2019.0542
- Stephens, S. J., Chino, F., Williamson, H., Niedzwiecki, D., Chino, J., & Mowery, Y. M. (2020). Evaluating for disparities in place of death for head and neck cancer patients in the United States utilizing the CDC WONDER database. *Oral Oncol*, 102, 104555. doi:10.1016/j.oraloncology.2019.104555
- Stevens, E. E., & Abrahm, J. L. (2019). Adding Silver to the Rainbow: Palliative and End-of-Life Care for the Geriatric LGBTQ Patient. *J Palliat Med*, 22(5), 602-606. doi:10.1089/jpm.2018.0382
- Sutherland, N., Ward-Griffin, C., McWilliam, C., & Stajduhar, K. (2016). Gendered Processes in Hospice Palliative Home Care for Seniors With Cancer and Their Family Caregivers. *Qual Health Res*, 26(7), 907-920. doi:10.1177/1049732315609571

- Taylor, J. S., Brown, A. J., Prescott, L. S., Sun, C. C., Ramondetta, L. M., & Bodurka, D. C. (2016). Dying well: How equal is end of life care among gynecologic oncology patients? *Gynecol Oncol*, 140(2), 295-300. doi:10.1016/j.ygyno.2015.12.012
- Taylor, J. S., Rajan, S. S., Zhang, N., Meyer, L. A., Ramondetta, L. M., Bodurka, D. C., . . . Giordano, S. H. (2017). End-of-Life Racial and Ethnic Disparities Among Patients with Ovarian Cancer. *J Clin Oncol*, 35(16), 1829-1835. doi:10.1200/jco.2016.70.2894
- Taylor, J. S., Zhang, N., Rajan, S. S., Chavez-MacGregor, M., Zhao, H., Niu, J., . . . Giordano, S. H. (2019). How we use hospice: Hospice enrollment patterns and costs in elderly ovarian cancer patients. *Gynecol Oncol*, 152(3), 452-458. doi:10.1016/j.ygyno.2018.10.041
- Townsend, A., March, A. L., & Kimball, J. (2017). Can Faith and Hospice Coexist: Is the African American Church the Key to Increased Hospice Utilization for African Americans? *J Transcult Nurs*, 28(1), 32-39. doi:10.1177/1043659615600764
- Turkman, Y. E., Williams, C. P., Jackson, B. E., Dionne-Odom, J. N., Taylor, R., Ejem, D., . . . Rocque, G. B. (2019). Disparities in Hospice Utilization for Older Cancer Patients Living in the Deep South. *J Pain Symptom Manage*, 58(1), 86-91. doi:10.1016/j.jpainsymman.2019.04.006
- Wallace, C. L. (2017). Examining hospice enrollment through a novel lens: Decision time. *Palliat Support Care*, 15(2), 168-175. doi:10.1017/s1478951516000493
- Wang, H., Qiu, F., Boilesen, E., Nayar, P., Lander, L., Watkins, K., & Watanabe-Galloway, S. (2016). Rural-Urban Differences in Costs of End-of-Life Care for Elderly Cancer Patients in the United States. *J Rural Health*, 32(4), 353-362. doi:10.1111/jrh.12160
- Wang, S. Y., Aldridge, M. D., Canavan, M., Cherlin, E., & Bradley, E. (2016). Continuous Home Care Reduces Hospice Disenrollment and Hospitalization After Hospice Enrollment. *J Pain Symptom Manage*, 52(6), 813-821. doi:10.1016/j.jpainsymman.2016.05.031
- Washington, K. T., Oliver, D. P., Smith, J. B., Kruse, R. L., Meghani, S. H., & Demiris, G. (2019). A Comparison of Rural and Urban Hospice Family Caregivers' Cancer Pain Knowledge and Experience. *J Pain Symptom Manage*, 58(4), 685-689. doi:10.1016/j.jpainsymman.2019.07.010
- Wasp, G. T., Alam, S. S., Brooks, G. A., Khayal, I. S., Kapadia, N. S., Carmichael, D. Q., . . . Barnato, A. E. (2020). End-of-life quality metrics among Medicare decedents at minority-serving cancer centers: A retrospective study. *Cancer Med*, 9(5), 1911-1921. doi:10.1002/cam4.2752
- Weaver, M. S., Lukowski, J., Wichman, B., Navaneethan, H., Fisher, A. L., & Neumann, M. L. (2021). Human Connection and Technology Connectivity: A Systematic Review of Available Telehealth Survey Instruments. *J Pain Symptom Manage*, 61(5), 1042-1051.e1042. doi:10.1016/j.jpainsymman.2020.10.010

Wilkie, D. J., Ezenwa, M. O., Yao, Y., Gill, A., Hipp, T., Shea, R., . . . Wang, Z. W. (2017). Pain Intensity and Misconceptions Among Hospice Patients with Cancer and Their Caregivers: Status After 2 Decades. *Am J Hosp Palliat Care*, 34(4), 318-324. doi:10.1177/1049909116639612

Worster, B., Bell, D. K., Roy, V., Cunningham, A., LaNoue, M., & Parks, S. (2018). Race as a Predictor of Palliative Care Referral Time, Hospice Utilization, and Hospital Length of Stay: A Retrospective Noncomparative Analysis. *Am J Hosp Palliat Care*, 35(1), 110-116. doi:10.1177/1049909116686733

Yaqoob, Z. J., Al-Kindi, S. G., & Zein, J. G. (2017). Trends and Disparities in Hospice Use Among Patients Dying of COPD in the United States. *Chest*, 151(5), 1183-1184. doi:10.1016/j.chest.2017.02.030

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**Project Name :** Heart N Soul Hospice Memphis

**Supplemental Round Name :** 1

**Certificate No. :** CN2403-007

**Due Date :** 4/30/2024

**Submitted Date :** 4/24/2024

**1. 4A. Purpose of Review**

Please select Establish a New Health Care Institution in response to Item 4A.

**Response :** The application has been corrected with New Health Care Institution checked in response to Item 4A.

**2. 6A. Name of Owner of the Facility, Agency, or Institution**

The address listed for the owner of the project does not match the address registered with the Secretary of State. Please revise the address in the main application.

**Response :** The correct address is 51 Century Blvd., Suite 110, Nashville Tennessee 37214. The address has been revised in the main application.

**3. 9A. Legal Interest in the Site**

Please attach a copy of the lease for the site as Attachment 9A. The current attachment is not a copy of the lease.

**Response :** Please see attached copy of executed lease included as Attachment 9A.

**4. 1E. Overview**

What setting(s) will hospice services be offered to patients? Please complete the following table:

<b>Location of Care</b>	<b>Yes</b>	<b>No</b>	<b>% of Patients</b>
Home			
Assisted Living Facility			
Nursing Facility			

Skilled Nursing Facility			
Inpatient Hospital Facility			
Other			

Please complete the following table identifying the types of hospice care services to be offered:

Hospice Levels of Care	Yes	No
Routine Home Care		
General Inpatient Care		
Continuous Home Care		
Respite Care		

**Response :** What setting(s) will hospice services be offered to patients? Please complete the following table:

Location of Care	Yes	No	% of Patients
Home	X		50
Assisted Living Facility	X		15
Nursing Facility	X		20

Skilled Nursing Facility	X		10
Inpatient Hospital Facility	X		5
Other			

**Please complete the following table identifying the types of hospice care services to be offered:**

Hospice Levels of Care	Yes	No
Routine Home Care	X	
General Inpatient Care	X	
Continuous Home Care	X	
Respite Care	X	

**5. 2E. Rationale for Approval**

Please confirm whether the applicant’s affiliated hospice agencies have reported any patient care measures to CMS at this time. Please list any affiliated hospice agencies for which comparable quality measures are available on the Medicare Care Compare website at this time.

**Response :** **Response:** Heart and Soul Hospice, LLC in Nashville has reported limited quality measures on the Medicare Compare website at this time. The agency has reported the

conditions that it treats, but otherwise has not provided meaningful patient care measures. At the next reporting period, more quality measures will be reported. Heart and Soul Hospice Memphis will contract with Healthcare First to monitor and analyze its quality assurance and performance improvement program just as Heart and Soul Hospice, LLC does.

