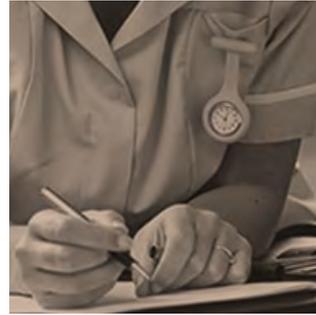


# 2018 REPORT

*Defining, Assessing and Planning Palliative Care in Louisiana*



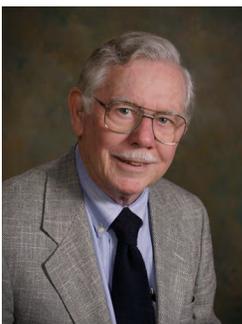
# Palliative Care SUMMIT

**20/20 VISION  
for Palliative Care  
in Louisiana**

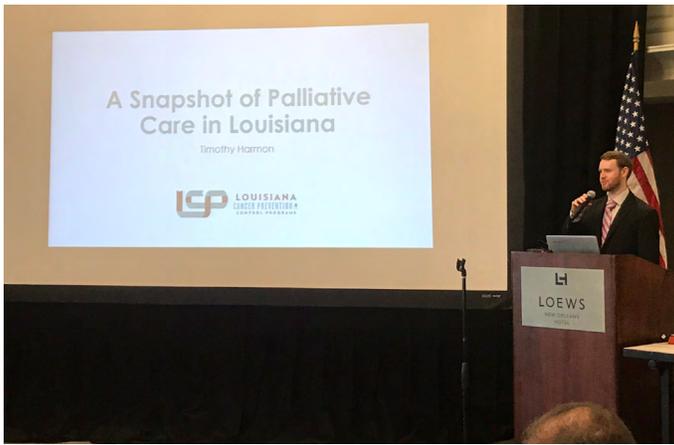


# Table of Contents

<b>Executive Summary</b>	<b>3</b>
<b>Definitions of Palliative Care in Louisiana</b>	<b>5</b>
<b>Research: Measuring the Demand of Palliative Care in Louisiana</b>	<b>6</b>
<b>Research: Louisiana Palliative Care Study, September 2018</b>	<b>12</b>
<b>Action Items for the Next Two Years</b>	<b>16</b>
<b>Roadmap for Palliative Care in Louisiana</b>	<b>18</b>



*This report is dedicated to Dr. Jack McNulty for his many years of service and perseverance to the mission of palliative care.*



## Executive Summary

Imagine a day where all patients who have been diagnosed with a serious illness – have access to care for survivorship, support for end of life decisions, and all stages in between. When the core group came together, a vision was created to establish Louisiana as a leader in Palliative Care.

As a result of our intensive day together, Louisiana has a plan for palliative care with the potential to make Louisiana a leading trainer and provider of palliative care in the south. Our workgroups created an approach for education/ alignment for palliative teams, scorecards to measure results, best practice sharing among the groups, required policy changes and definition, as well as a roadmap for progress. As a result, we created a format that other states can use to create new norms for high quality palliative provision at the health system level.

### BACKGROUND:

Although originally associated with hospice and end-of-life care, forty years ago, palliative medicine, care and services have evolved in post-Katrina Louisiana to emerge as vital components of comprehensive healthcare delivery systems for patients at any stage of illness, with or without other life sustaining or curative therapies. As practitioners have brought palliative care further “upstream” in the delivery of care, there has been a growing call among healthcare professionals and providers to “*get everyone on the same page*” with regards to (1) a common/working definition of palliative care in the state, along with (2) an assessment of our current capacity within the state to provide such care and (3) develop a network and plan for the continued growth of palliative support around the state.

The stars began to align in 2018 to hold a Summit when funding from a CDC grant was offered by the [Louisiana Cancer Prevention and Control program](#) and administered through [LSU’s School of Public Health](#) to the [Louisiana-Mississippi Hospice and Palliative Care Organization \(LMHPCO\)](#). LMHPCO was able to bring together various healthcare partners and practitioners, including the [Palliative Care Institute of Southeast Louisiana](#), the [Louisiana Healthcare Quality Forum](#), the

[Homecare Association of Louisiana](#), [Louisiana Hospital Association](#) and the [Louisiana Department of Health](#) to the same table for the first Palliative Care Summit in the state. An impressive 128 palliative care professionals and providers came together for the day to begin working on the 3 fundamentally unique palliative care questions/issues identified above. Quarterly post Summit conference calls are planned in order to continue the momentum and implement the Action Items identified (at the end of this Report) and to be completed over the coming two years.

Prior to the Summit and again following the Summit, a Palliative Care Survey, based on similar instruments used in California and Florida to measure their current capacity and utilization of palliative care resources, was widely distributed across the state to licensed healthcare facilities and practitioners. The result of the pre- and post-Summit surveys reveal only 2 parishes in the state with having the capacity to support 75% of the palliative care needs within their respective parishes; 1 parish has a 50% capacity to provide adequate palliative care; and data from 14 parishes indicate a capacity of somewhere between 50- 25%; but the vast majority of the state (i.e., 47 parishes) have less than a 25% capacity to provide palliative care within their community. The significance of this finding helps us to understand the higher costs and rehospitalizations episodes that plague Louisiana healthcare metrics.

It is our hope that this Summit, this first attempt to bring palliative care practitioners and providers together, has energized the efforts of practitioners and providers to make Louisiana a leading trainer and provider of palliative care in the south. While the Summit workgroups provided a foundational framework for the next 2 years, the efforts of this Summit will prove to inform the next generation of palliative medicine specialists, offering the people of Louisiana with not only an updated definition of palliative care, but also create an healthcare environment where both caregivers and practitioners have the necessary resources, support and compassion to ensures rewarding professional careers as

well as mitigation of burnout and caregiver fatigue. This 2018 Report is a product of the Summit and represents the first consensus document of this newly formed network of palliative care practitioners within the state. We hope that this 2018 Report can also serve as a model that other states can use to create higher expectations for quality palliative care and services throughout our national health system.

**Summit Planning Committee**

[Jamey Boudreaux, MSW, MDiv](#), Louisiana-Mississippi Hospice & Palliative Care Organization, Executive Director and Adjunct Professor, Tulane School of Social Work

[Nancy Dunn, RN, MS, CT](#), Louisiana-Mississippi Hospice & Palliative Care Organization, Education Director

[Mikal M Giancola, MPH](#), LSU School of Public Health

[Mark Kantrow, MD](#), Our Lady of the Lake Palliative Care Program; Baton Rouge

[Liz Langley](#), HomeCare Association of Louisiana

[Sonia Malhotra, MD, MS, FAAP](#), Tulane University, School of Medicine; University Medical Center, New Orleans

[Glen Mire, MD](#), Geriatric Medicine Specialist; Lafayette

[Linda Morgan](#), Louisiana Healthcare Quality Forum  
[Dana Muhlfeder, MD](#), Ochsner Baptist Medical Center; New Orleans

[Susan Nelson, MD](#), Ochsner Medical Center; New Orleans

[Floyd J Roberts, MD, FACP, FCCP](#), Louisiana Hospital Association

**Special Thanks to**

[DeAnna Davis, MBA](#) for her strategic leadership and skills in helping attendees identify key Action Items to work on over the coming 2 years.

[Tim Harmon](#), a MD/MPH candidate at LSUHSC for sharing his research and providing attendees with a [Snapshot of Palliative Care in Louisiana](#).

[Christian Sinclair, MD, FAAHPM](#), from the University of Kansas Medical Center and past President of [AAHPM](#) for providing invaluable insights into the national palliative care discussions.

