



2021

# Pinellas County Community Health Needs Assessment

SUNCOAST HOSPICE  
FOUNDATION





Friends of Empath Health,

In so many ways 2020 was an unprecedented year. For Empath Health we found new and innovative ways to serve more than 34,049 people, an average of 4,000 each day, through telemedicine, free grief counseling for seniors impacted by the pandemic, birthday parties that we brought to clients' homes, livestreamed memorial services and more. Many of these new initiatives brought unexpected costs and through our Suncoast Hospice Foundation we provided over \$4 million in uncompensated care.

*Every day we explore ways to care for more in our community no matter their ability to pay.*

In an effort to better serve those living with chronic, advanced and terminal illnesses in Pinellas County, Empath Health launched a Community Health Needs Assessment led by the Foundation. This tool identifies the strengths and resources available in the community and needed by its citizens, and provides a framework for developing and identifying services and solutions that support individuals living with chronic, advanced or terminal illness.

The Pinellas County Community Health Needs Assessment offered the opportunity for Empath Health to engage and collaborate with public health and community stakeholders. It allows our staff to identify and understand the issues faced daily by those living with chronic, advanced and terminal illnesses. It also provided insight into access to comprehensive and quality healthcare services for these populations.

A special thank you to those who participated in the assessment for your dedication, time and invaluable contributions as well as the involvement of the many community leaders who added considerably to this report.

The findings of this report will be used to develop a measurable 2022–2023 Community Health Plan addressing priority issues and in the development of strategies we hope will improve the lives of those living in our community.

Sincerely,

A handwritten signature in black ink that reads "Rafael J. Sciuillo". The signature is written in a cursive, flowing style.

Rafael J. Sciuillo  
CEO Empath Health





## EXECUTIVE SUMMARY

### Purpose

In January 2021, Empath Health launched a Community Health Needs Assessment (CHNA) to better understand the needs of individuals and families facing chronic, advanced and terminal illness in Pinellas County. The intent of this assessment is to identify community assets, issues and barriers, in order to guide how we can improve our programs, services and partnerships to better meet the needs of the community and create shared solutions to long-term challenges.



*“to better meet the needs of the community”*

### Community Health Needs Assessment Task Force

An internal CHNA Task Force was created to guide the assessment. This task force was comprised of nine senior leaders from within Empath Health, including hospice, HIV/AIDS services, spiritual care, strategy/business development, access and inclusion, and the foundation. An Advisory Council of Empath Health senior leaders was also established to oversee the process. In addition to these internal committees, a Community Advisory Council comprised of experts in the Pinellas County community provided review of the final report.

## Process

Qualitative data for this assessment was gathered through 51 Key Informant interviews/questionnaires and two focus groups. A broad range of community stakeholders participated between February and April 2021, including representatives from the Florida Department of Health, hospitals, health associations, healthcare providers, senior citizen service organizations, social service organizations, academia, community leaders, cultural groups, veterans services, religious institutions and patient families.

Given the wealth of quantitative data available regarding the socioeconomic and health context in Pinellas County with respect to chronic, advanced and terminal illness, the CHNA Task Force did not consider separate collection of quantitative survey data to be necessary. A number of secondary sources provided the quantitative data for this assessment.

## Key Findings:

### Community Strengths and Assets

Strengths and assets supporting people with chronic, advanced and terminal illness in Pinellas County include: organizational collaboration, healthcare services, public policies/programs, community support networks and the many resources that are available.

Pinellas County is home to a wealth of quality healthcare service providers as well as a wide range of organizations, businesses and institutions – public, private, for-profit, not-for-profit, community-based and faith-based – that play proactive and important roles in supporting people with chronic, advanced and terminal illness and their families. Many of these stakeholders collaborate well with each other, enhancing the care and support available. There are also strong public programs at the county level that are supporting chronic illness prevention.

### Main Issues and Barriers

**Cost:** The cost of healthcare and related services for managing chronic and advanced illness is a primary barrier – even for people who have health insurance. However, obtaining affordable insurance coverage that adequately covers care and treatment needs is also a major barrier, especially given the gaps in Medicaid coverage in Florida. In addition, while healthcare costs take a huge toll on household income, chronic illness can also impact employment, making it even more challenging for people with chronic, advanced and terminal illness to afford care and make ends meet. Limited financial support is available for non-healthcare, but nonetheless essential, needs and costs.



**Equity:** People with chronic, advanced and terminal illness face barriers stemming from systemic disparities that impact equitable access to quality care, treatment and support, such as race-based disparities and biases, disparities and biases related to LGBTQ identities, language barriers and a lack of culturally informed services. While Pinellas County is undoubtedly resource rich, there are also challenges in ensuring that these resources are being efficiently and equitably accessed by those in need of care and support.

**Access:** Many people in Pinellas County struggle to access timely and appropriate care, for the cost- and equity-related reasons outlined above, as well as for other reasons such as geography, ability to communicate and work schedules. Lack of transportation is an ongoing issue and a barrier with respect to accessing care. COVID-19 also affected access to care in 2020.

**Care Navigation:** Challenges related to navigating the complexity of the healthcare system emerged as an overall issue and a barrier to care. Some of these barriers are knowledge-related, but the challenges go beyond knowledge, awareness and the “what” of available resources. Care navigation barriers include the “how” of accessing available services, support and assistance; care coordination and communication across providers; and patient advocacy to ensure needs are met. Navigating these challenges is even more daunting for patients and families who are in the midst of crisis as they manage their illness.

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# I.

## PURPOSE

In January 2021, Empath Health launched a Community Health Needs Assessment to better understand the needs of individuals and families facing chronic, advanced and terminal illness in Pinellas County. Empath Health recognizes that our programs and services must be intentionally tailored to our community and the people we seek to serve. The intent of this assessment is to identify issues, community assets and barriers that can enable us to improve our programs, services and partnerships in order to better meet the needs of the community and create shared solutions to long-term challenges.



This Community Health Needs Assessment (CHNA) is based on publicly-available quantitative data and thematic analysis of newly gathered qualitative information regarding chronic, advanced and terminal illness in Pinellas County, Florida. The assessment was conducted between January and June 2021.

A CHNA Task Force was created to ensure representation from across key departments within Empath Health. This task force comprised nine senior leaders from hospice, HIV/AIDS services, spiritual care, strategy and business development, access and inclusion, and the foundation. See Appendix 1 for the list of CHNA Task Force Members.

# II. METHODOLOGY

## ASSESSMENT PROCESS





The task force met multiple times over several months to guide the assessment process. The roles and responsibilities of task force members included: identifying key informants and primary points of contact/resources; contributing to the development of key informant (KI) interview and focus group questions; connecting with KIs and where appropriate conducting KI interviews; reviewing thematic coding and analysis; reviewing the use of secondary quantitative data; and overview of the final assessment document. An Empath Health CHNA Advisory Council was also established to review and guide the overall process, identify task force members, outline roles and responsibilities of task force members and oversee progress of the overall process. The council consisted of 10 Empath Health senior

leaders (as of the onset of the process). See Appendix 1 for the list of Empath Health CHNA Advisory Council Members. In addition to the Empath Health CHNA Advisory Council and the CHNA Task Force, a Community Advisory Council comprised of experts in the Pinellas County community was created to advise and review the final report. See Appendix 1 for the list of Community Advisory Council Members.

There is a wealth of quantitative data available regarding the socioeconomic and health context in Pinellas County with respect to chronic, advanced and terminal illness. The CHNA Task Force therefore did not consider a separate collection of quantitative survey data necessary at this time. The following served as key sources of quantitative data for this assessment:

- U.S. Census Bureau, 2019 American Community Survey 5-Year Estimates<sup>1</sup>
- Florida Department of Health data for Pinellas County accessed via FL Health CHARTS<sup>2</sup>
- *Pinellas County Community Health Assessment*, Florida Department of Health in Pinellas County, 2018<sup>3</sup>
- *An Equity Profile of Pinellas County, Florida*, PolicyLink and the Program for Environmental and Regional Equity (PERE) at the University of Southern California, in partnership with UNITE Pinellas, 2019<sup>4</sup>
- *Community Assessment Survey for Older Adults (CASOA) Report of Results – Area Agency on Aging of Pasco-Pinellas*, 2019<sup>5</sup>
- United Way ALICE (Asset Limited, Income Constrained, Employed) data for Pinellas County, Florida<sup>6</sup>

Qualitative information was gathered through 51 in-person key informant interviews/written key informant questionnaires as well as through two focus groups, one with members of the Suncoast Hospice Family Advisory Group and one with directors of various Empath Health boards. Information about key informants, focus groups and the key informant questionnaire can be found in Appendices 2, 3 and 4, respectively. Information gathered from KIs and focus groups provided qualitative information to support identification of community strengths and assets and top issues and barriers for residents of Pinellas County facing chronic, advanced or terminal illness. A broad range of community stakeholders participated

between February and April 2021, including representatives from the Florida Department of Health, hospitals, health associations, healthcare providers, senior citizen service organizations, social service organizations, academia, community leaders, cultural groups, veterans services, religious institutions and patient families. It should be noted that the assessment launched during the height of the COVID-19 pandemic, which limited group settings and in-person interaction; therefore, interviews and focus groups were conducted primarily via the Zoom platform.

Thematic analysis of qualitative information utilized an open coding process. The KI questions – which focused on community strengths/assets; top issues facing people with chronic, advanced and terminal illness; barriers to care; and strategies for addressing barriers – provided the overarching grouping of responses in the analysis. Responses were then explored further by assigning codes (themes) and subcodes (sub-themes) to identify commonalities and differences among participant responses. The codes emerged from the information itself and each code was defined to clarify its use. In order to help reduce bias and error in thematic coding, two task force members coded the responses and all task force members had the opportunity to review the full analysis framework. Please see Appendix 5 for the results of thematic coding. In order to support thematic analysis, emerging themes were compared against the frequency of word use across respondents, based on their verbatim responses.