#### 6. 1E. Overview

Please confirm whether any of the project owners are based in the proposed service area.

Please discuss the applicant's history of providing hospice services to the target population proposed in this project.

**Response : Please confirm whether any of the project owners are based in the proposed service area.**

**Response:** While none of the project owners are currently based in the proposed service area, three of the principals reside in Tennessee. Their deep understanding of the State's healthcare landscape, regulatory requirements, and community needs will be crucial in establishing a hospice that successfully serves this region. They are dedicated to building local partnerships and recruiting staff who are deeply connected to the communities the Applicant intends to serve in Shelby, Tipton and Fayette counties.

**Please discuss the applicant's history of providing hospice services to the target population proposed in this project.**

**Response:** Some of the owners of Applicant have been involved in the establishment of the Heart and Soul Hospice, LLC, based in Nashville, which has been focused on providing hospice care to underserved populations in the middle Tennessee area. It has successfully served a larger minority patient base than many of the existing hospice agencies. The experience in establishing that hospice gives the owners valuable insights and the passion to ensure everyone is educated on the benefits of hospice and has access to high quality care. Heart N Soul Hospice Memphis is committed to learning and building upon this knowledge base to deliver exceptional services to the proposed population, which is expected to be an even larger minority population than that served by Heart and Soul Hospice, LLC.

#### 7. 4C. Accessibility to Human Resources

Please confirm whether the applicant intends to offer speech therapy, occupational therapy and speech language pathology services either directly or through a contracted third party?

**Response :** **Response:** Yes, Heart N Soul Hospice Memphis will offer speech therapy (ST), occupational therapy (OT), and physical therapy (PT) as part of the hospice benefit through a contracted third-party vendor. It is important to understand that in the context of hospice care, these therapies are focused on improving comfort, maintaining function, and maximizing quality of life rather than aggressive rehabilitation.

**8. 6N. Utilization and/or Occupancy Statistics**

Please complete the following table for Year 1- Year 2 projections:

Hospice Levels of Care	Patients Year 1	Patient Days Year 1	Patients Year 2	Patient Days Year 2	Total Patients Year 1- Year 2	Total Patient Days Year 1- Year 2	% Change Patients Year 1- Year 2	% Change Patient Days Year 1- Year 2
Routine Home Care								
General Inpatient Care								
Continuous Home Care								
Respite Care								
<b>Total</b>								

Please confirm whether the applicant's projection include palliative care patients?

**Response :** Please complete the following table for Year 1- Year 2 projections:

Hospice Levels of Care	Patients Year 1	Patient Days Year 1	Patients Year 2	Patient Days Year 2	Total Patients Year 1- Year 2	Total Patient Days Year 1- Year 2	% Change Patients Year 1- Year 2	% Change Patient Days Year 1- Year 2
Routine Home Care	100	7,009	226	15,833	126	8,824	126%	126%
General Inpatient Care	3	165	6	373	3	208	100%	126%
Continuous Home Care	9	660	21	1,490	12	830	133%	126%
Respite Care	6	412	13	931	7	519	117%	126%

Total	118	8,246	266	18,627	148	10,381	126%	126%
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Please note that because some of the numbers of patients and the differences between them are so small, and are rounded, the percentage change in patients does not match the percentage change in patient days.

**Please confirm whether the applicant's projection include palliative care patients?**

**Response:** Applicant does not plan to offer palliative care directly to its patients. To the extent those services are needed, Applicant will work with a palliative care provider to ensure services are rendered.

**9. 2E. Rationale for Approval**

Please discuss the applicant's research findings regarding lack of utilization of hospice services among African Americans, i.e. is it due to lack of access or education about hospice services.

What staffing strategies will the applicant utilize to address cultural hospice issues if that is a barrier to treatment?

**Response :** **Response:** The African American population does not utilize hospice services at the same rate as its white counterparts. This population deserves the same access and focus as other populations. Applicant will focus on providing hospice services to the underserved and minority community irrespective of race. Because the principals are African American, Applicant feels it is in a better position to meet the needs of this community than many other hospice agencies. The Principals of Applicant are developing relationships with many area providers and community agencies to ensure appropriate continuity of care. This is also manifested in Applicant’s connection to key faith-based community entities. Applicant believes, as a minority owned entity, it will be successful because serving the African American population requires a collaborative relationship with the religious community and other community providers and leaders from both an educational perspective and a service rendering perspective, which Applicant is uniquely positioned to provide.

Research has shown that African Americans are less likely to enroll in hospice than other populations. (American Journal of Hospice & Palliative Medicine, *Barriers to End-of-Life Care for African Americans from the Providers* (March 2015)). According to Duke

geriatric researchers, African Americans use hospice services at far lower rates than whites and are more likely to experience untreated pain at the end of their lives. (Tim Pitman, *Hospice Use Lower Among African Americans* (January 2018)). Researchers at Johns Hopkins Medicine and three collaborating institutions have reported that African American patients voluntarily seek substantially more intensive treatment, such as mechanical ventilation, gastrostomy tube insertion, hemodialysis, CPR and multiple emergency room visits in the last six months of life, while white patients more often choose hospice services. (Johns Hopkins Medicine, *Study Documents Racial Differences in U.S. Hospice Use and End-of-Life Care Preferences* (October 2020)). According to the National Hospice and Palliative Care Organization (“NHPCO”), the share of Medicare decedents who used hospice services by race are as follows: (i) white Americans – 50%; and (ii) African Americans – 35.6%.

#### 10. 4E. Project Cost Chart

Please provide a comparison of the lease vs fair market value of the office space for the project.

**Response : Response:** The building is 85,552 square feet and is appraised for \$3,284,300, or \$38.39 per square foot. The leased space is 1,600 square feet for a fair market value of \$61,424.

#### 11. 2N. Service Area

Please provide greater detail regarding the applicant's research into service disparities in the proposed service area. Please include source citations as appropriate.

Please provide more detail regarding the applicant's operational infrastructure in the service area as referenced on page 12 of the application.

The applicant references physical, occupational, and speech therapists in its staffing plan on page 12. However, the Project Staffing Chart does not include any of these positions. Please explain.

Please explain how many patients are represented in the 8,243 patient days projected for Year 1 of the project.

**Response : Please provide greater detail regarding the applicant's research into service disparities in the proposed service area. Please include source citations as appropriate.**

**Response:** Applicant recognizes that service disparities are a crucial issue in hospice care. To effectively serve Shelby, Tipton, and Fayette Counties, Applicant is committed to ongoing research and education for its prospective employees. Applicant’s analysis of Medicare data reveals a concerning gap in hospice services between white enrollees and those of other ethnicities, underscoring the urgent need to address disparities within the

proposed service area. Applicant’s focus includes addressing racial/ethnic disparities, examining barriers for rural populations, and developing culturally responsive care models. Sources like the Journal of Palliative Medicine (K. Johnson, “Racial and Ethnic Disparities in Palliative Care” (Nov. 2013)), the National Rural Health Association (J. Seigel, “National Minority Health Month: Health Disparities in Rural America” (April 2018)), the Center to Advance Palliative Care (H. Bhagwandin, “Acknowledging Barriers and Implementing Strategies to Reach Black People with Serious Illness” (June 2022)), and the Centers for Medicare & Medicaid Services (Abt Associates, “2022 Hospice Information Gathering Report” (December 2022)) provide valuable insights into these complex issues.

As a Black-owned hospice committed to serving the underserved, Applicant is particularly sensitive to these disparities. National research highlights factors such as:

- **Mistrust of the Healthcare System:** Historical experiences of discrimination and unequal treatment can make some groups hesitant to engage with hospice services.
- **Lack of Culturally Sensitive Care:** Underserved communities may have specific spiritual practices, communication styles, or family dynamics that aren't well-understood by traditional hospice models.
- **Limited Awareness and Outreach:** Underserved communities may not be fully aware of hospice benefits or how to access them.