**Attendees included:**

- Physicians 15
- Nurse Practitioners 15
- Physician Assistants 2
- Registered Nurses 55
- Social Workers 24
- Chaplains 7
- Administrators 6
- Academics 4

**Representing:**

- 23 Hospitals
- 13 Health Systems
- 9 State Associations
- 2 Dialysis Providers
- 12 Hospice Agencies
- 7 Home Health Agencies
- 3 Insurance/Managed Care Organizations
- 1 Community-Based Palliative Care Provider
- Louisiana Department of Health
- Veterans Affairs
- LSU School of Public Health
- Loyola New Orleans School of Nursing

**Summit Agenda**

- recognition of the variety of interested palliative care practitioners and providers within the state
- review of palliative care survey results conducted prior to the Summit
- review of indicators for growing need for palliative care services within the state
- identification of current palliative care resources within the state
- a survey of the national palliative care stage
- brainstorming of palliative care issues within the state
- developing a 2 year action plan for the state

*Funding for this one-day Summit was made possible by a grant to LMHPCO from the Louisiana Cancer Partnership and administered by the LSU School of Public Health*

# Louisiana currently has three definitions of Palliative Care

Louisiana has three different definitions of palliative care none of which include guidelines for national organizations or the federal government. A definition is important because it allows for accurate regulation, reimbursement, and advancement in the field of palliative care. A proper definition would give the framework to hold all palliative care programs to the same basic regulations and assure patients that they

are receiving a proper quality of care. It would provide the basis for insurance reimbursements for the full range of palliative care services allowing for clinics to grow and develop. Finally, a new definition would allow for advancement in the field by giving researchers accurate metrics to measure the effects of palliative care throughout the state.

## 1. Hospice Licensure Law

"Palliative care" means the reduction or abatement of pain or other troubling symptoms by appropriate coordination of all services of the hospice care team required to achieve needed relief of distress. *LA Rev Stat § 40:2183*

## 2. Louisiana Medicaid

"Palliative care focuses on comfort care and the alleviation of physical, emotional, and spiritual suffering." *LA Medicaid Manual*

## 3. Alternative Health Care Model

"Palliative care" means the reduction or abatement of pain or other troubling symptoms by appropriate coordination of the interdisciplinary team required to achieve needed relief of distress. *LA RS 40:2182*

### Why is a Definition Important?

#### REGULATION

Making sure that all palliative care programs are held in the same standards

Assurances that patients are receiving the best quality of care

#### REIMBURSEMENT

Complete legislative definition allowing for patients to bill Medicaid/Medicare for the full range of palliative care services

#### ADVANCEMENT

Allows for accurate metrics to track both palliative care programs and patients who qualify for these programs.

Accurate numbers lead to an increase in funding opportunities and clinical research developments

## Other currently recognized definitions of Palliative Care

### [Center to Advance Palliative Care \(CAPC\)](#)

- *Palliative care is specialized medical care for people living with serious illness. It provides relief from the **symptoms and stress**, improves quality of life for **both the patient and the family**, is provided by an **interdisciplinary team**, and appropriate at **any age and at any stage** in a serious illness and can be provided along with **curative treatment**.*

### [World Health Organization \(WHO\)](#)

- *Palliative care is an approach that improves the **quality of life of patients and their families** facing the problem associated with life-threatening illness, through the **prevention and relief of suffering** by means of early identification and impeccable assessment and treatment of pain and **other problems, physical, psychosocial and spiritual***

### [American Academy of Hospice and Palliative Care \(AAHPM\)](#)

- *Palliative care is a type of medical care that focuses on **improving patients' quality of life** by managing pain and other distressing symptoms of a serious illness. Palliative care should be provided **along with other medical treatments** for conditions that might be **curable, life limiting or chronic**.*

### [National Hospice and Palliative Care Organization \(NHPCO\)](#)

- *Palliative care is **patient and family-centered** care that optimizes **quality of life** by anticipating, preventing, and treating suffering. Palliative care **throughout the continuum of illness** involves addressing **physical, intellectual, emotional, social, and spiritual needs** and to facilitate **patient autonomy**, access to information and choice.*

Summit Attendees recommend that changes to Louisiana's definition of palliative care should mirror that of the [National Consensus Project](#) which include:

- *Provides relief from pain and symptoms*
- *Use team approach of interdisciplinary professionals*
- *Offers support system to patients and family (i.e., psycho-social, emotional and spiritual)*
- *Applicable in any stage of illness, with or without other life-sustaining or curative therapies*
- *Assurance that the personal goals and dignity of patient are a priority*

# The Demand for Palliative Care in Louisiana

## Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS is a national telephone survey that collects state data about U.S. residents regarding health-related risk behaviors, chronic health conditions, and use of preventive services. Recently a module providing information on those providing care to friends or family with a disability health problem was added. The data below is taken from the BRFSS survey and tailored to the state of Louisiana by Laurie Freyder in the report *Declining Self Sufficiency and Caregiving*.

Federal statute defines palliative care as providing “patient- and family-centered care that optimizes quality of life” (73 FR 32204). Therefore, when evaluating the effectiveness of a palliative care program the caregiver must be seen as an important part of the equation. Caregivers provide a wide range care to their family and friends; ranging from personal care such as medication administration to simple household tasks such as cleaning or money management. By looking at what tasks caregivers are providing palliative care programs can be tailored to help provide for the patients actual needs. By looking at what different medical conditions are being cared for palliative care can begin to focus on the areas that need the most help first.

### Social Determinants of Health

- Economic Stability
- Neighborhood and Physical Environment
- Education
- Food
- Community and Social Context
- Health Care Systems

### Social Determinants of Early Death

- Healthcare 10%
- Genetics 30%
- Individual Behavior 40%
- Social & Environmental Factors 20%

## Type of Care Provided in Louisiana

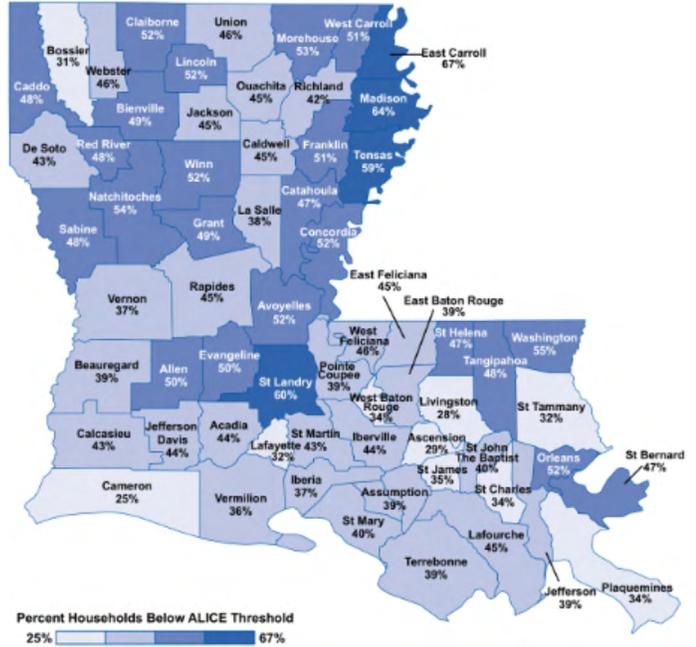
- Personal Care (54.4%)
  - Medication administration, feeding, clothing, bathing
- Household Tasks (76.5%)
  - Cleaning, money management, meal preparation
- Both (48.6%)
- Provide care to a wide range of conditions

Health Problem/Disability	% of Those Receiving Care	95% Confidence Interval
Arthritis/Rheumatism	6.0	4.1-8.0
Cancer	9.9	7.1-12.8
COPD	3.7	2.1-5.3
Dementia and other Cognitive Impairment Disorder	9.4	7.1-11.8
Developmental Disabilities	3.1	1.7-4.5
Diabetes	6.3	4.1-8.5
Heart Disease, Hypertension	6.0	4.1-7.8
Mental Illnesses (Anxiety, Depression, Schizophrenia)	3.3	2.1-4.6
Other Organ Failure or Diseases (Kidney or Liver Problems)	2.5	1.1-3.9
Other	47.8	43.6-52.1

The United Way produces an annual report detailing a subset of the population defined as Asset Limited, Income Constrained, Employed (ALICE). The ALICE project uses a set of measures to determine a household survival budget, the estimate of the total cost for household essentials (housing, child care, food, health care, etc.). This cost is termed the ALICE Threshold, below which individuals would not be able to afford household essentials. 46% of Louisiana households are below the ALICE poverty line for 2018.