# III.

## SERVICE AREA



### Geographic: Pinellas County

Pinellas County is located on a peninsula between Tampa Bay and the Gulf of Mexico in West Central Florida. With a land area of 274 square miles and a 2019 estimated population of 964,666, it is the most densely populated county in the state.<sup>7</sup> This population is projected to grow to nearly 1.04 million by 2030.<sup>8</sup> The county contains 24 cities/municipalities, with St. Petersburg being the largest city and Clearwater serving as the county seat. Nearly one third of the county is unincorporated, with services directly administered by the county government. Much of the county is designated by HRSA as Primary Care Health Professional Shortage Areas for the low income population, including notably the areas around St. Petersburg, Pinellas Park, Clearwater and Tarpon Springs.<sup>9</sup>

Empath Health serves all of Pinellas County, with four facilities located in the southern part of the county, three facilities located in the middle of the county, and two facilities located in the northernmost part of the county, as well as three Resale Shops.



### Specialized Target Population: Chronic, Advanced and Terminal illness

The Empath Health network serves individuals living with or impacted by chronic, advanced and terminal illness. In 2020, the most common conditions and illnesses that Empath Health affiliates cared for were related to cancer (notably lung, breast, pancreatic, colon and prostate cancer), heart disease, Alzheimer's disease and other forms of dementia, stroke, Chronic Obstructive Pulmonary Disease (COPD) and respiratory failure, kidney disease, and HIV/AIDS. We also cared for many patients with COVID-19.

The National Center for Chronic Disease Prevention and Health Promotion defines chronic diseases as "conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both."<sup>10</sup> This may include conditions such as heart disease, cancer, diabetes, stroke and COPD, among others. Chronic diseases

are among the leading causes of death, disability and high healthcare costs in the United States. The Coalition to Transform Advanced Care (CTAC) defines advanced illnesses as those which "occur when one or more chronic conditions progress to the point where general health and functioning declines and response to treatment is reduced."<sup>11</sup> This is a process that continues to the end of life. Healthcare providers who focus on chronic and advanced illness may also refer to "serious illness." A serious illness may be considered "a health condition that carries a high risk of mortality and commonly affects a patient for several years."<sup>12</sup> According to the Centers for Medicare and Medicaid Services, with respect to the federal hospice benefit, terminal illness is defined by "a medical prognosis of six months or less to live if the illness runs its normal course."<sup>13</sup>

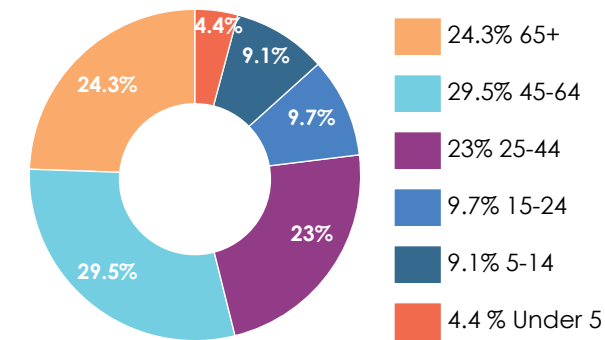




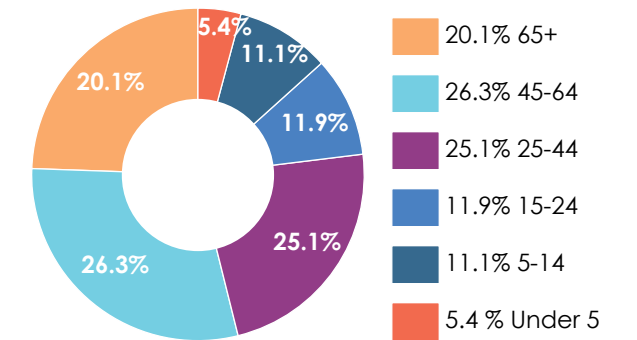
# IV.

## DEMOGRAPHIC AND SOCIO-ECONOMIC CHARACTERISTICS OF PINELLAS COUNTY

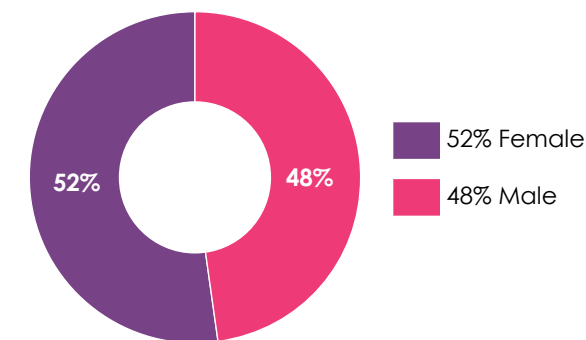
**Age Demographics**  
Pinellas County



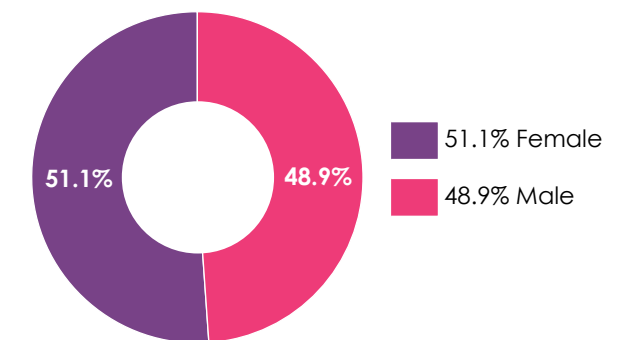
**Age Demographics**  
Florida



**Gender Demographics**  
Pinellas County



**Gender Demographics**  
Florida

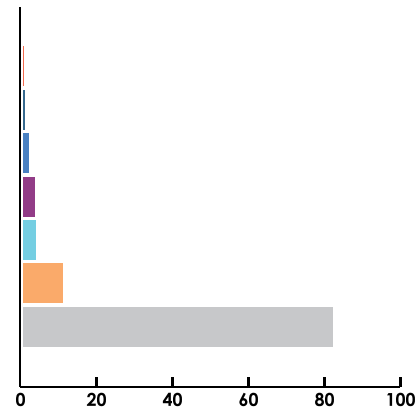


### Demographics

The majority of Pinellas County residents (85.6%) speak only English at home and 6.5% speak Spanish at home. The proportion of people who speak Spanish at home is notably lower in Pinellas County than in Florida overall. In Florida, 11.9% report speaking English less than “very well,” whereas in Pinellas 5.2% report speaking English less than “very well.”<sup>14</sup> For residents with less proficiency in English, it can be more difficult to access healthcare and other services.<sup>15</sup>

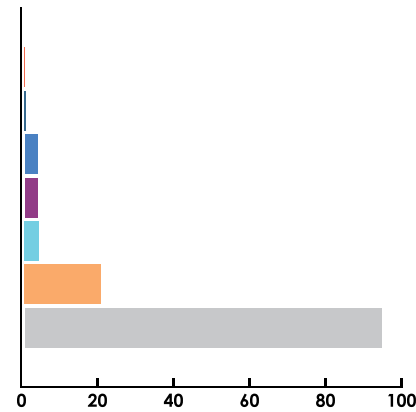
Pinellas County's population is older, on average, than the state population. The median age in Pinellas County is 48 years, which is nearly six years older than the median age in Florida (42), and 39.6% of households in Pinellas County have one or more people aged 65 or older, compared to 36.3% statewide.<sup>16</sup> According to information from the United Way, between 2010 and 2018, White households in Florida increased by 3% and had a larger proportion of people

**Race Demographics**  
Pinellas County



- 81.5% White
- 10.3% Black / African American
- 3.4% Asian
- 3.1% Two or more races
- 1.4% Other race
- 0.3% American Indian / Alaskan Native
- 0.1% Native Hawaiian / Other Pacific Islander

**Race Demographics**  
Florida



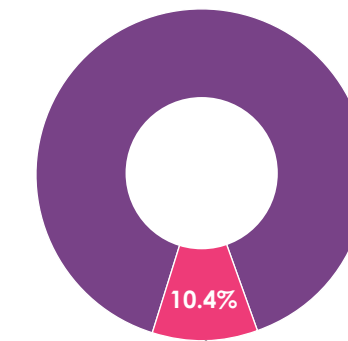
- 75.1% White
- 16.1% Black / African American
- 3.0% Other race
- 2.7% Two or more races
- 2.7% Asian
- 0.3% American Indian / Alaskan Native
- 0.1% Native Hawaiian / Other Pacific Islander

Source: U.S. Census Bureau, 2019 American Community Survey 5-Year Estimates

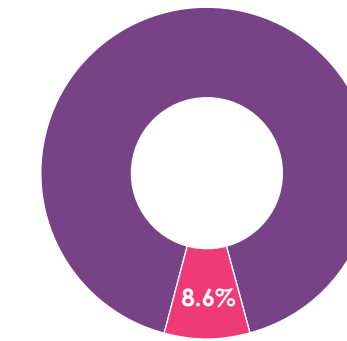
aged 65 or older.<sup>17</sup> This finding is consistent with the 2019 Equity Profile of Pinellas County, which highlighted that communities of color in Pinellas County are “more youthful than its White population.” The Equity Profile presents trends that project that between 2020 and 2050, Pinellas County will become increasingly diverse, with a particularly notable increase in the population share of the Hispanic population from 11% to 22%.<sup>18</sup> The dynamics of a more diverse working-age population and a large White elderly population will make diversity, equity and inclusion considerations increasingly important with respect to care and the care economy.