**Please provide more detail regarding the applicant's operational infrastructure in the service area as referenced on page 12 of the application.**

**Response:** The operational infrastructure applicant intends to have in the proposed service area include a highly trained staff, experienced management team, and the financial resources to successfully operate a hospice agency.

**The applicant references physical, occupational, and speech therapists in its staffing plan on page 12. However, the Project Staffing Chart does not include any of these positions. Please explain.**

**Response:** Applicant’s staffing model prioritizes individual patient needs above all else. While it does not directly employ physical therapists, occupational therapists, or speech therapists, it recognizes the importance of these services in certain cases. Applicant has established relationships with skilled contractors in these fields, allowing it to offer these services as needed, ensuring each patient receives the most appropriate, holistic care. The staffing chart has been revised to add these as contracted staff. Please see revised staffing chart below:



<b>Position Classification</b>	<b>Existing FTEs (enter year)</b>	<b>Projected FTEs Year 1</b>
<b>A. Direct Patient Care Positions</b>		
<i>Hospice Aide/Homemaker</i>	0.00	3.30
<i>Nurse, RN Case Manager</i>	0.00	2.10
<i>Nurse, Oncall</i>	0.00	0.90
<i>Nurse, LVN/LPN (incl in Nurse RNCM #)</i>	0.00	0.00
<i>Coordinator, Volunteer</i>	0.00	0.20
<i>Nurse, Oncall Triage</i>	0.00	0.00
<i>Admission Nurse</i>	0.00	0.30
<i>Bereavement Coordinator</i>	0.00	0.20
<i>Social Worker</i>	0.00	0.70
<i>Chaplain</i>	0.00	0.50
<b>Total Direct Patient Care Positions</b>	N/A	8.20

<b>B. Non-Patient Care Positions</b>		
<i>Manager, Office</i>	0.00	1.00
<i>Coordinator, Volunteer</i>	0.00	0.20
<i>Director, Executive</i>	0.00	1.00
<i>Chaplain</i>	0.00	0.50
<i>Site Billing Coordinator</i>	0.00	0.00
<i>Patient Care Manager</i>	0.00	1.00
<i>Coordinator, Admissions</i>	0.00	0.50

<i>Patient Care Secretary</i>	0.00	1.00
<i>Office Support (Recp/Other)</i>	0.00	0.40
<b>Total Non-Patient Care Positions</b>	0.00	5.60
<b>Total Employees</b> (A+B)	0.00	13.80
<b>C. Contractual Staff</b>		
<i>Physical Therapy, Occupational Therapy, Speech Therapy, Pharmacist, Massage, Music/Art Therapy</i>	0.00	1.20
<b>Total Staff</b> (A+B+C)	0.00	15.00

**Please explain how many patients are represented in the 8,243 patient days projected for Year 1 of the project.**

**Response:** This represents approximately 118 patients for Year 1 of the project.

## 12. 3N. Demographics

Is the African American population included in the target population for project? Is so please include relevant demographic data that is specific to this population in response to Item 3N.

The Service Area Demographic Chart, Attachment 3N.B. appears to contain the following errors:

TennCare Enrollees - State of Tennessee Total

Please revise and resubmit Attachment 3N.B (labeled as Attachment 3N.BR).

**Response : Response:** Please find an updated Service Area Demographic Chart included as Attachment 3N.BR, which is inclusive of all relevant corrections. This chart includes relevant demographic data that is specific to the population of ages 65+, and additionally, includes a second chart that provides relevant demographic data that is specific to the African American population that is aged 65+.

Applicant's service area is limited to three counties: Fayette, Shelby, and Tipton. As shown on Attachment 3N.B, the age 65+ population in the service area is expected to increase at a rate of 6.7% from 2024 to 2028. Further, the age 65+ African American population in the service area is expected to increase at a rate of 10.8% from 2024 to 2028. An analysis of hospice penetration by race/ethnicity in Shelby, Fayette, and Tipton counties reveals a lower hospice utilization rate compared to the overall population average. Applicant will prioritize targeted outreach, culturally sensitive care, and increased awareness of hospice benefits within these communities to combat this disparity.

### 13. 4N. Special Needs of Service Area

Please provide more robust data supporting the statement that the African American population does not utilize hospice services at the same rate as its white counterparts, specifically in the proposed service area.

What is the hospice penetration rate for African Americans in the service area vs. other racial groups?

How does the proposed service area compare to other areas of the State with large African-American populations in hospice utilization rate?

Please list specific community institutions, faith-based community entities and healthcare providers in the services area that the applicant has established relationships with and discuss their respective roles in supporting the applicant's ability to reach its target population.

What specific strategies does the applicant intend to employ to expand the utilization of hospice services among the African American population? How are these strategies expected to represent an improvement from the outreach services and programs offered by existing providers in the service area?

What programs does the applicant intend to incorporate into its operations that it considers to be unique among service area providers?

**Response : What is the hospice penetration rate for African Americans in the service area vs. other racial groups?**

**Response:**

The hospice penetration rate in Shelby County for the black population is significantly lower - 69% lower - than that for the white population and for the population overall. The penetration rate for the black population is also lower than that for the Asian population in Shelby County. These lower penetration rates indicate that the black population is not receiving services at the same rate as other patient populations. Please see the rates below.

**Hospice Medicare Utilization by Race/Ethnicity**

**Shelby County**

**2023**

	<b>MEDICARE ENROLLMENT</b>	<b>HOSPICE PENETRATION RATE</b>
<b>ALL ENROLLEES</b>	170,374	0.57
<b>WHITE</b>	78,388	0.70
<b>BLACK</b>	85,263	0.44
<b>HISPANIC</b>	901	0.33
<b>ASIAN</b>	1,933	0.57

**How does the proposed service area compare to other areas of the State with large African-American populations in hospice utilization rate?**

**Response:** As you can see from the table below, the hospice penetration rate for the black population in Hamilton County is also lower than the hospice penetration rate for the white patient population. Comparing these rates to those for Shelby County shows that the hospice penetration rates in Shelby County for the black population are much lower - 80% lower - than they are in Hamilton County.

**Hospice Medicare Utilization by Race/Ethnicity**

**Hamilton County**

**2023**

	<b>MEDICARE ENROLLMENT</b>	<b>HOSPICE PENETRATION RATE</b>
<b>ALL ENROLLEES</b>	84,522	0.98
<b>WHITE</b>	67,027	1.03
<b>BLACK</b>	14,061	0.79
<b>HISPANIC</b>	368	0.47
<b>ASIAN</b>	692	0.64

**Please list specific community institutions, faith-based community entities and healthcare providers in the services area that the applicant has established relationships with and discuss their respective roles in supporting the applicant's ability to reach its target population.**

**Response:** Applicant has established relationships with the following specific community institutions, faith-based community entities and healthcare providers in the service area, and such individuals have provided written support specifically noting their support of Applicant's application and ability to reach the target population: (i) Bishop Roy Davis, Princeton Avenue Baptist Church; (ii) Reverend Cory Johnson, Union Grove Missionary Baptist Church; (iii) Pastor Steevon Hunter, Georgia Avenue Baptist Church; (iv) Bishop Jonathan McReynolds, Fullview Baptist Church; (v) Reverend Kelvin Bowen, Christ Fellowship Church; (vi) Reverend Terrance D. Sesley, Morning Star Fellowship Church;

(vii) Reverend Ronald Turner, Faith Street Baptist Church; (viii) Reverend Quinton Ballard, Macon Baptist Church; (ix) Reverend Steven Young, Ardmore Terrance Baptist Church; (x) Van Turner, Jr., Former President of the National Association for the Advancement of Colored People (“NAACP”) Memphis Branch and Former Chairman of the Board of Commissioners for Shelby County; (xi) Millard Collins, MD, Meharry Medical College; and (xii) Joel Parker, MD, Iris Medical Group.