## Asset Limited, Income Constrained, Employed (ALICE)

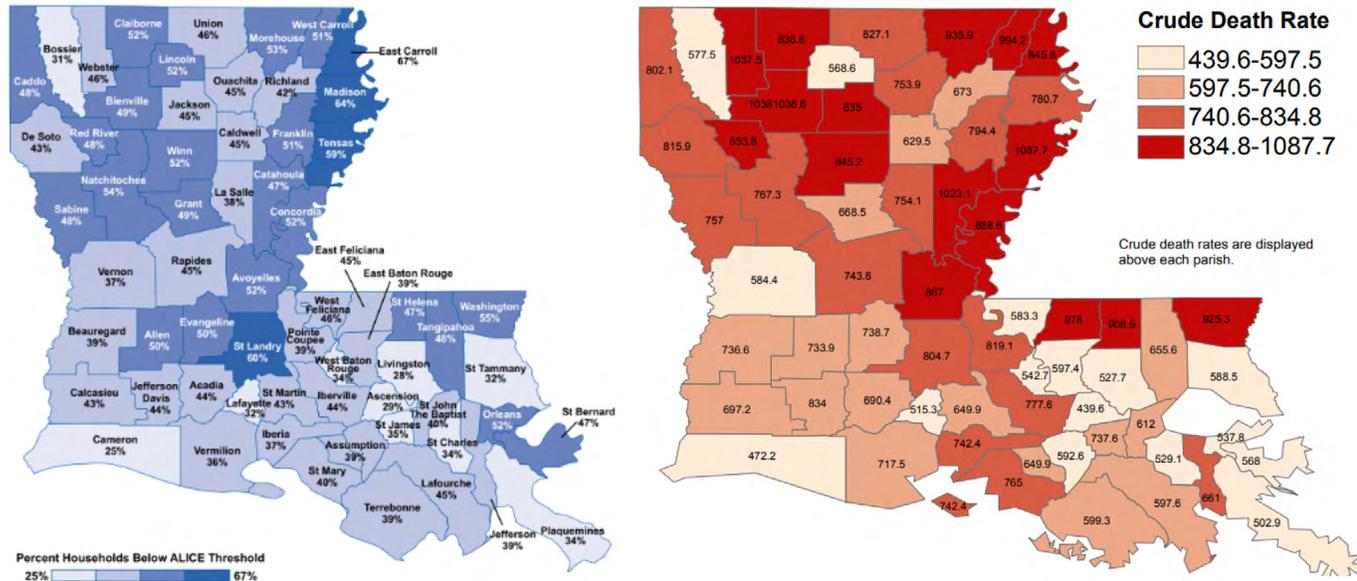
- Individuals and families who are working, but are unable to afford the basic necessities of housing, child care, food, transportation and health care
- 46% of Louisiana household are below the ALICE poverty line in 2018



The palliative care mortality rate is the estimated number of deaths per 100,000 that were caused by diseases/conditions that could have benefited from a palliative care program.

To calculate it we used the CDC's WONDER database to give us a parish by parish breakdown of mortality for the diseases and conditions commonly seen by palliative care facilities.

## ALICE Status and Palliative Care Mortality Rate



Source: American Community Survey, 2014, and the ALICE Threshold, 2014

Caregivers, more so than the general population, are below the ALICE poverty line. Caregivers have a significantly higher proportion in the \$15,000 to \$24,000 range and a significantly lower proportion in the \$50,000 when compared to non-caregivers. Caregivers also have higher rates of food and shelter insecurities when compared to non-caregivers. Many caregivers (20%) have the equivalent of a full-time job (more than 40 hours a week) providing care to their friend or family member. This can put a strain on finances and lead to the income trends seen above. Palliative care programs should consider these trends when dealing with patients and their caregivers and factor this into treatment plans.

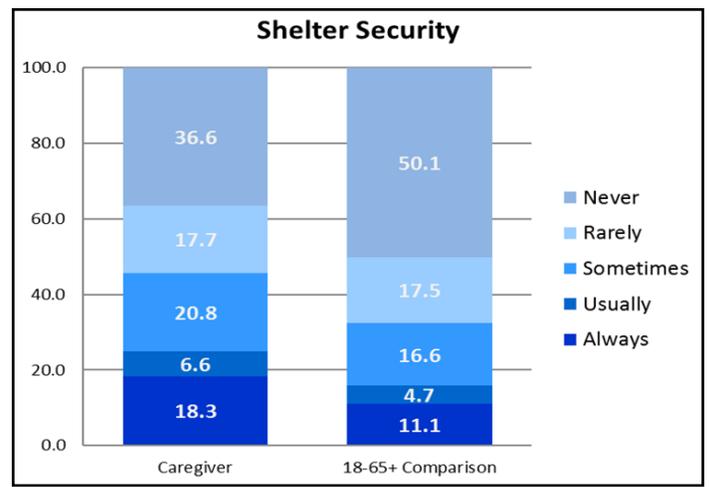
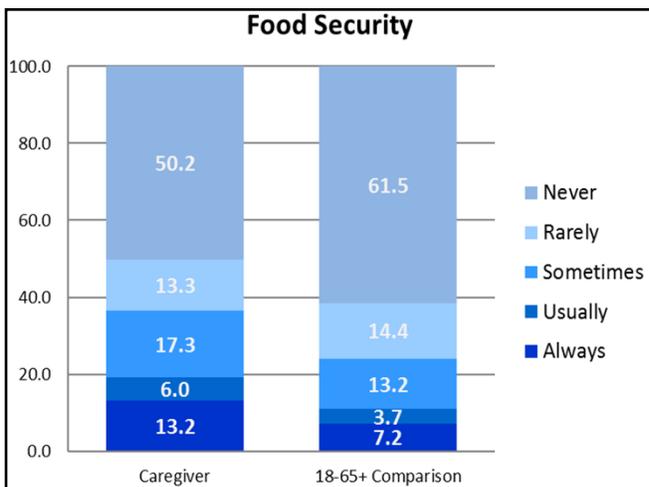
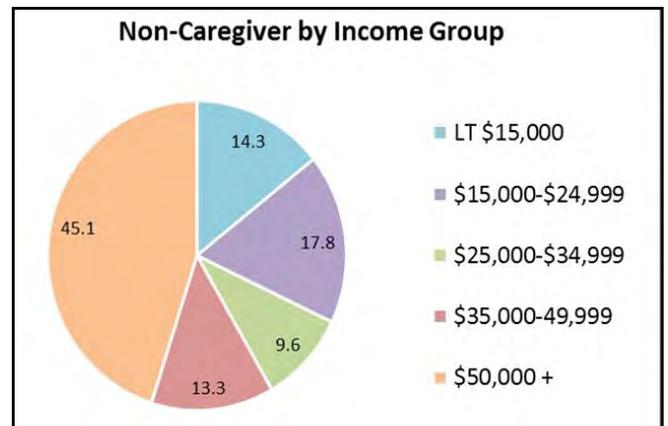
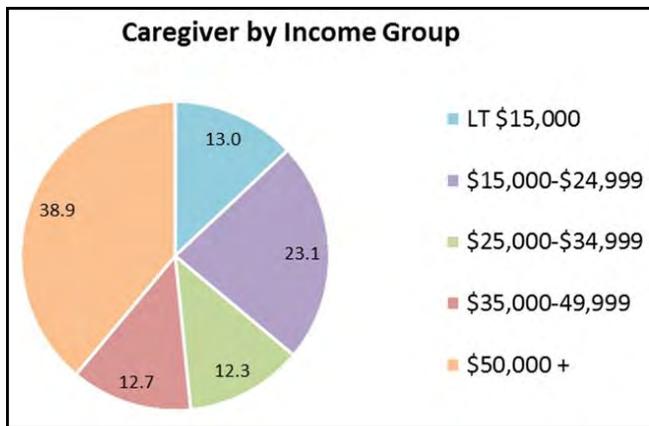
## Caregiver Economic Security in Louisiana