The rate of older adults living alone is notably higher in Pinellas County: 17.3% of households are comprised of someone 65 or older who is living alone, compared to 12.9% statewide.<sup>19</sup> Overall, 31% of Pinellas County residents who are 65 or older live alone, compared to 24% statewide.<sup>20</sup> A 2018 AARP survey found that 76% of Americans age 50 and older want to age in place in their current home.<sup>21</sup> In many cases, this requires support from a caregiver. According to the Community Assessment Survey of Older Adults (CASOA) for Pinellas and Pasco counties, which surveyed residents 60 or older, 24% of respondents reported that they receive assistance. Over a third of respondents (37%), reported providing care for one or more individuals who are also 60 or older, at an average of 13 hours of care

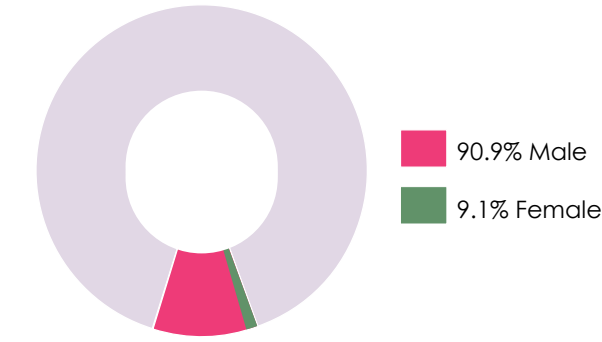
**Proportion of Veterans Population**  
Pinellas County



**Proportion of Veterans Population**  
Florida



**Proportion of Female Veterans Population**  
Pinellas County



per week. With respect to senior day care options in their community, 45% of CASOA respondents reported “don’t know” and only 22% reported these options to be good or excellent. The CASOA also highlighted the coming “caregiver crunch” in which “the average American will spend more years caring for parents than for their own children.”<sup>22</sup>

Aging results in an inevitable decline in health and a greater likelihood of serious and life-limiting illness. According to the CASOA, older adults in Pinellas and Pasco counties report better physical health than other communities in the U.S., with 75% of respondents rating their health as good or excellent and only 25% rating their health as

fair (20%) or poor (5%).<sup>23</sup> This accords with Department of Health data, which indicate that 77.9% of adults 65 or older in Pinellas County report good or better health status. However, it is also important to note that Black and Hispanic adults 65 or older are more likely to report fair or poor health than Whites.<sup>24</sup>

The proportion of the Pinellas County population who are veterans (10.4%) is notably higher than the proportion for both Florida (8.6%) and the U.S. overall (7.3%). Within the population of veterans in Pinellas County, 9.1% are female, which is similar to percentages of female veterans statewide (9.3%) and nationally (8.9%).<sup>25</sup>



### Economic Status

Economic constraints impact an individual's ability to access factors that are critical to health, such as housing, nutrition, insurance and education, among others. It also directly impacts access to medical care and treatment. In 2016, cost barriers prevented 17.2% of Pinellas County adults from seeing a doctor at least once in the previous year.

According to the 2019 five-year estimates from the U.S. Census Bureau's American Community Survey, the median household income in Pinellas County was \$54,090 (more than \$5,000 less than the median income for the state of Florida and more than \$8,700 less than the national median). Median income differs significantly across demographic groups: \$59,894 for Asian households, \$55,791 for White households, \$39,080 for Black households, and \$46,567 for Hispanic households.<sup>26</sup>

In 2019, the poverty rate in Pinellas County was 12.2% overall (slightly lower than the Florida state rate of 14%), and 10% for people 65 or older.<sup>27</sup> Poverty also differs significantly across racial demographic groups: 10.6% for Whites, 10.9% for Asians, 23.5% for Blacks and 16.6% for Hispanics.<sup>28</sup> It is important to note that the federal poverty level is determined based on the cost of food and does not reflect how household expenses have evolved since the measurement methodology was developed in the 1960s. Thus, it may be underestimating poverty.<sup>29</sup> The United Way studies what it calls the ALICE population: Asset Limited, Income Constrained, Employed. These are households that earn more than the federal poverty level, but less than the "ALICE threshold," which is a measure of the basic cost of living by county that includes housing, child care, food, transportation, technology, healthcare, and taxes. In 2018,

35% of Pinellas County households were above the federal poverty level but below the ALICE threshold. This rises to 45% for households that are 65 and older. This means there is a high proportion of households in Pinellas County – approaching half – that struggle or are unable to make ends meet.<sup>30</sup>

According to the Equity Profile of Pinellas County, the overall median hourly wage in Pinellas County in 2016 was \$19.30, with notable differences across demographic groups: \$20.20 for White workers, \$14.80 for Black workers and \$15.00 for Hispanic workers.<sup>31</sup> None of these medians reach the "living wage" level for a household with one working adult and one dependent.<sup>32</sup> Between 2000 and 2016, as the share of jobs in low-wage industries (e.g., retail and food service) grew, average earnings increased only 4% for those in low-wage industries (compared to a 10% increase for those in high-wage industries). Adjusted for inflation, wages have declined for the lower 50% of the county's workers since 1999. People of color are most impacted, having lower hourly median wages than Whites even across different education levels. These factors contribute to income inequality, which has been increasing in Pinellas County, as well as in the rest of the country, for decades. Beyond individual income, income inequality has its own impacts on health: reducing inequality is predicted to produce better overall health outcomes for our communities and reduce healthcare spending.<sup>33</sup>

The 2020 ALICE report for Florida anticipates that more Florida seniors will fall below the ALICE threshold in coming years. One factor is increased health costs, as out-of-pocket healthcare costs increase (due in large part to costs related to chronic conditions such as heart disease and diabetes).<sup>34</sup> Among respondents to the CASOA survey in Pinellas and Pasco counties, 39% reported that the cost of living in their community is good or excellent and 57% reported that it is fair or poor (with housing and insurance affordability being key factors). However, 66% reported that they do not have a problem with having enough money to meet daily expenses and only 17% reported that this was a moderate or major problem.<sup>35</sup>



## Housing

Housing is a social determinant of health. Unstable housing can make it much more difficult for people with chronic and advanced illnesses to access care and manage treatment regimens. Indeed, for people living with HIV, housing is one of the strongest predictors of access to treatment and life expectancy. Unsuitable, ill-equipped or poor-quality housing can also make it difficult for people with serious illnesses to live healthily and independently. The U.S. Department of Housing and Urban Development (HUD) defines households that pay more than 30% of their income for housing as “cost burdened.” By this measure, 33.7% of Pinellas County households are cost burdened. The proportion of income spent on housing impacts both housing stability and the ability of households to afford healthcare and other health-related needs, such as food and transportation.

Pinellas County is home to 407,546 households. Sixty-seven percent of households live in a residence that they own. For owner-occupied households, 25.6% are cost burdened.<sup>36</sup> White residents of Pinellas County are more likely to own their home than Black or Hispanic residents. This is important because home ownership helps support stable housing and lessen housing displacement and eviction risks.<sup>37</sup> Approximately 33% of households in Pinellas County are renters, and the median rent is \$1,112 (higher than the median rent nationwide).<sup>38</sup> Half of renter households in Pinellas County are cost burdened.<sup>39</sup> According to the National Low Income Housing Coalition, workers need to earn \$23.19 per hour (or \$48,240 annually) to be able to afford a two-bedroom rental apartment in Pinellas County. This is equivalent to 2.7 full-time jobs at minimum wage.<sup>40</sup>

According to HUD's 2020 Annual Homeless Assessment Report to Congress, Pinellas County (St. Petersburg/Clearwater/Largo) ranked among the top nationwide in our category (“other largely urban” areas) with respect to the largest numbers of homeless individuals (1,876) and largest numbers of people experiencing family homelessness (350). The county ranked first nationwide in our category for the largest numbers of veterans experiencing homelessness (265) and the largest numbers of chronically-homeless individuals (572).<sup>41</sup> People experiencing homelessness face high rates of chronic illness and greater challenges accessing factors essential to health, such as adequate nutrition. Chronically-homeless people often receive little or no healthcare and have a mortality rate that is significantly higher than the general population.<sup>42</sup>

Housing and its related costs impact the ability of older adults and people with serious illnesses to live independently. The Elder Care Index from the University of Massachusetts Boston measures the income required for

an older adult to live independently in a given jurisdiction. For Pinellas County, the Elder Index for a single renter in poor health is \$25,860 (\$2,155 per month). The bulk of this is housing costs, followed by health costs. The most costly housing situation is for a single elderly homeowner who is still carrying a mortgage: \$30,540 per year.<sup>43</sup> Among older adults in Pinellas and Pasco counties, 82% reported owning their home (28% with a mortgage and 54% with no mortgage). Twenty-five percent reported that having enough money to pay their property taxes is a problem. With respect to factors that impact independent living, 40% of older adults reported having installed accessibility features in the bathroom and 38% reported that maintaining their home is a problem. Less than a third of CASOA respondents rated the availability of affordable housing in their community as good or excellent; however, long-term care options and the variety of housing options in Pinellas and Pasco counties were rated as good or excellent by 32% and 40% of respondents, respectively.<sup>44</sup>



### Transportation

Transportation is a social determinant of health that impacts an individual's ability to access healthcare services and practice healthy behaviors. In Pinellas County, 7.7% of households have no vehicle available, which is higher than the overall percentage for Florida (6.3%).<sup>45</sup> In 2019, prior to the pandemic, most people in Pinellas County were reliant on a vehicle to get to work, with 78% driving on their own and 8% carpooling. Only 1.7% of workers commuted via public transport, 1.7% walked, and 3% took another non-vehicle means. Black and Hispanic households in Pinellas County are less likely to have a vehicle and more likely to be dependent on public transport, compared to White households.<sup>46</sup>

According to the CASOA, 26% of older adults in Pinellas and Pasco counties reported that having safe and affordable transportation available was a problem. Half of respondents (50%) reported that ease of travel by public transport in their community was fair or poor and 25% reported "don't know", which is not surprising as 89% reported that they had not used public transport at all in the previous 12 months. However, 45% of older adults surveyed felt that the accessibility of sidewalks for wheelchairs and other mobility devices was good or excellent in their community.<sup>47</sup>