**What specific strategies does the applicant intend to employ to expand the utilization of hospice services among the African American population? How are these strategies expected to represent an improvement from the outreach services and programs offered by existing providers in the service area?**

**Response:** Applicant will provide significant outreach to the African American community and will also use non-traditional small business media (radio and print) to share the hospice story. It is important that when a hospice agency thinks about education for the African American community that the team understands the end-of-life care issues specific to African American communities: history of healthcare, disparities in healthcare, the importance of spiritual and cultural beliefs, values and traditions regarding care, and cultural perspectives on death and dying. The team must educate, support, and listen to the community, address what hospice is and is not, and ensure that patients understand that the ability to pay should not be an issue with the Medicare patient population, which is the primary age group serviced by hospice. Applicant plans to hire African American professionals in leadership roles and staffing roles. Additionally, Applicant plans for its employees to be active participants in various civic organizations including the local NAACP. It is Applicant’s goal to change the existing stigma attached to the term “hospice” that exists within the African American community. Applicant believes that breaking down barriers will not only help Heart N Soul Hospice Memphis, but will ultimately help other providers in the service area increase services provided to this patient population, which will in turn benefit the African American community.

**What programs does the applicant intend to incorporate into its operations that it considers to be unique among service area providers?**

**Response:** Applicant will offer several unique programs to address specific patient populations. Such programs include:

- **End-Stage Cardiac Care Program:** This program will be tailored for patients with advanced heart failure or other complex cardiac conditions. Applicant’s team will partner with a cardiologist to manage symptoms, minimize hospital readmissions, and ensure optimal comfort during this critical phase.
- **End-Stage Renal Disease Program:** Heart N Soul Hospice Memphis will be included in a grant proposal to study the effects of End Stage Renal Disease (ESRD) patients to concurrently receive hospice services and dialysis.
- **Dementia Program:** Heart and Soul Hospice, LLC in Nashville, has been accepted to participate in the CMS Innovation Centers GUIDE program, Guiding an Improved Dementia Experience Model. The plan is to include Heart N Soul Memphis in track 2 which will begin with training July, 2025.

#### 14. 5N. Unimplemented services

There appear to be two hospice agencies which are either licensed in the service area or have a licensure application pending which have not reported to the Joint Annual Report. Please address the presence of AccentCare Hospice and Palliative Care of Tennessee, LLC and PruittHealth Hospice and Palliative Care-Western Tennessee which overlap with the applicant's proposed service area. Specifically, please address the projections included in the CON application for CN2202-007 for those counties which overlap with the applicant and discuss the impact on the need formula for those counties as referenced in response to Item 1N - Hospice Criteria and Standards #17.

**Response :** **Response:** Applicant believes that AccentCare Hospice and Palliative Care of Tennessee, LLC bought Goshen Hospice and Palliative Care. It appears that the provider was originally licensed in 2020. Applicant does not know why it has not reported any data on the JAR reports.

PruittHealth, CN2202-007 is not yet operational, and its licensure application is pending. There is overlap in Fayette and Tipton Counties, but PruittHealth will not be licensed in Shelby County. Because the applicant anticipates that the majority of the patients it serves will reside in Shelby County, it does not believe it will have much, if any, impact on PruittHealth.

The Applicant does not believe that it will have a significant impact on either of these hospice agencies, in large part because it has a specific focus on serving the African American population.

#### 15. 5N. Unimplemented services

The historical utilization data provider in Attachment 5N does not appear to be specific to the applicant's proposed service area. Please revise and resubmit all historical utilization data to reflect the service area only.

The data on utilization by race of the service area hospice agencies is noted, however, additional context regarding the specific counties represented as well as the percentage of the age 65+ populations would provide helpful context for the data.

**Response :** **Response:** Please find an updated historical utilization chart attached herein as Attachment 5NR. The previously submitted historical utilization chart in 5N included all service area providers, but represented all patients served (as demonstrated in the applicable Joint Annual Report). The updated historical utilization chart in 5NR similarly represents all service area providers, but has been revised to represent only patients served in Fayette, Shelby, and Tipton Counties.

Additionally, the data on utilization by race of the service area hospice agencies has been updated in Attachment 5NR. The previously submitted utilization by race charts in 5N included all service area providers, but represented all African American patients served. The updated utilization by race charts in 5NR similarly represent all service area providers, but have been revised to represent only African American patients served in Fayette, Shelby, and Tipton Counties. Furthermore, the utilization by race charts include (i) percentage of African American patients represented in the data and (ii) the number of patients aged 65+ represented in the data.

## 16. 6N. Utilization and/or Occupancy Statistics

Please describe the referenced specialty care programs, referral relationships and underserved populations in greater detail.

**Response :** Applicant recognizes that hospice care needs can vary greatly. Applicant will offer specialized programs to address specific patient populations:

- **End-Stage Cardiac Care Program:** This program will be tailored for patients with advanced heart failure or other complex cardiac conditions. Applicant's team will partner with a cardiologist to manage symptoms, minimize hospital readmissions, and ensure optimal comfort during this critical phase.
- **Alzheimer's Disease & Dementia Care:** Applicant understands the unique challenges faced by patients with Alzheimer's and other forms of dementia. Applicant's program will provide compassionate care, memory support activities, and respite for families.
- **Newly Diagnosed Stage IV Cancer Program:** Patients receiving a sudden Stage IV cancer diagnosis often require immediate emotional and logistical support. Applicant's program will offer comprehensive guidance on navigating treatment options, pain management, and end-of-life decisions, ensuring a smooth transition to hospice care.
- **COPD**

### **Building Strong Referral Relationships:**

To ensure seamless access to hospice care, Applicant will establish strong referral partnerships with:

- **Hospitals & Medical Practices:** Building relationships with physicians, oncologists, and other healthcare providers who can refer patients to Applicant's specialized programs.
- **Home Health Agencies:** Collaborating with home health agencies to identify patients who may benefit from hospice services.
- **Faith-Based Organizations:** Partnering with churches and faith-based organizations within Shelby, Fayette, and Tipton counties, particularly those that serve underserved communities. These partnerships will allow Applicant to connect with patients and families who may not readily consider hospice care.

### **Reaching Underserved Populations:**



Applicant is deeply committed to health equity and ensuring all residents in the service area have access to high-quality hospice services. Applicant will focus on:

- **Culturally Sensitive Outreach:** Developing culturally sensitive outreach materials and programs specifically tailored to black and brown communities. This may include partnerships with community leaders, faith-based organizations, and organizations that serve these populations.
- **Rural Outreach:** Addressing the needs of rural communities by offering telehealth consultations, transportation assistance, and flexible scheduling options to overcome geographic barriers.
- **Community Education:** Providing educational workshops and seminars within underserved communities to raise awareness about hospice care, dispel myths, and promote early discussions about end-of-life care.

Applicant believes by offering specialty programs, building strong referral networks, and implementing targeted outreach strategies, it can reach all individuals who can benefit from compassionate and dignified hospice care, regardless of race, ethnicity, or socioeconomic background.

**17. 7N. Outstanding CoN**

Please confirm whether a final project report has been submitted for CN2306-016 Heart and Soul Hospice, LLC.

**Response : Response:** The final project report form for CN2306-016 Heart and Soul Hospice, LLC has been submitted.

**18. 2C. Insurance Plans**

Please explain why two commercial payors have been selected by the applicant, but no commercial revenue is listed in response to Item 10C. Payor Mix Chart.

**Response : Response:** The amount of revenue from commercial payors is generally very small for hospice services. The Applicant anticipates receiving about 1 percent of revenue from commercial payors in the first year of operation and 3% in the second year of operation and has accordingly revised the Payor Mix Chart.

**Applicant’s Projected Payor Mix**

**Project Only Chart**

	<b>Year 1-2025</b>	<b>Year 2-2026</b>

Payor Source	Gross Operating Revenue	% of Total	Gross Operating Revenue	% of Total
Medicare/Medicare Managed Care	\$1,332,992	90%	\$3,156,385	89%
TennCare/Medicaid	\$133,299	9%	\$283,720	8%
Commercial/Other Managed Care	\$14,811	1%	\$106,395	3%
Self-Pay		0%		0%
Other (Specify) _____				
Total*	\$1,481,102	100%	\$3,546,500	100%
Charity Care	\$22,500		\$67,500	

**19. 3C. Effects of Competition and/or Duplication**

Please discuss the applicant's unique approach to culturally appropriate care and community education in the context of this service area and target population.