- **Income**

- Significantly higher percentage of caregivers in the \$15,000 to \$24,000 income bracket
- Significantly lower percentage of caregivers in the \$50,000 plus income bracket

- **Food and Shelter Security**

- Caregivers report significantly higher amounts of both food and shelter insecurities compared to the 18-65+ control



# Caregiver Time Commitment in Louisiana

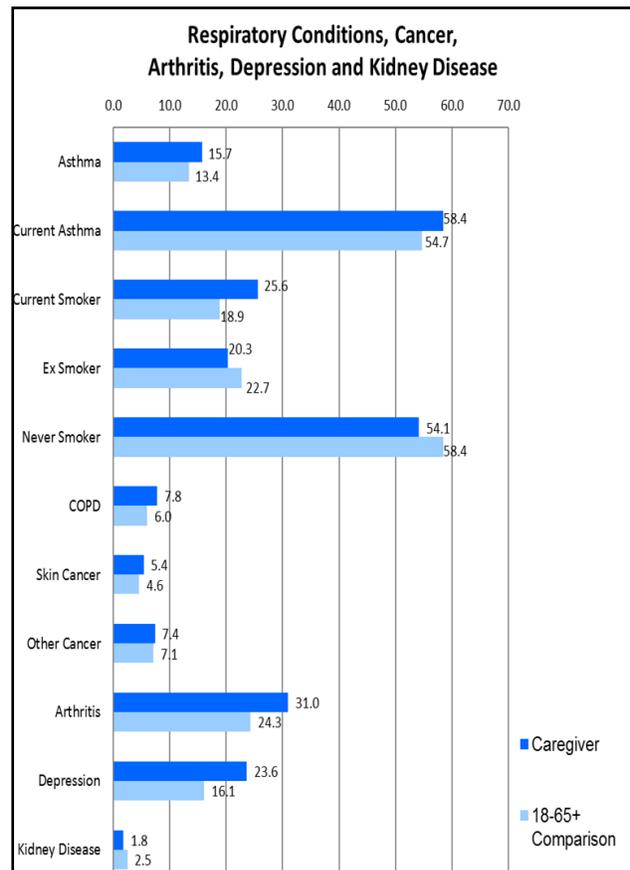
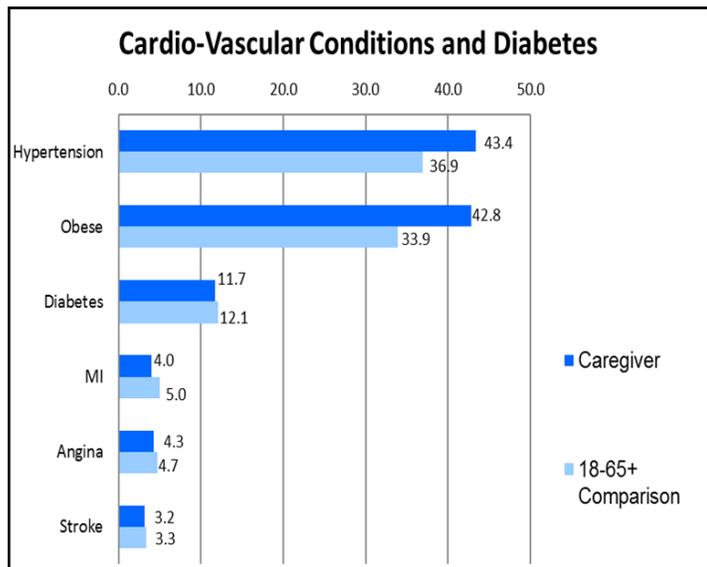
Being a caregiver can often be both a long-term and full-time commitment

Time Providing Care	% of Caregivers	95% Confidence Interval
Less than 30 days	17.2	14.3-20.1
1 to 6 Months	14.3	11.3-17.3
6 Months to 2 Years	19.1	15.7-22.5
2 Years to less than 5 Years	18.8	15.8-21.8
More than 5 Years	30.6	26.8-34.4

Hours per Week Providing Care	% of Caregivers	95% Confidence Interval
Up to 8 hours per week	52.3	48.1-56.5
9 to 19 Hours per Week	13.5	10.5-16.6
20 to 39 Hours per Week	14.0	11.2-16.8
40 Hours or More	20.2	16.9-23.5

# Caregiver Health Profile in Louisiana

Palliative care providers need to be aware that the caregivers of their patients are more likely to be at risk for certain health conditions. A caregiver who is sick may not be able to provide as high quality of care as one who is healthy. Caregivers suffer from significantly higher rates of hypertension and obesity and are more likely to have asthma, arthritis, and depression. Also 25% of caregivers smoke compared to 19% of non-caregivers. The home environment has a huge impact on the health outcomes of those residing in it. A caregivers health profile could provide valuable information into the home environment of the palliative care patient and better allow palliative care provider to better tailor the care plan to the individual patient.



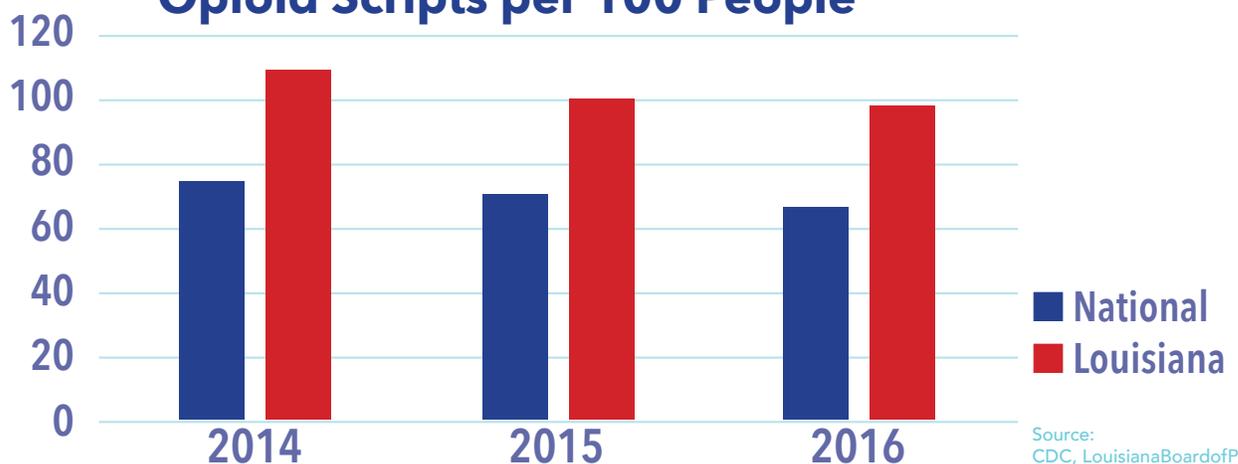
Although we have high opioid and controlled substance use in Louisiana, and some would say abuse, these are the same medications that are needed for our most vulnerable and sickest patients, some nearing the end of life, others struggling with cancer and serious illness.