### Technology

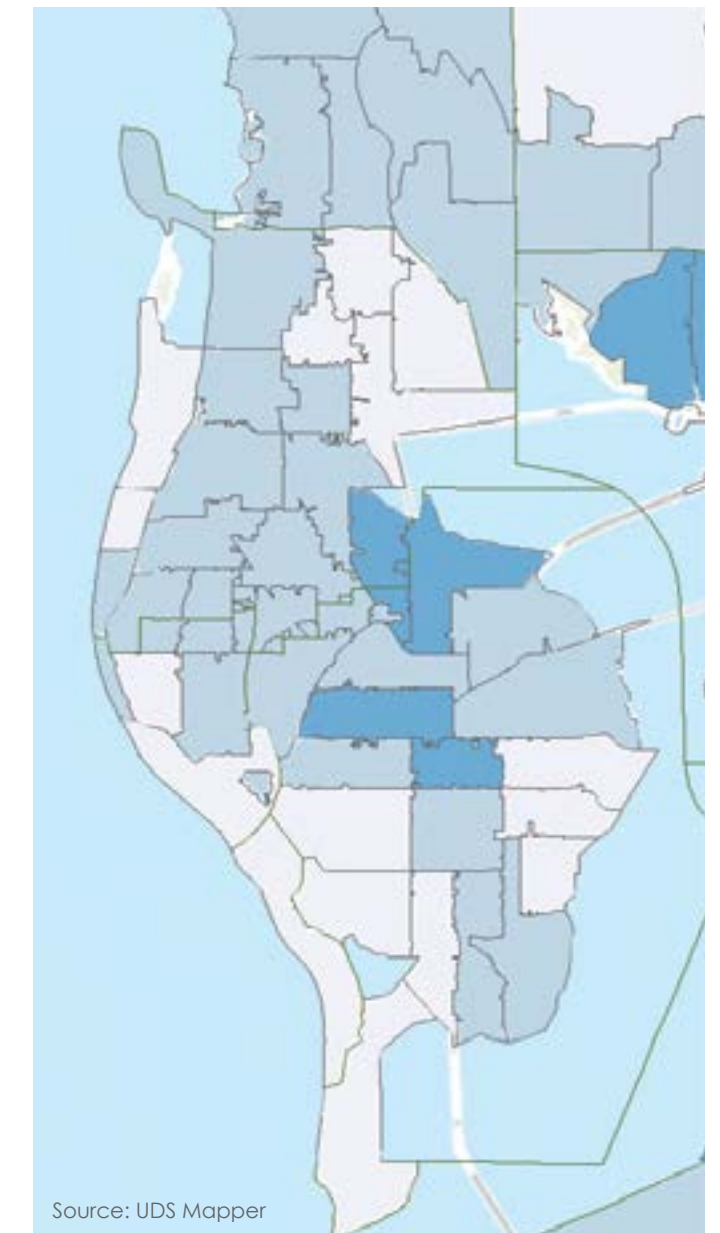
Almost 83% of households in Pinellas County have a broadband internet subscription.<sup>48</sup> The AARP's annual nationwide technology survey found that older adults' use of technology increased notably in 2020, although 54% of respondents said they "want a better grasp of the devices they've acquired" and 37% still lack confidence in using technology.<sup>49</sup> People without adequate internet access or skills increasingly face a "digital divide" and are at risk of being left further and further behind as access to healthcare and healthcare systems becomes increasingly reliant on technology.

### Health Insurance Coverage

Nearly 11% of Pinellas County residents lack health insurance coverage, which is lower than the Florida state rate of 12.8%.<sup>50</sup> As of 2016, there were notable demographic differences in insurance coverage for people in Pinellas County age 26 or older, with 88% of Whites having coverage, 81% of Blacks, 80% of Asians and Pacific Islanders, and 71% of Hispanics.<sup>51</sup> Lack of health insurance coverage may mean that these residents go without preventative care or needed medical treatment. The 2018 Pinellas County Community Health Assessment found that residents who make less than \$25,000 per year were significantly less likely to have insurance coverage and that almost 15% of adults had not been able to see a doctor

when they needed care at some point in the past year due to cost.<sup>52</sup> The CASOA found that 29% of older adults surveyed in Pinellas and Pasco counties reported that finding affordable health insurance was a problem.<sup>53</sup>

**Map of Uninsured People in Pinellas County**  
(Darker shading indicates a higher percentage of uninsured)



Source: UDS Mapper



# V.

## CHRONIC, ADVANCED AND TERMINAL ILLNESS IN PINELLAS COUNTY

LEADING CAUSES OF DEATH PINELLAS COUNTY, 2019	DEATHS	PERCENT OF TOTAL DEATHS
Heart Disease	2,616	21.48%
Cancer	2,564	21.05%
Unintentional Injury	851	6.99%
Chronic Lower Respiratory Disease	730	5.99%
Stroke	608	4.99%
Diabetes	329	2.7%
Alzheimer's Disease	286	2.35%
Suicide	189	1.55%
Chronic Liver Disease & Cirrhosis	185	1.52%
Nephritis, Nephrotic Syndrome & Nephrosis	174	1.43%
Hypertension	152	1.25%
Septicemia	139	1.14%

Source: FL Health Charts, Leading Causes of Death - Pinellas County, Florida 2019

As of 2019, life expectancy in Pinellas County was on par with Florida overall, approximately 79 years (76 years for men and 82 years for women).<sup>54</sup> The overall leading cause of death in Pinellas County in 2019 was heart disease, followed by cancer. Heart disease was the leading cause of death for men and across the White, Black and Hispanic populations. However, for women, the leading cause of death in 2019 was cancer, with heart disease second.<sup>55</sup> According to the 2018 Pinellas County Community Health Assessment, there is a trend of increasing deaths due to unintentional injury, (a category which includes motor vehicle accidents, drug overdose, falls, drowning, and others), Alzheimer's disease and suicide.<sup>56</sup>

According to the CDC, chronic diseases are the leading drivers of death, disability and healthcare costs in the U.S. Six in 10 Americans live with chronic disease and 90% of U.S. healthcare expenditures are for people with chronic and mental health conditions.<sup>57</sup> The Global Burden of Disease project, which seeks to quantify health loss by looking at both prevalence and relative harm caused by different diseases and risk factors, found that the top five causes of death and disability in Florida in 2019 were heart disease, drug use disorders, low back pain, Chronic Obstructive Pulmonary Disease (COPD) and diabetes.<sup>58</sup>

CHRONIC ILLNESS / CONDITION	PINELLAS			FLORIDA		
	Adults who have ever been told they had it (2016)	Hospitalizations (per 100,000, 2017-19)	Deaths (age adjusted per 100,000, 2017-19)	Adults who have ever been told they had it (2016)	Hospitalizations (per 100,000, 2017-19)	Deaths (age adjusted per 100,000, 2017-19)
Diabetes	10.5%	2,253.2	21.0	11.8%	2,320.9	20.3
Chronic Lower Respiratory Disease		279.6	39.8		301.1	38.1
Stroke	3%	217.0	29.4	3.5%	233.3	40.7
Coronary Heart Disease	6%	255.7	93.5	4.7%	278.1	91.1
Kidney Disease (Nephritis, Nephrotic Syndrome & Nephrosis)	2.4%		9.8 (2019 only)	3.2%		10.1 (2019 only)

Source: FL Health Charts, County Chronic Disease Profile, Pinellas County Florida - 2019

There are demographic differences with respect to chronic disease prevalence and outcomes. Black individuals in Pinellas County are more than twice as likely as White individuals to be hospitalized for or die from diabetes.<sup>59</sup> According to the community survey that was part of the Pinellas County Community Health Assessment in 2018, Black women, Hispanic men and individuals with income under \$25,000 per year may have higher overall rates of diabetes than others in Pinellas County. The Community Health Assessment's analysis of increasing preventable diabetes-related hospitalizations highlighted that people with diabetes in Pinellas County may be going undiagnosed or may lack what they need to manage their condition.<sup>60</sup>

Black individuals in Pinellas County are also more likely than White individuals to be hospitalized for or die from coronary heart disease, and more than twice as likely to be hospitalized for (although slightly less likely to die from) chronic lower respiratory disease (including asthma). They are also more than twice as likely to die from kidney disease.<sup>61</sup> In addition, the Pinellas County Community Health Assessment survey found that households with greater income were at less risk for stroke, possibly due to having more access to healthcare and/or less overall stress.<sup>62</sup>

CANCER	PINELLAS		FLORIDA	
	Incidence (new cases, age-adjusted per 100,000, 2017-19)	Deaths (age-adjusted per 100,000)	Incidence (new cases, age-adjusted per 100,000, 2017-19)	Deaths (age-adjusted per 100,000)
Breast	125.6	19.8	119.5	19.0
Prostate	85.8	15.2	87.7	17.0
Melanoma (Skin)	32.5	2.9	25.1	2.2
Lung	61.8	39.5	56.9	35.3

Source: FL Health Charts, County Chronic Disease Profile, Pinellas County Florida - 2019

### Cancer

Pinellas County is in the least favorable quartile of counties in Florida with respect to new cases of breast cancer and new cases of melanoma. However, prostate, colorectal and cervical cancer rates are lower than state averages.<sup>63</sup> In Pinellas County, 45.7% of cancer cases are diagnosed at an advanced stage. With respect to differences across demographic groups, Black individuals in Pinellas are more likely than White individuals to be diagnosed with cancer at an advanced stage and more likely to die from cancer. Black individuals are more than twice as likely to die from cervical cancer and more than three times more likely to die of prostate cancer.<sup>64</sup>

### Alzheimer's Disease

Alzheimer's disease is a degenerative brain disease that begins with mild memory loss and progressively affects memory, thinking and behavior. It is the most common cause of dementia and over time can seriously impact an individual's ability to carry out activities of daily living. It can result in very high care needs and costs. Women are more likely to suffer from Alzheimer's than men, and Black and Hispanic individuals are more likely to suffer from Alzheimer's than White individuals.<sup>65</sup> In Pinellas County in 2020, the rate of "Probable Alzheimer's Cases" for individuals 65 or older was 13.3% (compared to 12.7% statewide). Pinellas County is in the least favorable quartile of Florida counties with respect to probable cases. The true extent of people with Alzheimer's is unknown.





### Alzheimer's Disease (cont)

and probable rates are estimated based on the diagnosed rates within certain age groups.<sup>66</sup> The death rate from Alzheimer's disease in Pinellas County in 2019 was 13.4 per 100,000 population (age-adjusted), which was lower than the statewide rate of 18.8.<sup>67</sup> Across the US, death rates and costs of care due to from Alzheimer's are increasing.