**Response :** **Response:** Applicant understands that effective hospice care goes beyond clinical expertise – it requires deep cultural sensitivity and an understanding of the specific needs of diverse communities in Shelby, Fayette, and Tipton counties. Applicant’s approach will focus on:

- **Diverse and Inclusive Team:** Applicant is committed to building a staff that reflects the racial and cultural makeup of the communities it will serve. Applicant will prioritize recruiting healthcare providers who speak diverse languages, understand cultural nuances, and are connected to local organizations serving Applicant’s target population.
- **Tailored Education and Outreach:** Applicant won't take a one-size-fits-all approach. Applicant’s education materials and community presentations will be specifically designed for different cultural groups. Applicant will partner with faith-based leaders, community centers, and advocacy groups to reach black, brown, rural, and other underserved populations.
- **Addressing Misconceptions:** Applicant recognizes that cultural beliefs and taboos around death and dying can vary significantly. Applicant’s outreach efforts will focus on dispelling myths, addressing fears, and building trust around the concept of hospice care within diverse communities.

- **Humility and Collaboration:** Applicant doesn't presume to know all the answers. Applicant will actively seek to continue to build on its lived experiences and ongoing feedback from community stakeholders to continuously refine its approach. Cultural competence is a journey, and Applicant is committed to learning and adapting along the way.

#### 20. 4C. Accessibility to Human Resources

What nurses are being referred to on page 18. Has the applicant identified its potential nursing staff for this project?

Please discuss the applicant's plan for providing all four levels of hospice care in the service area.

**Response :** **Response :** At this stage, Applicant has not yet recruited or identified individual nurses for this project. Applicant's primary focus has been developing a robust recruitment strategy to ensure it attracts skilled and compassionate nurses to its team. It plans to implement a multi-pronged approach, including:

- **Partnerships with Educational Institutions:** Actively target nursing schools and continuing education programs in the region to build relationships and promote its hospice agency to potential candidates.
- **Community-Based Hiring Events:** Host hiring events at churches, community centers, and other local gathering places within Shelby, Fayette, and Tipton counties to reach nurses who are deeply connected to these communities.
- **Online Recruitment:** Utilize job boards, social media, and professional nursing networks to cast a wide net and attract qualified candidates.

Applicant's goal is to build a nursing team that not only has excellent clinical skills but also reflects the cultural diversity of the communities it serves. Applicant is confident its recruitment strategy will allow it to identify dedicated nurses who share Applicant's commitment to providing exceptional hospice care.

Applicant will provide all four levels of hospice care (routine home care, continuous home care, general inpatient care, and respite care) in the service area. To ensure this, Applicant has a detailed plan to provide all four levels of hospice care. Applicant will prioritize hiring registered nurses, licensed social workers, hospice aides, and chaplains – the backbone of a multidisciplinary hospice team. Applicant will also seek partnerships with area universities, community colleges, and technical schools. Applicant's training plan includes in-depth orientation, mentorship, and ongoing education focusing on providing

care across routine home care, continuous home care, general inpatient care, and respite care. Additionally, Applicant will establish clear protocols for seamless transitions between levels of care.

## 21. 5C. License/Certification

Are the applicant's affiliates which share common ownership also CHAP accredited?

Please confirm that the applicant is pursuing licensure and CMS Certification for this project as a separate corporate entity from Heart and Soul Hospice, LLC.

Will the applicant establish a new NPI number from its affiliate - Heart and Soul Hospice, LLC?

Please discuss any overlap in the operational and management structure if this hospice agency and its affiliates, specifically with regard to the development and implementation of the agency's quality standards.

It appears that the applicant has registered an additional entity Heart N Soul Hospice of Florida LLC with the Tennessee Secretary of State. Please include this entity in any discussion of the previous question regarding the overlap in operational and management structure of the applicant.

**Response : Are the applicant's affiliates which share common ownership also CHAP accredited?**

**Response:** Applicant has some common ownership with Heart and Soul Hospice, LLC, but it is not necessarily considered an affiliated entity. Heart and Soul Hospice, LLC is CHAP accredited. David Turner is a common owner in Heart and Soul Hospice, LLC in Nashville, as well as in the applicant for Memphis. Sandy McClain and Andre Lee are common owners for both the Nashville agency and the proposed Memphis agency. Tracy Wood is an owner for the proposed Memphis agency. Combined, the applicant owners have over 40 years of hospice operational and management experience, and with that comes the ability to ensure the highest possible quality standards.

**Please confirm that the applicant is pursuing licensure and CMS Certification for this project as a separate corporate entity from Heart and Soul Hospice, LLC.**

**Response:** Applicant is a separate legal entity and as such will have separate licensure and CMS certification than Heart and Soul Hospice, LLC.

**Will the applicant establish a new NPI number from its affiliate - Heart and Soul Hospice, LLC?**

**Response:** Applicant is a separate legal entity from Heart and Soul Hospice, LLC and will have its own NPI.

**Please discuss any overlap in the operational and management structure if this hospice agency and its affiliates, specifically with regard to the development and implementation of the agency's quality standards.**

**Response:** Although distinct legal entities, the knowledge of Applicant's owners allows it to draw upon shared resources and best practices in developing the necessary and appropriate quality standards. The Applicant anticipates adopting policies for quality standards that are substantially similar to those of Heart and Soul Hospice, LLC.

**It appears that the applicant has registered an additional entity Heart N Soul Hospice of Florida LLC with the Tennessee Secretary of State. Please include this entity in any discussion of the previous question regarding the overlap in operational and management structure of the applicant.**

**Response:** Heart N Soul Hospice of Florida is in the planning stages and does not have a physical location in Florida at this time. It used the Nashville office as a temporary mailing address and registered the entity with the Tennessee Secretary of State's office so that it could open a bank account for the new Florida entity. Heart N Soul Hospice of Florida will not conduct any business or submit any applications in the State of Tennessee.

**22. 6C. Historical/Projected Data Chart**

Please discuss why no contractual adjustments are listed in the Projected Data Chart.

**Response Response:** There are no contractual adjustments because the applicant does not have a charge that : different than the Medicare payment.

<b>PROJECTED DATA CHART</b>		
	<b>Year - 2025</b>	<b>Year - 2026</b>
<b>A. Unit of Measure - Patient Days</b>	8,243	18,6

<b>B. Revenue of Services to Patients</b>		
Inpatient Services	\$0	\$
Outpatient Services	\$1,481,102	\$3,440,5
Emergency Services	\$0	
Other Operating Revenue	\$0	\$
<b>Total</b>	<b>\$1,481,102</b>	<b>\$3,440,5</b>
<b>C. Deductions from Gross Operating Revenue</b>		
Contractual Adjustments	\$0	
Provision for Charity Care	\$22,500	\$67,5
Provision for Bad Debt	\$21,442	\$48,1
<b>Total</b>	<b>\$43,942</b>	<b>\$115,6</b>

<b>Total Net Revenue</b>	<b>\$1,437,160</b>	<b>\$3,324,9</b>
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**23. 7C. Calculated Project Charges**

It appears that the gross charges per patient day in Year 1 and Year 2 are lower than the Medicare Reimbursement Rates. Please explain how the applicant's gross charges were projected.

**Response :** Medicare has two separate rates for routine home care – the rate for the first 60 days is higher and decreases after that. The applicant has used a blended rate that is an average between the two tiers to come up with a more accurate number for planning purposes.

	<b>Previous Year to Most Recent Year Year</b>	<b>Most Recent Year</b>	<b>Year One 2025</b>	<b>Year Two 2026</b>	<b>% Change (Current Year to Year 2)</b>
<b>Gross Charge (Gross Operating Revenue/Utilization Data)</b>	\$0.00	\$0.00	\$179.68	\$184.71	0.00
<b>Deduction from Revenue (Total Deductions/Utilization Data)</b>	\$0.00	\$0.00	\$5.33	\$6.21	0.00
<b>Average Net Charge (Net Operating Revenue/Utilization Data)</b>	\$0.00	\$0.00	\$174.35	\$178.50	0.00

**24. 10C. Project Only Payor Mix**

Please explain the absence of Commercial, Self-Pay or Other types of revenue for this project.