### Highest Number of Prescriptions in Louisiana PMP by Generic Name Calendar Year 2017

Controlled Substance/ Generic Name	Drug Type	Number of Prescriptions	Percent of Total
Hydrocodone/Acetaminophen	opioid	2,187,230	18.3%
Alprazolam	benzodiazepine	1,044,946	8.8%
Dextroamphetamine	amphetamine	991,238	8.3%
Tramadol	opioid	941,210	7.9%
Oxycodone/Acetaminophen	opioid	692,401	5.8%
Zolpidem	sedative	680,059	5.7%
Clonazepam	benzodiazepine	625,787	5.2%
Lisdexamfetamine Dimesylate	amphetamine	465,168	3.9%
Lorazepam	benzodiazepine	350,311	2.9%
Methylphenidate	respiratory and CNS stimulant	302,935	2.5%
Diazepam	benzodiazepine	291,197	2.5%
Phentermine	amphetamine derivative	238,594	2.0%
Oxycodone	opioid	233,479	2.0%
Other Controlled Substances		2,889,764	24.2%
<b>Total Prescriptions</b>		<b>11,934,319</b>	<b>100%</b>

Source: Prepared by legislative auditor's staff using information from LABP's presentation to the PMP Advisory Council on January 10, 2018.

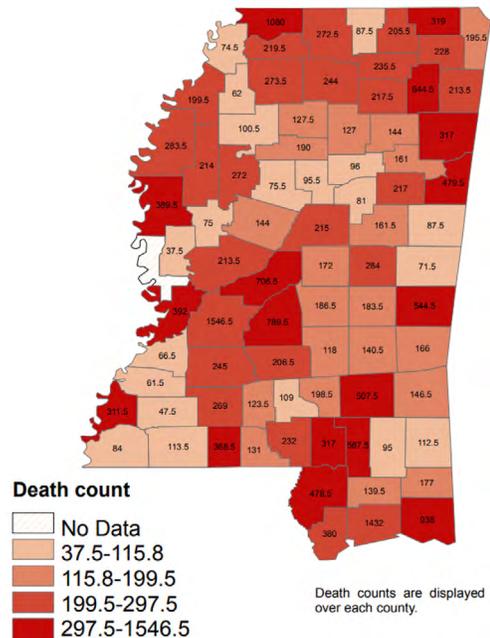
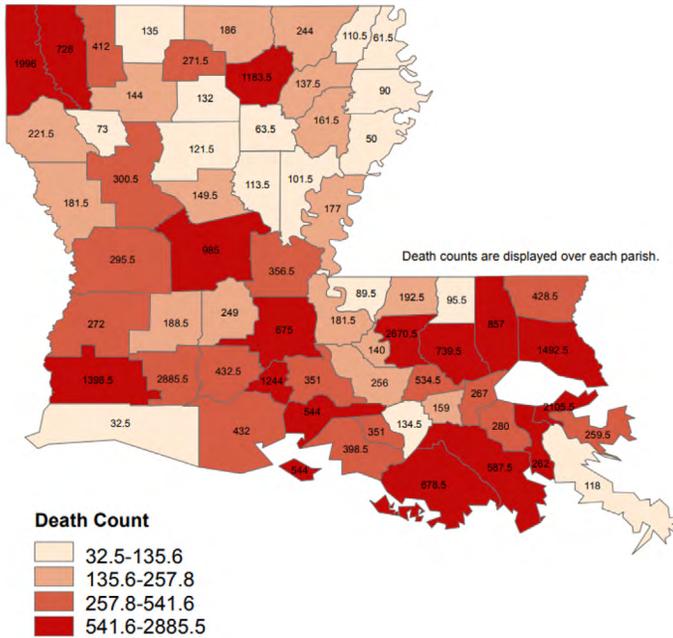
### Opioid Scripts per 100 People



# ONLY 20% OF OUR DEMAND IS BEING MET TODAY!

One metric for determining the effectiveness of palliative care across a state is to see if the current capacity of palliative care providers matches the demand for palliative care by patients. The CDC's WONDER Database provides statistics on death rates (all rates are per 100,000 people) and counts for various conditions. Palliative care demand can be estimated by using the causes of death that patients would commonly have been referred to palliative care programs. This provides an estimate for the demand for palliative care programs in the state.

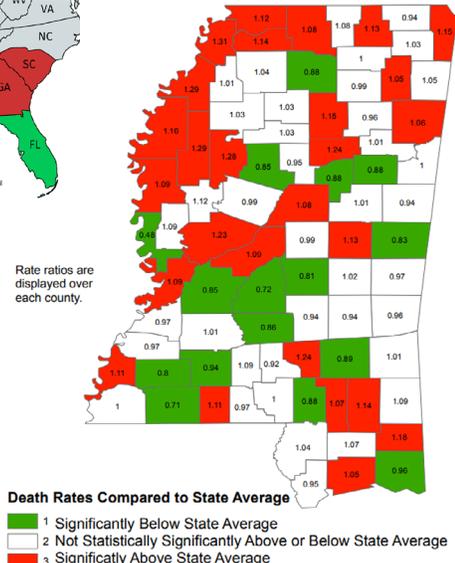
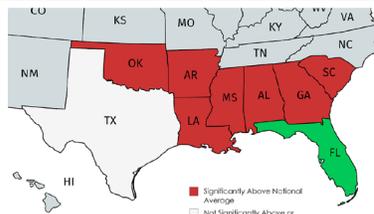
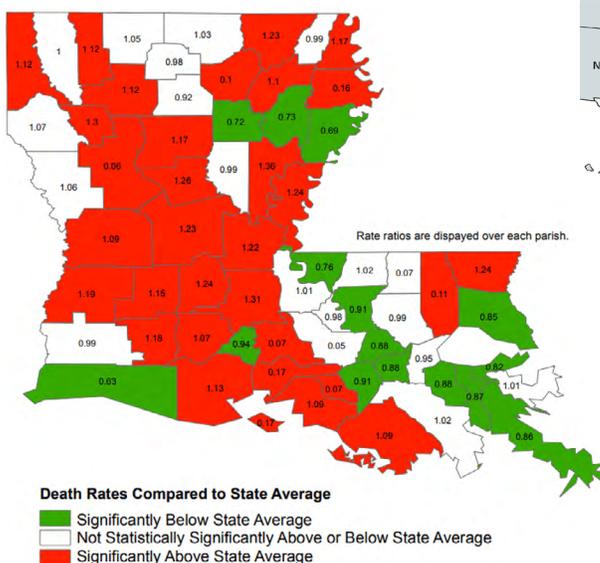
## Palliative Care Demand 2016



The palliative care mortality rate is the estimated number of deaths per 100,000 that were caused by diseases/conditions that could have benefited from a palliative care program.

To calculate it we used the CDC's WONDER database to give us a parish by parish break down of mortality for the diseases and conditions commonly seen by palliative care facilities.