### HIV

The human immunodeficiency virus (HIV) is an infectious disease that weakens the body's immune system. Left untreated, it can lead to acquired immunodeficiency syndrome (AIDS) and eventual death. Once acquired, HIV is a life-long condition. Although there is currently no cure for HIV, it can be effectively controlled and suppressed with proper medical care and treatment. It can also be effectively prevented through safe practices, pre-exposure prophylaxis (PrEP) treatment and immediate post-exposure prophylaxis (PEP) treatment. According to the Florida Department of Health, there were 4,853 people living with HIV (PLWH) in Pinellas in 2019 and 196 new HIV diagnoses, ranking seventh among Florida counties. Communities of color and the LGBTQ

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*Although there is no cure for HIV, it can be effectively controlled and suppressed with proper medical care and treatment.*

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community are disproportionately impacted by HIV. Critical to meeting state and national HIV reduction goals is ensuring that all PLWH are aware of their status, rapidly linked to and retained in care and achieving viral suppression. However, in 2019, 20% of PLWH in Pinellas County were not retained in care and 24% were not virally suppressed.<sup>68</sup>

### Risk Factors

Many chronic diseases are caused by just four main risk behaviors: (1) tobacco use/secondhand smoke, (2) poor nutrition, (3) lack of physical activity and (4) alcohol consumption.<sup>69</sup> According to the Global Burden of Disease project, the top-10 risk factors that most drive death and disability in Florida are: tobacco use, high body-mass index (an indicator of overweight or obese), high fasting plasma blood glucose (an indicator of diet and diabetes risk), high blood pressure, dietary risks (e.g., diets low in "good" elements such as fruits

and vegetables and/or high in "bad" elements such as sodium and trans fat), drug use, alcohol use, high LDL (high "bad" cholesterol), kidney dysfunction (a factor in cardiovascular diseases, chronic kidney disease, among others), and occupational risks (e.g., occupational exposure to carcinogens and other health hazards).<sup>70</sup> According to the project, "[i]f, over time, people engage in less risky behavior, or if fewer people live in risky conditions, then the incidence of health problems associated with that risk factor should go down."<sup>71</sup>

Diet and nutrition are important factors that can contribute to health or increase risk for chronic conditions such as heart disease, diabetes, hypertension, certain cancers and other issues. Food insecurity refers to people who do not have "consistent access to enough food for an active, healthy life."



**Risk Factors (cont)**

According to the Florida Department of Health, 12.9% of the Pinellas County population was food insecure in 2018, compared to 13% in Florida overall.<sup>72</sup> According to the 2020 ALICE report for Florida, food insecurity is increasing for both young and older adults. Seniors who are food insecure are more likely to have depression, asthma, heart attacks and congestive heart failure.<sup>73</sup> Among CASOA respondents, 31% report that availability of affordable quality food in their community is fair or poor, 14% report that maintaining a healthy diet is a moderate or major problem (25% report it to be a minor problem), and 14% report that having enough food to eat is a problem for them.<sup>74</sup>

Obesity refers to a weight that is significantly higher than what is considered as healthy for a given height, defined for adults by a body-mass index (BMI) of 30.0 or higher.<sup>75</sup>

Obesity increases risk for a number of different chronic diseases, such as diabetes and heart disease. According to data from the Behavioral Risk Factor Surveillance System (BRFSS), 28.1% of adults in Pinellas County were obese in 2016 (compared to 27.4% statewide) and 35.8% were overweight. Demographically, 38.8% of Black adults were obese, 26.9% of White adults, and 22% of Hispanic adults.<sup>76</sup> For Pinellas County residents age 65 or older, 34.9% were obese in 2016 (compared to a state rate of 25.8%), with Whites more likely to be obese than Hispanics (26.9% compared to 22%) and Blacks more likely to be obese than Whites (38.8%).<sup>77</sup>

Physical activity reduces risk of serious illnesses and can help manage conditions and complications related to some chronic diseases. According to BRFSS data, 54.4% of adults in Pinellas County were inactive or insufficiently active in 2016 and 47.3% meet aerobic activity recommendations. The CASOA found that 42% of older adults in Pinellas and Pasco counties participate in

PINELLAS	FLORIDA	
15.4%	13.4%	Residents living with a disability
33.3%	32.8%	Residents 65 years or older with a disability
4.8%		Hearing difficulty
2.9%		Vision difficulty
5.6%		Cognitive difficulty
8.7%		Ambulatory difficulty
3.1%		Self-care difficulty
6.5%		Independent living difficulty

Source: U.S. Census Bureau, 2019 American Community Survey 5-Year Estimates

moderate or vigorous physical activity.<sup>78</sup> Pinellas County has higher rates of adults who are current smokers and heavy drinkers, compared to state rates. We have the sixth highest percentage of adults who are heavy drinkers in the state, when compared to other counties.<sup>79</sup> According to BRFSS data, 20.3% of adults in Pinellas County are current smokers and 20.9% report engaging in heavy or binge drinking. The data indicate that White adults are more likely to be heavy drinkers than Black adults (21.5% and 15.2%, respectively), and Hispanic adults are more likely to be heavy drinkers (22.8%) than both White and Black adults. Black adults are more likely to be current smokers (36.7%) than both White adults (18.9%) and Hispanic adults (15.1%).<sup>80</sup> For residents over the age of 65, 8.6% report being a current smoker and 12.5% report heavy drinking, compared to 8.4% and 8.7% statewide, respectively.<sup>81</sup>

**People Living with Disabilities**

Having a disability does not mean an individual is unhealthy. However, people with disabilities may be at greater risk for some chronic health conditions and preventable chronic diseases due to, for example, lack of access to adequate healthcare, nutrition, or physical activity; smoking; and broader social determinants that impact their overall health.<sup>82</sup>



# VI.

## COMMUNITY STRENGTHS AND ASSETS

As part of qualitative information gathering for this assessment, key informants (KIs) were asked what they considered to be “the strengths and assets of the Pinellas community that can help improve chronic, advanced and terminal illness.” The question was open-ended with respondents able to highlight any strengths or assets they felt were important. In total, 88 responses were received to this question, with respondents able to provide multiple responses. To help identify and contextualize key themes, thematic analysis was supported by looking at the verbatim words that KIs chose to use in their responses. The top two words used with the greatest frequency in KI responses around strengths and assets were “community” and “organizations.”

The following main themes around strengths and assets emerged from analysis of KI responses and focus group discussions.

### Collaboration

This was the theme with the highest number of related responses. Fourteen responses (16%) highlighted strong collaboration, partnerships and communication across organizations that serve people with or impacted by chronic, advanced or terminal illness. This was notably highlighted by respondents from nonprofit organizations.

*“Overall, there is a really solid spirit of cooperation in the community – from donors who want to help, to organizations partnering with each other, to communication.”*

– Nonprofit respondent

*“St. Pete has a tremendous community that works hard to improve the health of the population, healthcare organizations reach out to form powerful alliances and partnerships with state programs, local agencies, schools, faith organizations, businesses and clubs.”*

– Government respondent



### Healthcare Services

Eleven responses (12.5%) highlighted the quantity and quality of healthcare services and providers present in the county, including nonprofit providers. Both focus groups conducted as part of this assessment also noted the availability of high-quality healthcare providers and services. This is corroborated by the CASOA, which found that 68% of Pasco-Pinellas' older residents rated the availability of preventative health services as "excellent" or "good."<sup>83</sup>

*"Pinellas County has a number of effective hospitals, research institutions and nonprofit organizations whose collaboration can improve chronic, advanced and terminal illness."*

– Nonprofit respondent

### Community Support

Responses in this theme, in particular those from nonprofit respondents, noted how different aspects of the community, such as particular institutions and social networks, support health and play important roles in supporting people with chronic, advanced and terminal illness. In addition, in response to the question about community strengths and assets, more than half of respondents took the opportunity to mention specific community organizations, institutions or businesses. Not counting Empath Health affiliates, stakeholders that received multiple specific mentions included: the Area Agency on Aging, the Foundation for a Healthy St. Petersburg, the local department of health, the Tampa Bay Healthcare Collaborative, Meals on Wheels, and the Free Clinics. Among Empath Health affiliates, Suncoast Hospice received the most specific mentions as a community strength/asset. Examples of strengths and assets related to community support are included in the following quotes:

*"In the African American community we have a history of helping and supporting one another in crisis and that is an asset. I believe that our strong faith community and the role of the Black church, not just spiritually but also activism, education and Black Life – these institutions are important to help with providing information, promoting health and support."* – Nonprofit respondent

*"Businesses such as banks, post offices and shops. Voluntary and community groups such as faith groups, sports clubs. Active retirement groups and charities such as St. Vincent de Paul, Goodwill and Meals on Wheels. Additional assets include individuals such as volunteers, families and community leaders, as well as the physical environment such as parks and public buildings constitute the strengths and assets that can be leveraged by chronic, advanced and terminally-ill residents to improve their health outcome."* – Government respondent



### Public Policy

Responses on this theme came from government, nonprofit and private sector respondents and mentioned public policies and programs as a strength or asset. Most mentions referred to county programs, with the county's efforts on preventative care receiving multiple mentions.

*“Pinellas County is unique in that the county has its own insurance program allowing many who otherwise would not receive care.”*

– Nonprofit respondent



### Resource Rich (but)

A number of responses mentioned that there are a lot of organizations present in the county that provide services for people with chronic, advanced and terminal illness and their families. However, a nearly equal number of responses also highlighted that while Pinellas is a resource-rich county, there are challenges in ensuring these resources are being efficiently and equitably accessed. Respondents noted, for example, duplication, lack of alignment or integration of resources, challenges with getting information about resources out to the community and challenges with ease of access.