It is noted that Charity Care is projected by the applicant, but the applicant states in response to Criterion #5 of the Hospice Criteria and Standards that it does not expect the need to fundraise to support charity care of its patients. Please explain.

Which community clinic is the applicant referring to on page 24?

**Response :** Please explain the absence of Commercial, Self-Pay or Other types of revenue for this project.

**Response:** The Applicant anticipates only a small percentage of commercial insurance patients and no self-pay. Because Medicare is the overwhelming payor, there are generally no other significant payor sources for hospice services. The Project Only Payor Chart has been revised to show minimal commercial insurance and is included below:

**Applicant’s Projected Payor Mix**

**Project Only Chart**

Payor Source	Year 1-2025		Year 2-2026	
	Gross Operating Revenue	% of Total	Gross Operating Revenue	% of Total
Medicare/Medicare Managed Care	\$1,332,992	90%	\$3,156,385	89%
TennCare/Medicaid	\$133,299	9%	\$283,720	8%
Commercial/Other Managed Care	\$14,811	1%	\$106,395	3%
Self-Pay		0%		0%
Other (Specify)_____				
Total*	\$1,481,102	100%	\$3,546,500	100%
Charity Care	\$22,500		\$67,500	



**It is noted that Charity Care is projected by the applicant, but the applicant states in response to Criterion #5 of the Hospice Criteria and Standards that it does not expect to need to fundraise to support charity care of its patients. Please explain.**

**Response:**

Applicant acknowledges the potential confusion regarding its approach to charity care funding. Applicant wants to emphasize its commitment to providing care regardless of a patient's ability to pay.

A breakdown of Applicant's strategy follows:

- **Financial Planning:** Applicant factors in a reasonable budget for charity care as an essential cost of operating a hospice service in its proposed service area. This ensures that Applicant has the resources to support indigent patients without relying solely on fundraising.
- **Philanthropic Foundation:** Heart and Soul Hospice currently has a foundation that can also be used to support broader philanthropic efforts in Shelby, Fayette, and Tipton counties. The foundation periodically has fundraisers and may also receive donations in memory of patients for which it has provided care.

Attached is a copy of a flyer for an upcoming fundraiser and an obituary for Bart Durham, one of Heart and Soul Hospice LLC's recent patients, in which the obituary requested donations to the foundation.

- This foundation may raise funds for a variety of purposes beyond directly subsidizing charity care, such as:
  - **Community Outreach & Education:** Increasing awareness of hospice services within underserved communities.
  - **Support Services:** Offering grief counseling or bereavement support programs to families.

**Which community clinic is the applicant referring to on page 24?**

**Response:** Applicant intends on establishing partnerships with several community clinics such as:

- **Christ Community Health Services:** A major network of clinics serving low-income and uninsured residents across the Memphis area (including Shelby County). They have multiple locations. <https://www.christcommunityhealth.org/>
- **The Church Health Center:** A large faith-based clinic with a main location in Memphis (Shelby County) that offers comprehensive care based on a sliding fee scale. <https://churchhealth.org/>

**25. 3Q. Accreditation/Certification/Licensure Plans**

It is noted that the applicant is projecting that it will begin serving hospice patients in July 2024. What is the projected timeframe for the applicant to obtain CMS certification and CHAP Accreditation for its new hospice agency.

How will these timeframes impact that applicant's payor mix in the first two years of the project?

Has the applicant contacted any of the service area HMOs to confirm that they are accepting applications for new providers into their networks for the three service area counties?

**Response :** **Response:** Although Applicant is targeting July 2024 to begin serving hospice patients, Applicant recognizes that achieving CMS certification and CHAP accreditation are dependent on external factors. Here's an estimated general timeframe for Applicant's process:

- **State Licensure:** Applicant will initiate the state licensure application process within 30 days of receiving CON approval.
- **Concurrent Preparation:** While awaiting licensure, Applicant will simultaneously:
  - **Recruit & Build Team:** Proactively identify and hire qualified staff for all key roles.
  - **Establish Community Partnerships:** Continue outreach to healthcare providers and referral sources.
- **CMS & CHAP Applications:** Upon receipt of state licensure, Applicant will immediately submit applications for CMS certification and CHAP accreditation.
- **Readiness & Surveys:** Applicant will dedicate itself to thoroughly preparing for the necessary on-site surveys by CMS and CHAP.

### **Realistic Expectations**

Obtaining both CMS certification and CHAP accreditation can typically take several months. Applicant will maintain open communication with regulatory bodies and accrediting agencies to navigate the process efficiently. Applicant is committed to providing patient care at the earliest possible date following successful completion of all licensing and accreditation requirements.

As a part of the accreditation process, Applicant will need patients to which it is providing service (without reimbursement) to comply with the process. Applicant anticipates that it will start accepting patients in July 2024 and will become accredited by the end of 2024.

Because Applicant anticipates receiving accreditation by the end of 2024, it does not anticipate that its projections will be affected.

## 26. 8Q. Staffing

It is noted that no occupational, speech or physical therapist staff are included in the staffing chart. Please confirm whether this is accurate.

Why are positions listed for 0.0 FTE for three different position classifications in the staffing chart?

What will the contractual staff positions include?

**Response :** **Response:** Applicant's immediate staffing chart does not directly include occupational, speech, or physical therapists. To ensure these services are available to patients who require them, Applicant has established a model that utilizes skilled contractors in these disciplines.

This approach offers several benefits:

- **Patient-Centered Care:** Applicant can provide occupational, speech, and physical therapy services when they are specifically needed, tailoring treatment plans to individual patient needs.
- **Cost-Effectiveness:** Contracting allows Applicant to manage overhead costs while maintaining access to qualified therapists within the proposed service area.
- **Collaboration:** Applicant's core hospice team will collaborate closely with contracted therapists to ensure seamless care coordination and optimal outcomes for patients.

The 0.0 FTE listings for certain positions in our staffing chart reflect Applicant's adaptable approach to growth and our commitment to both patient care and employee well-being. Some of these positions will not be needed or hired until the second year when the utilization justifies it.

Specifically, the nurse triage position will be added strategically as our patient average daily census grows beyond 40. We anticipate the ADC reaching that number in year two of operation. Many hospices rely on their on-call nurses to manage both triage duties and additional patient visits. Applicant strongly believes that this can lead to burnout and potentially compromise care quality. By creating a dedicated nurse triage role, we can ensure:

- **Prompt Response to Patient Needs:** A dedicated triage nurse allows for timely, focused attention to urgent calls, especially during nights and weekends.
- **Support for On-Call Team:** Applicant's on-call nurses can focus on patient visits without the added burden of continuous triage responsibilities.
- **Employee Well-being:** This approach promotes a sustainable work environment for Applicant's nurses, fostering their ability to provide exceptional care over the long-term.

This model reflects Applicant's commitment to supporting its staff so they can provide the best possible care to the patients and families that Applicant will serve.

Contractual staff positions

- **Therapists:**

- **Physical Therapists:** Provide pain management, mobility support, and functional improvement as needed.
  - **Occupational Therapists:** Assist with activities of daily living, adaptive equipment, and energy conservation.
  - **Speech Therapists:** Address communication and swallowing difficulties.

- **Other Specialists:**

- **Pharmacist:** Expertise in medication management for complex pain and symptom control.
  - **Complementary Therapists** (Massage, Music/Art Therapy): to enhance patient comfort and quality of life, contracted as needed.