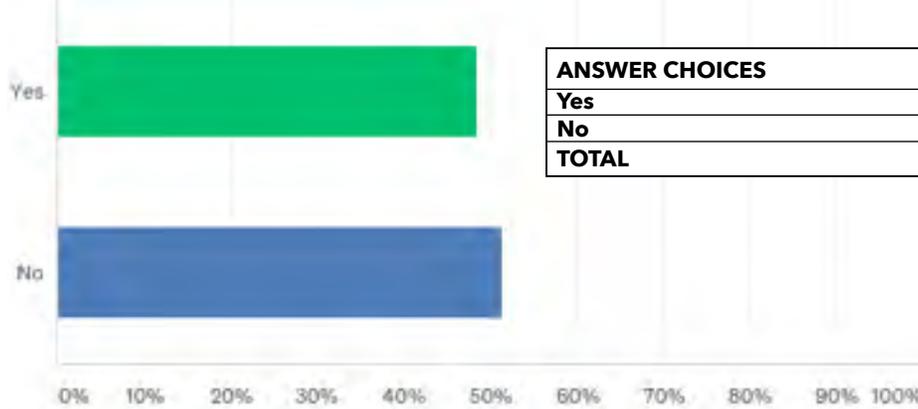
## Parish/State Low Estimate Palliative Care Mortality Rate Comparison



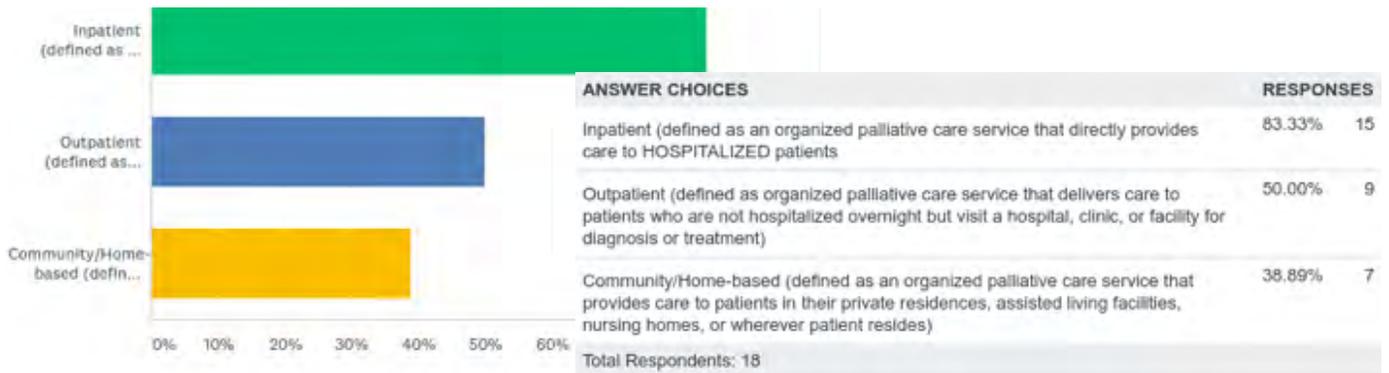
# LOUISIANA PALLIATIVE CARE SURVEY

A survey from LMHPCO was sent to palliative care providers in Louisiana asking for the number of patients they provide care for and the parishes their facility serves. Using this information each parish in Louisiana was assigned a capacity for palliative care based on the number and size of palliative care providers that serve that parish. To see if the demand is being met sufficiency is calculated taking palliative care capacity and dividing it by the demand. Sufficiency is measured as a percentage and indicates the amount of the palliative care demand each parish is capable of serving with their current resources.

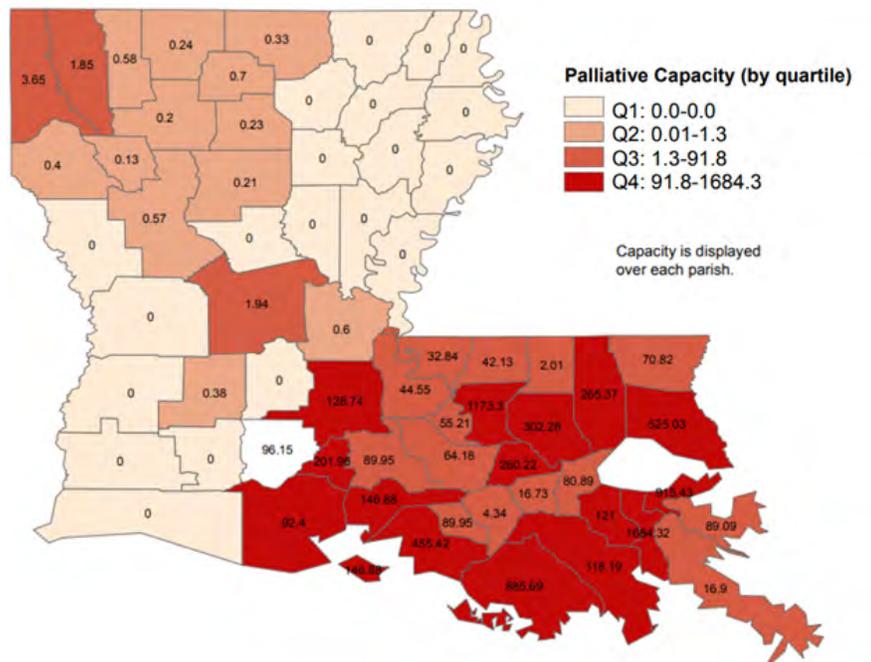
**Q1: Does your program provide palliative care services (excluding hospice)?** NOTE: This survey is not intended to identify availability of hospice services. Do NOT report on hospice patients.



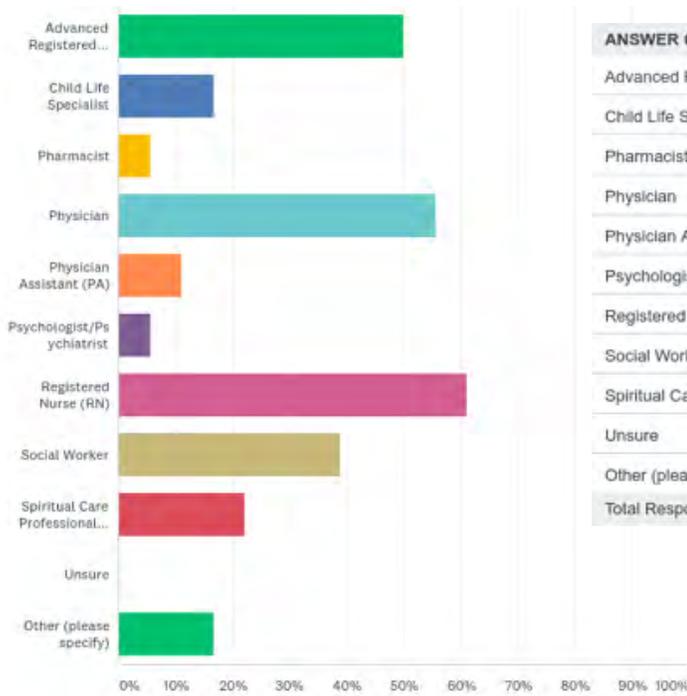
**Q2: Which of the following services are provided by your palliative care program? Check all that apply.**



**Q3: How does your parish's palliative care capacity compare across the state? Check all that apply.**

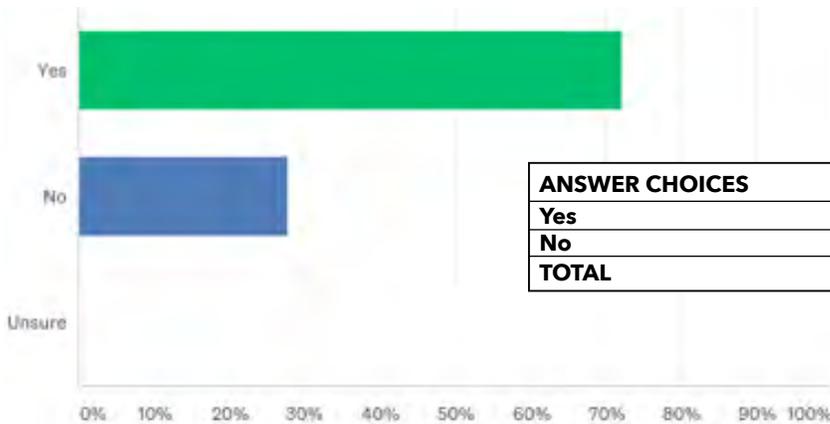


Q4: Does your palliative care program have dedicated (half to full-time) palliative care staff/specialists in any of the following professional disciplines? Check all that apply .