*“A strength is that we are a resource rich county. However, the resources are not easily accessed by certain populations within the county.”*

– Nonprofit respondent

*“The strength and asset is the fact that our community is inundated with information and resources. However, we struggle to get the information out to the community.”*

– Nonprofit respondent



# VII.

## KEY ISSUES AND BARRIERS

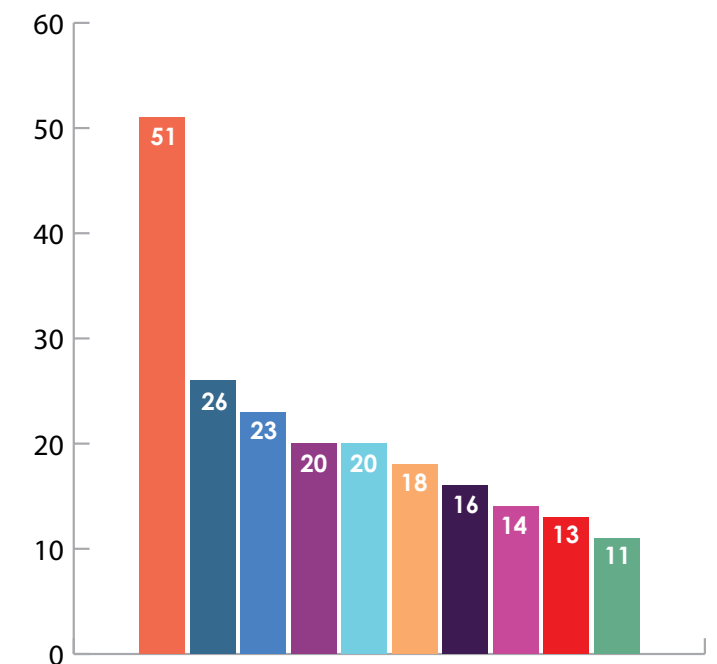
In the key informant questionnaire, KIs were asked about “the three most pressing issues facing those with chronic, advanced and terminal illness in Pinellas County” and separately asked to speak to “the greatest barriers to care for those with chronic, advanced and terminal illness” based on their experience. These questions were open-ended and respondents were free to raise any issues or barriers they felt were important. Thematic analysis showed considerable overlap and similarities between the responses to these two questions, and they are therefore addressed together in this section. In total, 279 responses were received to these questions, with respondents able to provide multiple responses.

Thematic analysis was supported by looking at the verbatim words that KIs chose to use in their responses. The three words used with the greatest frequency in responses to the question about issues included “resources,” “lack” and “access.” The top three most frequently-used words in response to the question about barriers to care included “services,” “support” and “access.”

**The following main themes around issues and barriers emerged from analysis of KI responses and focus group discussions.**

### Issues/Barriers

- **51** Cost, financial issues and insurance
- **26** Equity
- **23** Access
- **20** Care navigation
- **20** Knowledge
- **18** Transportation
- **16** Home-based care and housing issues
- **14** Mental well-being
- **13** Healthcare providers
- **11** Fear/Stigma





### Cost, Financial Issues and Insurance

With 18% of the total responses falling within this theme, this was the theme with the highest number of responses. Cost of healthcare and related services for managing chronic and advanced illness was highlighted as a primary, if not the primary leading barrier to care. Cost was highlighted in 43% of responses under this theme by nonprofit, private sector, religious and government respondents, as well as in both

focus groups. According to KI responses, the cost of healthcare, medications, ancillary services and long-term care are all high. Even people who are insured face high costs to cover what insurance doesn't pay for, which results in people not accessing care or treatment for their chronic or advanced illness. Certain illnesses face particular burdens of care with needs that are not covered by insurance (e.g., dementia care).

*“Affordability – Healthcare costs continue to skyrocket. Access to quality, affordable care is becoming harder to find.”* – Nonprofit respondent

*“Money to pay for care in the home or in a nursing home.”* – Private sector respondent

*“The cost is the greatest barrier.”* – Nonprofit respondent

*“Costs of care (i.e. medical doctor / drug copays, out-of-pocket expenses, expenses for ancillary care services, etc.)”* – Private sector respondent

Closely related to cost barriers are overall financial issues, such as poverty and available economic resources to meet competing needs, which were mentioned in 31% of responses under this theme and in the focus group conducted with representatives from the Empath Health board. Healthcare costs take a huge toll, and chronic illness can impact employment, making it even more challenging to afford care and make ends meet. However, support in the form of financial resources may be very limited. In addition, financial issues can be a chronic stressor that can exacerbate illness.

*“Lack of resources available to families to meet their child’s needs and the basic needs of the family. Some parents have to choose between going to work or losing a day’s pay to bring their child to an appointment. Some employers will not tolerate consistent missed days.”*

– Nonprofit respondent

*“Barriers to ADEQUATE healthcare that aren’t going to bankrupt you include: Access to income or financial support for things other than medical needs (support that is above the federal poverty line).”* – Academic respondent

Another issue that is closely linked to cost barriers is insurance, which was noted in a quarter of the responses under this theme and in both focus groups. Reported barriers with respect to insurance include the ability to find affordable coverage, the ability to afford adequate coverage, and what treatments and care are/are not covered by Medicaid/Medicare or private insurance (and thus up to the patient to pay or forego), and network limitations. People who are uninsured or underinsured face significant hurdles in accessing and affording care. In responding to different parts of the KI questionnaire, the lack of expanded access to Medicaid coverage in Florida was noted by multiple respondents. These responses are corroborated by the CASOA, which found that “finding affordable health insurance” was one of the most common healthcare issues reported by older residents of Pasco-Pinellas.<sup>84</sup> This barrier is also corroborated by The Commonwealth Fund’s 2020 scorecard of State Health System Performance, in which Florida ranked 48th on access and affordability, largely due to the number of people who are uninsured, the costs of care, and the costs of insurance coverage.”<sup>85</sup>

*“Affordability of health insurance.”* – Nonprofit respondent

*“Inadequate insurance.”* – Nonprofit respondent

## Equity

Equity-related issues and barriers to care arose organically in nearly 10% of responses. These issues were primarily mentioned by nonprofit respondents, but were also echoed by private sector, government and academic respondents, as well as in the focus group with Empath Health board representatives. People with chronic, advanced and terminal illness face various issues and barriers to care stemming from systemic disparities and demographic factors that impact equitable access to care. Barriers mentioned include language, lack of culturally-informed services, immigration status, ageism, and, notably, race-based disparities with respect to both access to quality care and social determinants of health. Multiple respondents mentioned the impact that disparities have on Black individuals' access to adequate care, including early diagnosis of health issues. Responses also note the impacts of implicit bias within the healthcare system and chronic stressors (such as racism) on individual health. Respondents noted specific health disparities experienced by people of color and by individuals who identify as LGBTQ. Some respondents highlighted insufficient attention to diversity, equity and inclusion within organizations, and one respondent noted that a lack of will to address health equity is in itself a barrier. These findings

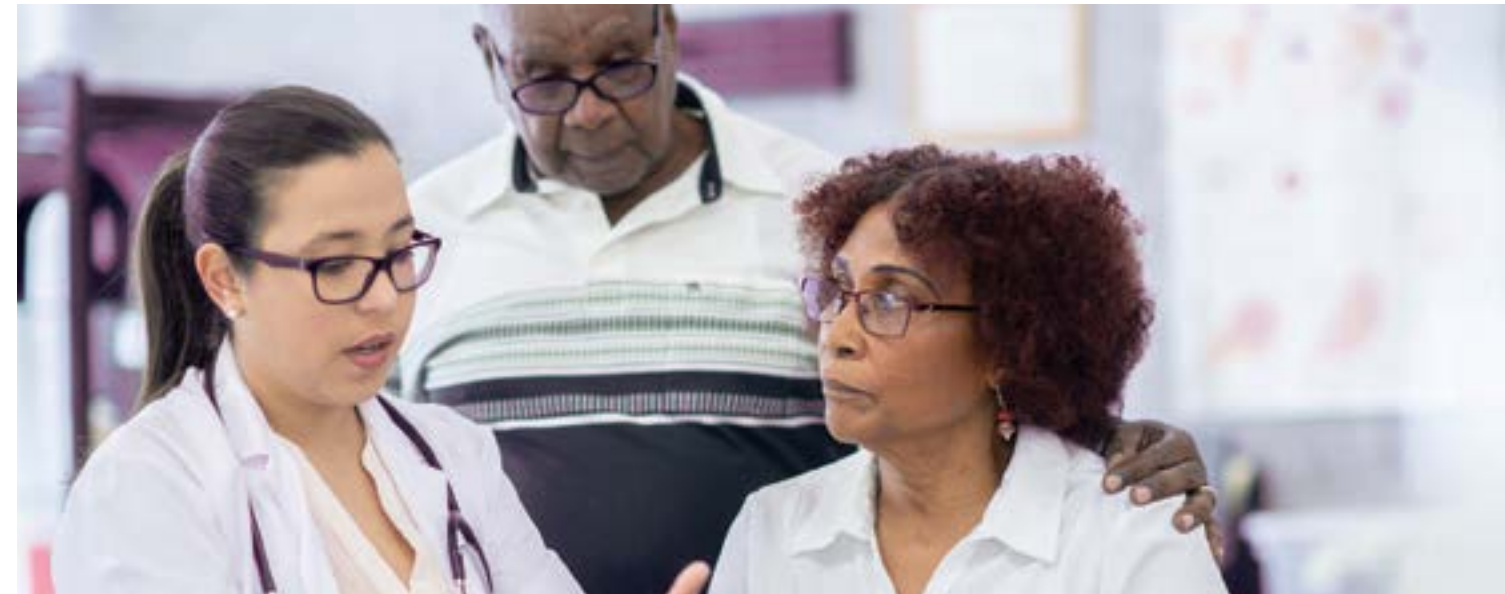
are supported by the 2020 ALICE report for Florida, which noted institutionalized racism as a contributing factor with respect to gaps in access to healthcare.<sup>86</sup>

*“From a diversity standpoint, and as discussed in meetings with African American and Black stakeholders, one of the barriers is that doctors are failing to identify memory impairments. Doctors are not testing communities of color for Alzheimer’s disease, at the same frequency they may discuss and test other patients.”*

– Nonprofit respondent

*“There needs to be a focus on how chronic illness is impacted by stress, the correlation of racism and chronic illness in certain populations as it relates to heart disease and high blood pressure.”*

– Nonprofit respondent



*“Racial inequity in the healthcare system. People of color are more likely to experience implicit bias with respect to care, pain management, empathy and getting the same types of treatments.”*

– Academic respondent

*“Language barriers and cultural differences in their view of medical care should be addressed.”*

– Nonprofit respondent

*“At a substantial cost to society, many disparities in chronic conditions, disability and mental distress observed in younger LGB adults persist, whereas others, such as cardiovascular disease risks, present in later life.”*

– Government respondent

*“Ensuring that careful attention is given throughout the organization to meet the D&I standards...from the board and including staffing from top to bottom.”*

– Nonprofit respondent



## Access

Many responses and the focus group conducted with Empath Health board representatives highlighted that access to care, and notably access to timely and appropriate care, is a key issue. Reported barriers to access include timely diagnosis, geography (underserved areas), ability to communicate and work schedules. COVID-19 and associated lockdowns also affected access to care in 2020. Access was highlighted by both nonprofit and private sector respondents. (Note: several critical barriers to accessing care, such as affordability and insurance coverage, are explored in more depth within other themes.)