Please see revised staffing chart below:

<b>Position Classification</b>	<b>Existing FTEs (enter year)</b>	<b>Projected FTEs Year 1</b>
<b>A. Direct Patient Care Positions</b>		
<i>Hospice Aide/Homemaker</i>	0.00	3.30
<i>Nurse, RN Case Manager</i>	0.00	2.10

<i>Nurse, Oncall</i>	0.00	0.90
<i>Nurse, LVN/LPN (incl in Nurse RNCM #)</i>	0.00	0.00
<i>Coordinator, Volunteer</i>	0.00	0.20
<i>Nurse, Oncall Triage</i>	0.00	0.00
<i>Admission Nurse</i>	0.00	0.30
<i>Bereavement Coordinator</i>	0.00	0.20
<i>Social Worker</i>	0.00	0.70
<i>Chaplain</i>	0.00	0.50
<b>Total Direct Patient Care Positions</b>	0.00	8.20

<b>B. Non-Patient Care Positions</b>		
<i>Manager, Office</i>	0.00	1.00
<i>Coordinator, Volunteer</i>	0.00	0.20
<i>Director, Executive</i>	0.00	1.00
<i>Chaplain</i>	0.00	0.50
<i>Site Billing Coordinator</i>	0.00	0.00
<i>Patient Care Manager</i>	0.00	1.00
<i>Coordinator, Admissions</i>	0.00	0.50
<i>Patient Care Secretary</i>	0.00	1.00
<i>Office Support (Recp/Other)</i>	0.00	0.40
<b>Total Non-Patient Care Positions</b>	0.00	5.60
<b>Total Employees</b>	0.00	13.80
(A+B)		

<b>C. Contractual Staff</b>		
<i>Physical Therapy, Occupational Therapy, Speech Therapy, Pharmacist, Massage, Music/Art Therapy</i>	0.00	1.20
<b>Total Staff</b> (A+B+C)	0.00	15.00

**27. 1N. Criteria and Standards**

**Attachment 1N, Hospice Criterion #1. Adequate Staffing**

Please discuss the applicant's strategy for staffing this project in greater detail, including any relationships it has with local staffing resources such as universities or training programs.

Please discuss further the applicant's presence in the service area and familiarity with the hospice staffing market?

Who will serve as the Medical Director for this hospice agency?

**Response : Response:** Applicant’s staffing strategy is centered around attracting a skilled, compassionate team deeply connected to the Shelby, Fayette, and Tipton County communities. Applicant will implement a multi-pronged approach, prioritizing the following:

- **Local Recruitment:** Applicant’s goal is to build a team that reflects the diversity and understands the cultural nuances of the populations it serves. Applicant will focus on:
  - **Community Engagement:** Partner with churches, community centers, and local organizations to host job fairs and targeted recruitment events.
  - **Online Outreach:** Utilize job boards, local social media groups, and professional networks specifically tailored to the healthcare field.
- **Educational Partnerships:** Applicant seeks to build relationships with nursing schools, allied health programs, and continuing education organizations within the region. This includes:
  - **Internship & Mentorship Programs:** Offer opportunities for hands-on experience and early career development, attracting passionate new graduates.

- o **Guest Lectures:** Contribute knowledge and expertise to nursing programs, raising our profile among prospective employees.

· **Contracted Specialists:** To ensure access to specialized care, Applicant has established a network of highly qualified, contracted professionals including a medical director, physical therapists, occupational therapists, speech therapists, and others, as needed.

· **Employee-Centric Culture:** Applicant recognizes that attracting top talent requires a commitment to employee well-being. This includes competitive salaries, flexible scheduling, and ongoing professional development. A key example is Applicant's dedicated nurse triage position, ensuring on-call nurses aren't overburdened by providing support during nights and weekends.

### **Ongoing Development**

Applicant remains adaptable, continuously monitoring its staffing needs as its patient census grows. Applicant will explore additional recruitment strategies and partnerships based on local resources and the evolving healthcare landscape in the proposed service area.

While Applicant is seeking approval for a new hospice agency in Shelby, Fayette, and Tipton County area, Applicant's commitment to this region runs deep. Several members of Applicant's leadership team are long-time Tennessee residents, providing a strong foundation for understanding the state's healthcare landscape and the unique needs of the communities that Applicant aims to serve. Applicant recognizes that attracting a compassionate, skilled hospice team requires integrating ourselves into the fabric of these communities. Applicant has begun to establish relationships with healthcare providers in the proposed service area and has attended local health fairs to raise its visibility and connect with potential staff.

Additionally, Applicant has proactively researched the hospice staffing market. Applicant's findings indicate there is a pool of qualified nurses, social workers, and chaplains within the region. Applicant understands the competitive landscape and is prepared to offer attractive compensation packages that align with industry standards for the area. Applicant recognizes recruitment may present some challenges and has developed specific strategies such as flexible scheduling and potential sign-on incentives to attract qualified staff to these areas.

Applicant's commitment to building a successful hospice agency in Shelby, Fayette, and Tipton counties extends beyond providing care – Applicant is dedicated to becoming an integral part of the community and a respected employer within the hospice field. Applicant is excited by the prospect of building a dedicated team that shares our mission of providing exceptional end-of-life care.

Applicant is currently in the process of identifying a highly qualified Medical Director for its hospice agency. Applicant understands the crucial role this individual plays in ensuring excellent medical oversight and patient care. Applicant is actively seeking a physician who possesses the following:

- **Specialized Expertise:** Board certification in hospice and palliative medicine is ideal. If not board-certified, Applicant seeks a physician with extensive experience in this field.
- **Community Understanding:** Preference will be given to candidates who are already practicing within the Shelby, Fayette, and Tipton region and demonstrate an understanding of local healthcare resources and needs.
- **Collaborative Spirit:** Applicant's ideal Medical Director will be a team player, working closely with our interdisciplinary team to guide care plans and support Applicant's staff.

Applicant is confident that the region offers a pool of skilled physicians who align with Applicant's mission. Applicant is committed to finding the best possible candidate to lead Applicant's medical team.

## 28. 1N. Criteria and Standards

### Attachment 1N, Hospice Criterion #2. Community Linkage Plan

Please identify the healthcare providers and community agencies which the applicant's principals have developed a relationship within the service area.

Please describe and/or provide documentation of the applicant's relationships with appropriate health care system providers/services and working agreements with other related community services assuring continuity of care focusing on coordinated, integrated systems.

Please confirm whether the applicant intends to provide any letters from area physicians in support of the application detailing specific instances of unmet need.

**Response :** **Response:** Please see list of Applicant's established relationships with the specific community institutions, faith-based community entities and healthcare providers in the service area detailed in response to Item 4N.

## 29. 1N. Criteria and Standards



## Attachment 1N, Hospice Criterion #4 Access

Please discuss how patients who are not covered by Medicare or Medicaid will be handled.

If the applicant is requesting special consideration under Rule 0720-11-.01(1), please provide more detailed support for the limited access of the target population in the service area.

**Response : Please discuss how patients who are not covered by Medicare or Medicaid will be handled.**

**Response:** Patients without Medicare or Medicaid coverage will be carefully evaluated during the intake process. For those with commercial insurance, Applicant will verify eligibility and benefits. If a patient is found to be indigent, Applicant will adhere to its established eligibility process and, in line with traditional Medicare guidelines, admit and provide care if the patient qualifies for hospice services.

**If the applicant is requesting special consideration under Rule 0720-11-.01(1), please provide more detailed support for the limited access of the target population in the service area.**

**Response:** The applicant is not seeking special consideration. However, the Applicant strongly feels it will be providing services to a minority patient population that is not being served at the same rate as its white counterparts. As is demonstrated in the application and elsewhere in these supplemental responses, particularly in the discussion on hospice penetration rates, the black population clearly does not receive hospice services at the same rate as the white population does. The black population penetration rate for hospice services is significantly lower than that of the white population penetration rate for hospice services in Shelby County.

## 30. 1N. Criteria and Standards

### Attachment 1N, Hospice Criterion #5. Indigent Care

Please provide more specific information the applicant's plan for care of its indigent patients including:

- a. Demonstration of a plan to work with community-based organizations in the Service Area to develop a support system to provide hospice services to the indigent and to conduct outreach and education efforts about hospice services.
- b. Details about how the applicant plans to provide this outreach.

c. Details about how the applicant plans to fundraise in order to provide indigent and/or charity care.

**Response :** **Response:** Applicant is firmly committed to providing compassionate hospice care to all residents of Shelby, Fayette, and Tipton counties, regardless of their ability to pay. Applicant recognizes this as a core responsibility of operating a hospice service. To support this, Applicant is developing a comprehensive plan for indigent care, and will use the foundation dedicated to this mission.