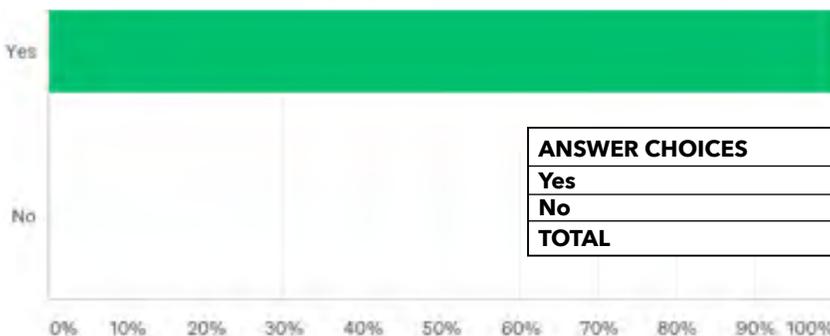
ANSWER CHOICES	PERCENTAGE	RESPONSES
Advanced Registered Nurse Practitioner (ARNP)	50.00%	9
Child Life Specialist	16.67%	3
Pharmacist	5.56%	1
Physician	55.56%	10
Physician Assistant (PA)	11.11%	2
Psychologist/Psychiatrist	5.56%	1
Registered Nurse (RN)	61.11%	11
Social Worker	38.89%	7
Spiritual Care Professional (including Chaplains)	22.22%	4
Unsure	0.00%	0
Other (please specify)	16.67%	3
<b>Total Respondents:</b>		<b>18</b>

Q5: Was your palliative care program in operation 12 full months during the 2017 calendar year?



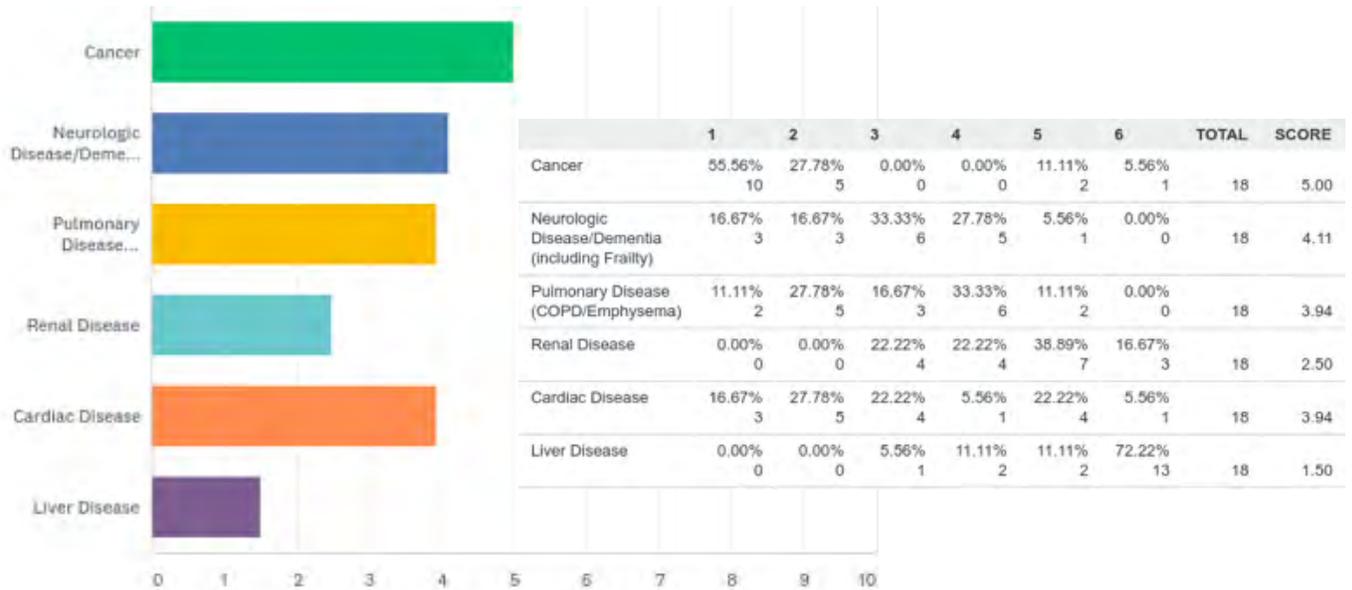
ANSWER CHOICES	PERCENTAGE	RESPONSES
<b>Yes</b>	<b>72.22%</b>	<b>13</b>
<b>No</b>	<b>27.78%</b>	<b>5</b>
<b>TOTAL</b>		<b>18</b>

Q9: Does your palliative care program provide services to cancer patients?

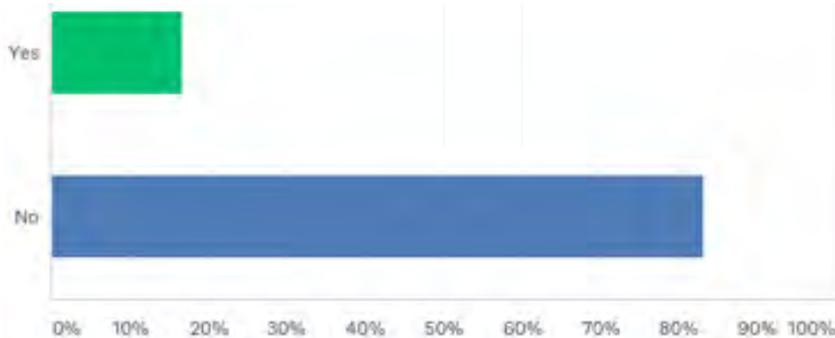


ANSWER CHOICES	PERCENTAGE	RESPONSES
<b>Yes</b>	<b>100.00%</b>	<b>18</b>
<b>No</b>	<b>0.00%</b>	<b>0</b>
<b>TOTAL</b>		<b>18</b>

Q10: What is the primary palliative medicine diagnosis of your palliative care program? Please rank in order

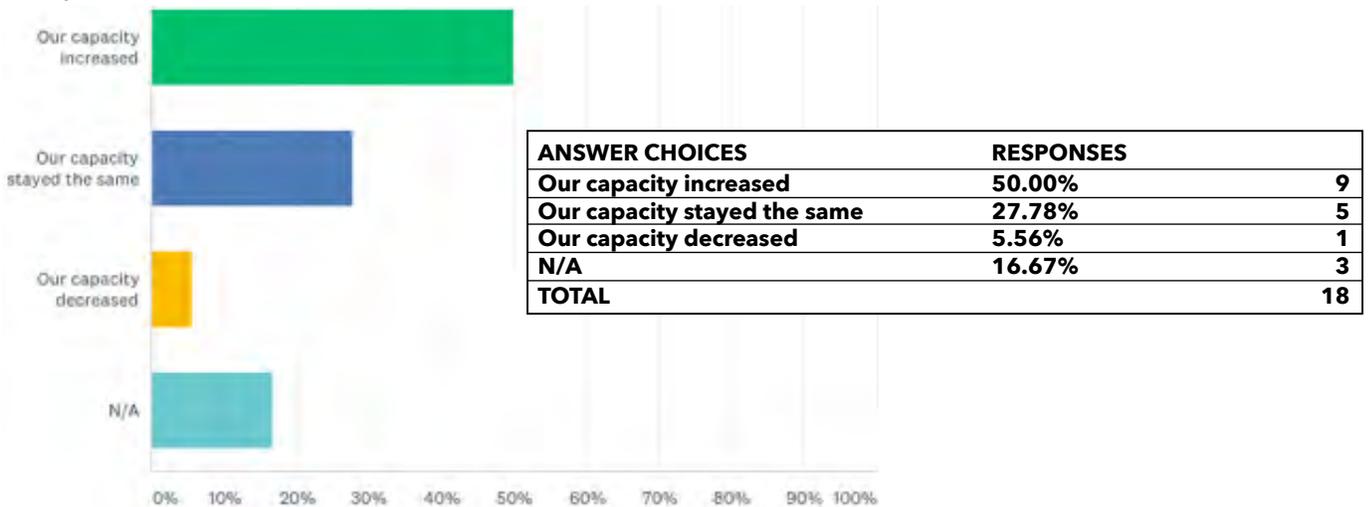


Q11: Is your palliative care program owned by a Hospice?