*“Timely access to appropriate care.”* – Nonprofit respondent

*“Access to timely diagnosis and treatment.”*

– Private sector respondent

*“Accessing care in underserved areas.”*

– Private sector respondent

## Care Navigation

Challenges related to navigating the complexity of the healthcare system were highlighted in both focus groups and in responses from government, nonprofit, private sector and academic respondents, emerging as an overall issue and a barrier to care for people facing chronic, advanced and terminal illness. These challenges go beyond awareness of what care, services and resources are available (indeed a few respondents even noted an overwhelming amount of resources and/or resource lists as part of the complexity). Care navigation challenges include understanding how to access and afford available and relevant resources/services, navigating eligibility and enrollment for support and assistance (such as Medicaid and other benefits), managing care coordination and communication across providers and services (e.g., continuity of care; referrals; dealing with multiple doctors, hospitals and doctor privileges), how to advocate within the system to get a patient's needs met, and even digital communication barriers such as the ability to look for resources online. The focus group conducted with the Family Advisory Group highlighted a specific navigation issue around pain management at different stages of illness: negotiating the complexities of accessing prescribed pain medications due to legal regulations, pharmacy supply/stock limitations, and stigma around these controlled substances. Navigating these multiple levels of complexity is even more of a challenge and burden for a patient/family that is in crisis.

*“Education about the universe of options that they have for treatment as they navigate their illness and seek better quality of life, they do not know how to move through the barrier.”*

– Government respondent

*“Getting the care can be confusing. From getting insurance to knowing what you can do with the insurance once you have it. Communication with the health world is confusing.”*

– Nonprofit respondent

*“Here in Florida, which should be the gold standard in geriatric care, we have terrible coordination of care. There are a lot of issues to deal with and providing care, finding resources, coordinating all aspects of care and decision making can become very complicated.”*

– Private sector respondent

## Knowledge

Lack of knowledge was highlighted as a key issue and a barrier with respect to patients being able to access the care they need. It was also raised in the focus group conducted with the Suncoast Hospice Family Advisory Group. Knowledge-related issues and barriers include lack of knowledge of what the options are, of what services and resources are available to assist and support patients and of what help and care is available at end of life (and before). It also includes lack of knowledge about their illness/diagnosis, what palliative care and hospice are, what they can ask for and the services they are entitled to receive. Issues around lack of knowledge were noted by private sector, nonprofit, government and religious respondents.

*“Knowledge-base/Educational – some patients are unaware of questions to ask, how to be their own advocate, tests to request/insist upon, etc.”*

– Private sector respondent

*“Knowledge of services available.”*

– Nonprofit respondent

*“Health awareness about chronic disease progression, management and prognosis.”*

– Government respondent

## Transportation

Responses from private sector, nonprofit, government, academic and religious respondents, as well as the focus group conducted with Suncoast Hospice's Family Advisory Group, noted lack of transportation as an ongoing issue in Pinellas County and a barrier with respect to accessing care. Although ridesharing services and other new alternatives have provided for more options, lack of transportation to medical appointments and other services and resources remains a key concern.

*“Transportation to the point of care is also a barrier in our county.”*

– Nonprofit respondent

*“Transportation challenges are related to lack of car ownership, age and medical-related loss of driving privileges, transportation costs, and technology challenges with hailing rideshare.”*

– Government respondent

## Home-based Care and Housing Issues

Responses related to home-based care and housing/homelessness came from government, nonprofit and private sector respondents. Home-based care was also raised in both focus groups, and homelessness was raised in the focus group with Empath Health board representatives. While these issues do not necessarily have the same root causes or solutions, they highlight the importance of the linkage between housing and healthcare. More individuals want to receive care in their homes, but home-based care and support are costly and waitlists for home and community-based services are reported to be long. The presence of a personal support network is also linked to being able to receive care at home, and the focus group with Empath Health board representatives noted that the system is not set up to care for people who don't have a support network. Responses also highlighted gaps in the social safety net with respect to adequate housing solutions for low-income people with chronic and advanced illnesses, an issue that is exacerbated by the limited availability of affordable housing in Pinellas County. This was supported by the 2019 Pinellas



County Citizen Values Survey, which found that support services for the homeless and housing affordability were among survey respondents' top five gaps with respect to community characteristics they believe are important but for which the county is not living up to expectations.<sup>87</sup>

*“The expense of in-home care, especially if 24/7 care is needed. In addition, staffing at many agencies is not enough to provide consistent needed care (high turnover, and many agencies do not keep additional staff on board to provide quick response to emergencies).”*

– Nonprofit respondent

*“From diagnosis, it is likely a person is losing employability and from that point to obtaining the benefits from SSI/SSDI takes months to years. It is important to note that in this interim, the only housing safety net often is a shelter and if the individual is unable to care for themselves and live independent in the shelter setting, where do they go? How can the community come together to address this very large gap to care for our chronically ill, medically needy, individuals who have lost their housing due to illness?”* – Nonprofit respondent

## Mental Well-being

Mental health and well-being related concerns were mentioned as key issues facing people with chronic, advanced and terminal illness in Pinellas County. These concerns highlighted depression, loneliness/isolation and coping with the stress of the illness. The 2019 Pinellas County Citizen Values Survey found that “availability of mental and behavioral health resources” was among survey respondents’ top five “expectation vs. experience gaps” with respect to things they believe are important for the community but on which the county is falling short.

*“Care of psychosocial aspects of chronic, advanced and terminal illness.”*

– Nonprofit respondent

## Healthcare Providers

Issues and barriers related to healthcare providers were mentioned in a number of KI responses and in the Family Advisory Group focus group. They include challenges in finding the right personnel (e.g., with the right skills, training or specialty), but more often healthcare providers were mentioned with respect to some attitudes, practices or poor communication skills that can be an issue or result in barriers for patients.

*“Private physicians and long-term care facility delay in referring eligible patients/residents to a more appropriate type of care.”*

– Nonprofit respondent

*“The other barriers are not feeling welcomed or understood by those that are treating you, especially the physicians and the support staff, like the person at the front desk of the office.”*

– Nonprofit respondent

*“Physicians being honest and open with patients re: condition/diagnosis/prognosis.”*

– Nonprofit respondent

## Fear/Stigma

The often interrelated issues of fear and/or stigma emerged in multiple KI responses and both focus groups. Certain illnesses and diseases carry stigma that can be a barrier to care (specific examples cited included dementia and HIV). Fear also serves as a barrier: fear related to stigma, fear related to the diagnosis or prognosis and fear related to what hospice means.

*“The stigma of dementia is also a tremendous barrier, some folks may not even want to know that they are presenting signs of dementia.”*

– Nonprofit respondent

*“Fear of the official diagnosis.”*

– Nonprofit respondent



*Mental well-being is a key issue for patients with serious illness*

# VIII.

CONCLUSION



## *“Our Pinellas Community is Strong”*

Pinellas County has many strengths and assets that support people facing chronic, advanced and terminal illness. The county is home to a wealth of quality healthcare services providers, many of whom collaborate well with each other and with other organizations that serve and support this population. The county also has a wide range of organizations, businesses, and institutions – public, private, for-profit, nonprofit, community-based and faith-based

– that play proactive and important roles in supporting people with chronic, advanced and terminal illness and their families. In addition, there are some strong public programs at the county level that are supporting chronic illness prevention. While Pinellas County is undoubtedly resource rich, there are also challenges in ensuring that these resources are being efficiently and equitably accessed by those in need of care and support.

The cost of healthcare and related services for managing chronic and advanced illness is a primary barrier to care in Pinellas County. Even people who are insured face high costs to cover what insurance doesn't pay for, which results in people not accessing care or treatment. Obtaining affordable insurance coverage that adequately covers care and treatment needs is also a major barrier, exacerbated by the lack of expanded access to Medicaid coverage in Florida. Many people facing chronic or advanced illness are also struggling with broader financial issues, for which support is limited. Healthcare costs take a huge toll, and chronic illness can impact employment, making it even more challenging to afford care and make ends meet.

Interrelated socioeconomic and demographic factors such as, but not limited to, gender, gender identity, sexual orientation, race, culture, ethnicity, religion, education, and economic status impact health-related behaviors in complex ways that affect how individuals prevent, experience and manage chronic and advanced illness. People with chronic, advanced or terminal illness also face barriers stemming from systemic disparities that impact equitable access to quality

care, treatment and support, such as race-based disparities and biases, disparities and biases related to LGBTQ+ identities, language, and a lack of culturally-informed services.

Many people in Pinellas County struggle to access timely and appropriate care, for the cost and equity-related reasons outlined above, as well as for other reasons such as geography, ability to communicate, and work schedules. COVID-19 also affected access to care in 2020.

Challenges related to navigating the complexity of the healthcare system emerged from the assessment as an overall issue and a barrier to care for people facing chronic, advanced and terminal illness. There are certainly knowledge-related barriers to care, but navigation challenges go beyond knowledge, awareness, and the "what" of available resources. Care navigation barriers include the "how" of accessing available services, support and assistance; care coordination and communication across providers; and patient advocacy to ensure needs are met. Navigating these challenges is even more daunting for patients and families who are in the midst of crisis as they manage their illness.

People facing chronic, advanced or terminal illness in Pinellas County share challenges related to transportation and affordable housing that many residents of Pinellas County face regardless of health status. However, these challenges take on a greater level of severity when they impede access to the levels of care that people with chronic, advanced and terminal illness require. There are important linkages between housing and healthcare, and related barriers to and gaps in care. More individuals want to receive care in their homes, but home-based care and support are costly and waitlists for home and community-based services are long. There are also gaps in the social safety net with respect to adequate housing solutions for low-income people with chronic and advanced illnesses.