**a. Community Collaboration:**

· **Partnership Identification:** Applicant has begun proactively identifying community-based organizations, including faith-based groups, social service agencies, and healthcare providers, that serve low-income populations and align with our mission.

· **Needs Assessment:** Applicant will work collaboratively with these organizations to perform a comprehensive needs assessment, pinpointing specific barriers to hospice access for indigent patients.

· **Outreach & Education:** Together with those partners, Applicant will develop culturally sensitive outreach and educational programs designed to increase awareness and understanding of hospice within underserved communities.

**b. Outreach Strategies**

· **Targeted Events:** Collaborate with community partners to host health fairs and informational sessions in areas with high concentrations of indigent populations.

· **Train-the-Trainer Model:** In concert with our community educators Applicant will equip leaders in community organizations with the knowledge and tools to educate their own members about hospice benefits and eligibility.

· **Diverse Materials:** Develop multilingual and culturally appropriate brochures, presentations, and resources for distribution through community partners.

**c. Fundraising for Indigent Care**

· **Dedicated Foundation:** Applicant's foundation will focus specifically on securing resources to support the care of indigent patients.

· **Grant Seeking:** Actively pursue grants from foundations, government agencies, and philanthropic organizations committed to expanding healthcare access for underserved populations.

· **Community Events:** Organize fundraising events (e.g., walks, auctions, dinners) in collaboration with community partners, fostering awareness and support.

. **Individual Donations:** Create a simple, accessible platform for individuals in the community to make direct donations in support of indigent care.

### 31. 1N. Criteria and Standards

#### Attachment 1N, Hospice Criterion #6 Quality Control and Monitoring

Please identify and document the existence of Quality Control and Monitoring policies and procedures of the applicant, i.e. do they already exist, will they be shared across multiple affiliates, etc.?

Please describe the applicant's specific plan for data reporting, quality improvement, and outcome and process monitoring.

Please provide a summary or overview of the applicant's affiliate agencies' latest surveys/inspections and any Department of Justice investigations and/or settlements as the applicant shares 65% common ownership with Heart and Soul Hospice, LLC.

**Response : Response:** Applicant plans to be accredited by CHAP and will follow its quality standards. CHAP divides its Standards of Excellence into three key areas: patient centered care, safe care delivery, and sustainable organizational structure. Each key performance area has standards and evidence guidelines. Applicant will also provide the HFC with such information as it reasonably requests related to quality.

Heart and Soul Hospice, LLC is fully accredited and had half of the number of deficiencies on its last state survey as it understands hospice providers usually have (6 versus 13). It has no DOJ investigations or settlements.

### 32. 1N. Criteria and Standards

#### Attachment 1N, Hospice Criterion #8. Education

Please provide a more detailed response of the applicant's plan in the Service Area to educate physicians, other health care providers, hospital discharge planners, public health nursing agencies, and others in the community about the need for timely referral of hospice patients, specifically as it related to enhancing outreach to the target population of this project.

**Response :** Applicant recognizes the importance of community education and outreach for hospice services in Shelby, Fayette, and Tipton counties. To address this need, Applicant will hire dedicated community educators who will be solely focused on this region. Applicant’s educators will utilize guided tools and resources to effectively engage with diverse populations, including:

· **Physicians & Healthcare Providers:**

- ○ Develop targeted educational materials highlighting hospice eligibility guidelines, emphasizing early referral benefits for the target population.
- ○ Conduct in-service presentations and workshops at hospitals, clinics, and long-term care facilities, fostering open conversations about end-of-life care choices.

· **Hospital Discharge Planners:**

- ○ Establish strong relationships with discharge planners, providing information that supports hospice referrals for patients meeting eligibility criteria, particularly within the target population.
- ○ Offer guidance on how hospice services can facilitate smoother transitions from hospital to home.

· **Public Health Nursing Agencies:**

- ○ Collaborate closely to identify potentially eligible patients within the target population, sharing resources and coordinating referrals.
- ○ Offer joint educational sessions for public health nurses to deepen their understanding of hospice care and its benefits for underserved communities.

· **Community Outreach:**

- ○ Partner with faith-based organizations, community centers, and advocacy groups serving the target population to address specific cultural, linguistic, and informational needs about hospice.
- ○ Develop culturally sensitive materials in relevant languages to dispel myths and provide clear information about the benefits of hospice care.

### 33. 1N. Criteria and Standards

#### Attachment 1N, Hospice Criterion #17 Need Formula

Please present data from the most current TDH Need formula which includes 2021-2022 data.

Please provide discussion regarding whether the applicant has met the need formula thresholds of 100 patients, and a positive need is shown in each service area county.

**Response : Response:** Please find attached a revised Attachment 1NR (Criteria and Standards Data) that includes 2021-2022 data for Criteria #14 and Criteria #17.

As stated in the discussion on the penetration formula in the application, even if the penetration rate is greater than the statewide median hospice penetration rate, an applicant may be able to provide good reason why the proposed service area counties should be included provided that the HFC determines that the inclusion of such county/counties contributes to the orderly development of health care. The application goes on to state that “[t]he Division believes that hospice services in Tennessee are underutilized, most likely as a result of community and societal norms and a need for more education to the general public on the benefits of hospice.” Applicant agrees that hospice services in Tennessee are underutilized, particularly for the African American population. Although penetration rates provide one way to determine need, another method for determining need for this particular application is to look at the extent to which African American and white patients receive hospice services. As previously noted, NHPCO studies report that the share of Medicaid decedents who used hospice services by race are as follows: (i) white Americans – 50%; (ii) African Americans – 35.6%. Instead, African Americans are more likely than white Americans to choose aggressive, life-sustaining interventions, including resuscitation and mechanical ventilation, even when there is little chance of survival. (see Association of American Medical Colleges, “Family, Fear, and Faith: Helping Black Patients with End-of-Life Decisions,” (July 2022)). At the root of the resistance, say researchers and African American physicians, is a toxic distrust of a health care system stemming from the “infamous Tuskegee syphilis experiment... gravediggers who exhumed the bones of enslaved people for anatomy lessons [and] researchers who used Henrietta Lacks’ cells without her consent.” (Id.). A hospice like the one Applicant proposes will work to educate the African American community in the proposed service area on the benefits of hospice.

#### 34. 1N. Criteria and Standards

##### Attachment 1N, Hospice Criterion #18 Assessment Period

Please address CN2202-007 Pruitt Health Hospice and Palliative Care of Western Tennessee, which does not appear to have reported data in the most recent JAR - 2023 but maintains an outstanding CON.

**Response : Response:** It is our understanding that licensure for PruittHealth is pending so it has not yet started serving patients.

**Project Name :** Heart N Soul Hospice Memphis

**Supplemental Round Name :** 2

**Certificate No. :** CN2403-007

**Due Date :** 5/2/2024

**Submitted Date :** 4/25/2024

### 1. 1N. Criteria and Standards

Please incorporate the supplemental responses to the Criteria and Standards into Attachment 1N and upload a revised Attachment 1N (labeled as Attachment 1NR).

**Response :** Please find a revised Attachment 1NR (Criteria and Standards Narrative) attached, which incorporates the supplemental responses submitted in connection with this application.

### 2. 4N. Special Needs of Service Area

Please include a source citation or link for the CMS Hospice data provided in response to Item 4N on pages 12 and 13 of Supplemental #1.

**Response :** HealthPivots DataLab, Hospice Penetration Rates by County. (Note: 2023 data represents Oct. 2022 to Sep. 2023). <https://datalab.healthpivots.com/>

### 3. 8Q. Staffing

Please discuss the inclusion of some positions in both the direct patient care and non-patient care positions categories of the Staffing Chart.

**Response :** The only positions on both the direct patient care and non-direct patient care position categories reflected on the Staffing Chart are Chaplain and Volunteer Coordinator ("VC"). Both of these roles will spend some time providing Direct Patient Care and some time doing community engagement, education, and outreach. The VC will also recruit additional volunteers to make sure Applicant has an adequate pool of volunteers for office and patient support.