People with chronic, advanced and terminal illness in Pinellas County face challenges with depression, loneliness/isolation, and coping with the stress of the illness. More options for care and support for mental well-being may be needed. In addition, the attitudes and communication skills of healthcare providers can serve as barriers to care for patients, as can stigma and fear related to conditions and prognoses.



# IX.

## EMPATH HEALTH



Empath Health is a nonprofit, integrated network of care in Tampa Bay that provides expert medical, counseling and support services for anyone living with a chronic, advanced or terminal illness, or who is grieving. Empath Health began its mission as the first and only hospice provider in Pinellas County in 1977 when a group of pioneering community volunteers carried out their dream of compassionate care for the dying and their families. Today, Empath Health cares for hospice, home health, palliative care, private duty, veteran and pediatric patients, aging seniors and people living with HIV. We also offer caregiver and family support, health education, testing for HIV and sexually transmitted infections (STIs) and community counseling. In addition, we offer a licensed, in-house and full-service pharmacy and durable medical equipment services, further supporting our clients' needs. Our goal is to treat physical pain and enhance overall care and well-being for those we serve, according to their beliefs and wishes. We help nurture emotional, spiritual and social well-being, coordinate resources, educate caregivers, guide in healthcare decision making and provide support.



Empath Health is a community-based organization committed to providing life-changing care that meets the needs of all in our community, regardless of age, gender, race, ethnicity, religion, sexual orientation or ability to pay. In 2020, Empath Health touched the lives of more than 34,049 individuals through our fully-integrated network and provided \$4.3 million in uncompensated care to the community. Empath Health provides organizational leadership and administration, human resources, information technology, accounting and payroll services, patient/client records, community outreach and volunteer services, and philanthropy support for an integrated network of healthcare organizations. In Pinellas County these organizations include: Suncoast Hospice, Suncoast PACE (Program of All-inclusive Care for the Elderly), EPIC (Empath Partners in Care), Empath Community Health and Empath Home Health.

*To be the leader in life-changing healthcare.*

# Your Experts In Life-Changing Care

## Suncoast Hospice

Hospice care is provided in patients' homes or residential and care settings by interdisciplinary teams of expert professionals and trained volunteers who ease the physical, emotional and spiritual pain and stress of patients and families. We also have three in-patient Care Centers to provide 24-7 short-term care for pain and symptom management within a peaceful setting. Hospice care is available during the last six months of life, and the Suncoast Supportive Care program can expand this care out to the last year of life. Suncoast Hospice also has a pediatric program, with teams who are experts in caring for children of all ages as they reach the final stages of an illness and life. We provide bereavement support for families, and our team can support families and healthcare professionals with advance care planning processes and discussions.

## Suncoast PACE

The Program of All-Inclusive Care for the Elderly (PACE) aims to fully support and care for seniors facing chronic illness and aging. Our current services include primary care, therapies, skilled care, social and emotional support, and day care at our Suncoast PACE Day Center and Medical Clinic, in-home care and support, and transportation.

## EPIC

Previously known as AIDS Service Association of Pinellas, EPIC (Empath Partners in Care), our HIV/AIDS services include case management, linkage to care, housing assistance, mental health services, food and personal needs pantries, transportation, and wrap-around support for people living with HIV, as well as education, support and prevention services for people who are at high risk of acquiring HIV or other STIs. Our aim is to ensure that clients stay healthy, housed and in care.

## Empath Community Health

Palliative care is specialized medical care and support for patients living with a serious or life-limiting illness. The focus of Empath Health's Palliative Care program is to relieve pain, symptoms and stress at any time during a serious illness and to support patients and families as they work through difficult medical decisions.

Community Counseling services are provided for anyone in our community by licensed therapists who specialize in grief-related issues for both adults and children experiencing unexpected traumatic loss.

## Empath Home Health

Home health services cover skilled and unskilled care for homebound individuals and can be provided in tandem. Skilled care includes visits from clinical experts providing pain and symptom management, various therapies, disease-related education and caregiver training. Private-duty services, nonclinical care, include personal assistance with bathing and grooming, light housekeeping and laundry, companionship and caregiver respite.

## Suncoast Hospice Foundation

The Foundation provides needed funds for programs and services that are not otherwise reimbursed. These funds are raised through community member donations, fundraising event, major gifts, bequests, grants and more.





# X.

## APPENDICES

### APPENDIX 1

#### Community Health Needs Assessment Task Force

**Jim Andrews**, Suncoast Hospice  
Director of Spiritual Care

**Rachelle Hutchens**, Suncoast Hospice  
Regional Program Director

**Scott Kistler**, Empath Health  
Vice President Strategy & Business  
Development

**Karen Davis-Pritchett**, Empath Health  
Vice President Diversity, Access & Inclusion

**Joy Winheim**, EPIC  
Executive Director

**Kathy Rabon**, Suncoast Hospice Foundation  
Chief Philanthropy Officer (Vice President  
Advisor)

**Brooke Boccacino**, Suncoast Hospice  
Foundation  
Director of Corporate Philanthropy  
(Assessment Co-Lead)

**Amy Keith**, Suncoast Hospice Foundation  
Grants Director (Assessment Co-Lead)

**Rachel Lewis**, Suncoast Hospice Foundation  
Special Events Coordinator (Assessment  
Administrative Support)

#### Empath Health CHNA Advisory Council

**Cathi Carr**, Empath Health  
Vice President Care Support Services

**Wade Childress**, Empath Health  
Vice President Operations and Human  
Resources

**Lynne Craver**, Empath Health  
Chief Mission Implementation Officer

**Karen Davis-Pritchett**, Empath Health  
Vice President Diversity, Access & Inclusion

**Jennifer Kaminsky**, Empath Health  
Vice President Elder Services

**Scott Kistler**, Empath Health  
Vice President Strategy & Business  
Development

**Laura Mosby**, Empath Health  
Vice President Organizational Excellence &  
Compliance

**Stacy Orloff**, Empath Health  
Vice President Innovation & Community  
Health

**Marci Pruitt**, Suncoast Hospice  
Vice President Hospice

**Kathy Rabon**, Suncoast Hospice Foundation  
Chief Philanthropy Officer



## APPENDIX 2

### Key Informants

Qualitative information was gathered from 51 Key Informants via interviews and questionnaires between February and April 2021.

Participants included representatives from:

- Florida Department of Health
- Hospitals and healthcare providers
- Health associations
- Senior citizen service organizations
- Social service organizations
- Academia
- Community leaders
- Cultural groups
- Veterans' organizations
- Religious institutions

CATEGORY	NUMBER OF RESPONDENTS
Nonprofit	13
Nonprofit Healthcare	13
Government	6
Private Healthcare	12
Other	7
<b>TOTAL</b>	<b>51</b>

### Community Advisory Council

**Ulyee Choe, DO**  
 Director, Florida Department of Health  
 in Pinellas County

**Martha Lenderman**, Board Member,  
 Suncoast Hospice

**Dr. Sheron Brown, PhD, CHC**  
 Executive Director, Tampa Bay Healthcare  
 Collaborative

**Zayne Smith**  
 Associate State Director of Advocacy, AARP  
 Florida

**Linsey Grove, DrPH, CPH, CHES**  
 Health Sciences Instructor and St. Petersburg  
 Campus Program Coordinator, USF College  
 of Public Health

**Susie Paterson, PhD**  
 Research Consultant

## APPENDIX 3

### Focus Group Participants Suncoast Hospice Family Advisory Group

Kim Beidelschies  
 Diane Cary  
 Dianna Gilmore  
 Pam Metz-Easley  
 Michele Roling  
 Joseph Williams  
 Jennifer Khodadoost  
 Louann Hatch  
 Susan Lesh

### Focus Group Participants Representatives of Empath Health Affiliates' Boards of Directors

**Martha Lenderman**, Suncoast Hospice  
 Board of Directors

**James Steg**, OPTUM Health  
 Suncoast Hospice Board of Directors

**Linda Plaster**, National Bill Audit Services, LLC  
 Empath Health Board of Directors

**D. Rep DeLoach III**, DeLoach, Hofstra & Cavonis, P.A.  
 Suncoast PACE Board of Directors

**Ruby Hope**, Kindred Hospital  
 Suncoast Hospice Board of Directors

**Ben Hayes**, Tampa Bay Times  
 Empath Health Board of Directors

## APPENDIX 4

### Pinellas County Community Health Needs Assessment Key Informant Questionnaire

**Name:**

**Company/Organization:**

**Title:**

1. What is your role and responsibilities within your organization?
2. What do you consider to be the strengths and assets of the Pinellas community that can help improve chronic, advanced and terminal illness?
3. What do you believe are the 3 most pressing issues facing those with chronic, advanced and terminal illness in Pinellas County?
4. From your experience, what are the greatest barriers to care for those with chronic, advanced and terminal illness?
5. What are the strategies that could be implemented to address these barriers?
6. Is there any additional information that should be considered for assessing the needs of the community?

## APPENDIX 5

### Emerging Themes

Thematic coding of KI responses found the following themes emerging two or more times:

STRENGTHS/ASSETS	COUNT
Collaboration	14
Healthcare services	11
Public Policy	8
Community support	8
Resource rich	6
Resource rich but	5
Equity	3
Healthcare providers	2
Knowledge	2

ISSUES/BARRIERS	COUNT
Equity	26
Access	23
Cost	22
Care navigation	20
Knowledge	20
Transportation	18
Financial issues	16
Mental wellbeing	14
Insurance	13
Healthcare providers	13
Fear/Stigma	11
Home-based care	10
Specific condition	8
Support Network	7
Housing/Homelessness	6
Caregivers	6
Funding	6
Treatment	6
Public policy	5
Support services	5
Advance planning	4
Pain	4
Healthcare services	4
Food insecurity	3
Technology	2
Empowerment	2
Collaboration	2

**Note:** Responses that were exact duplicates across the issues question and the barriers question (i.e. cut-and-paste) have only been considered once.

## ENDNOTES

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## About Suncoast Hospice Foundation

The Suncoast Hospice Foundation is a nonprofit organization financially supporting the mission and vision of Empath Health and its members.

As a member of Empath Health, our focus is ensuring resources are available to those served today and into the future.



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[SuncoastHospiceFoundation.org](http://SuncoastHospiceFoundation.org)