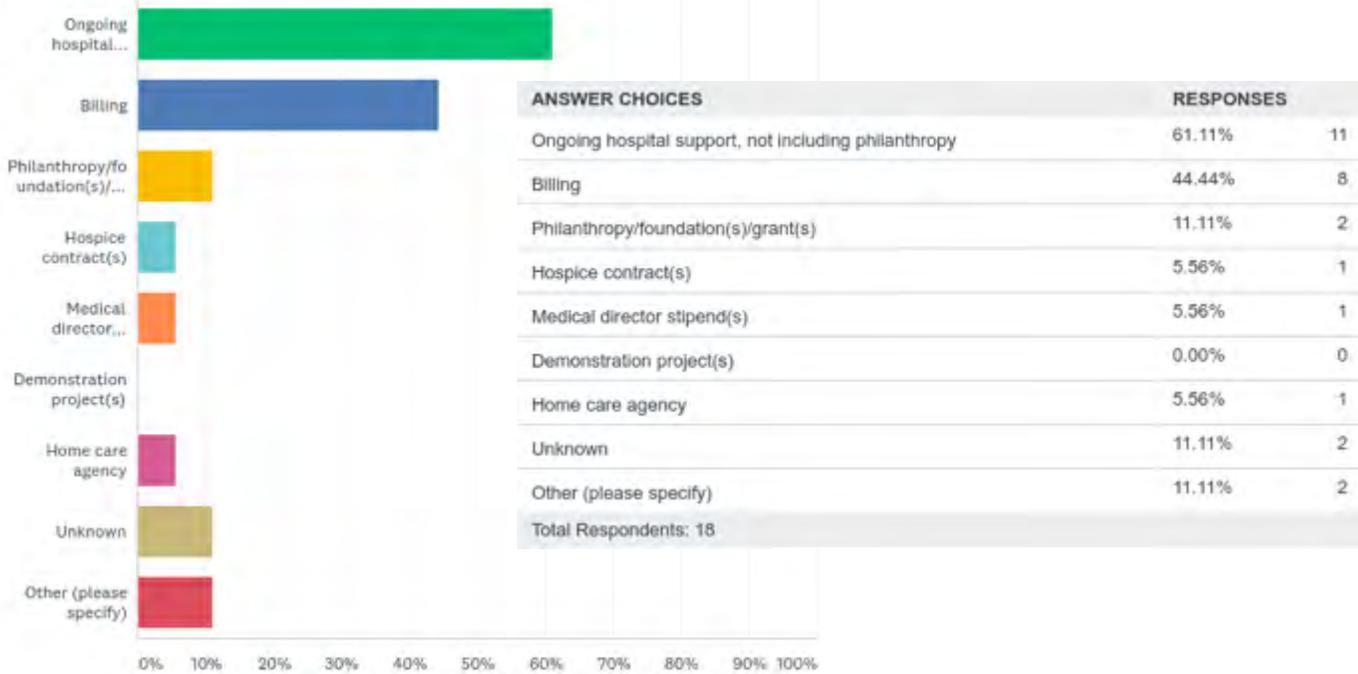


ANSWER CHOICES	RESPONSES
Yes	16.67% 3
No	83.33% 15
<b>TOTAL</b>	<b>18</b>

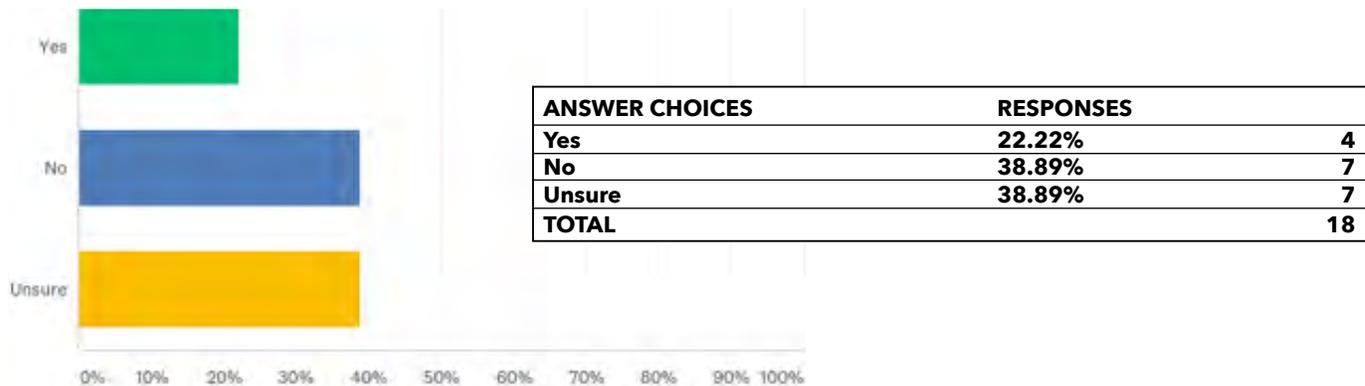
Q12: In 2017, which of the following would best describe your palliative care program's overall capacity (e.g., funding, staff, patients served)?



**Q13: How is your palliative care funded (choose all that apply)?**



**Q14: Looking into the future of your palliative care program, are there any barriers or challenges that could cause it to be discontinued?**



**A**t its current resource level Louisiana is only able to provide palliative care services to 25% of the patients who could benefit from it. A 25% rate is disappointing, but many parishes are even worse with 47 parishes having below a 25% sufficiency and 20 parishes having NO palliative care capacity at all. As a whole the state of Louisiana needs to improve its palliative care capacity but this data also shows which parishes are in the greatest need of effective palliative care programs.

**ARE WE MEETING THE DEMAND? IS OUR CURRENT CAPACITY SUFFICIENT?**

- Using the CDC Wonder Data as one number of deaths and the Palliative Summit Survey Data on patient capacity a sufficiency for the state can be calculated
- Sufficiency is calculated by dividing the capacity by the average number of palliative care related deaths calculated for that county.

RANGE	# OF PARISHES
<b>Less than 25%</b>	<b>47</b>
<b>25% - less than 50%</b>	<b>14</b>
<b>50% - less than 75%</b>	<b>1</b>
<b>Greater than 75%</b>	<b>2</b>

# Palliative Care Summit Action Plans for the next two years

## PROFESSIONAL EDUCATION

The Palliative Care Summit empowered physician, nurse, social work and chaplaincy educators to convene and draft a statewide plan for Palliative Care. The plan has been created to address educational deficiencies over a two year period. In the first year educators will compile a repository of evidence based data for Palliative

Care and draft a definition of what Palliative Care is that can be used statewide. Year 1's work will further the development of a Palliative Care curriculum in Year 2 to span across multiple disciplines including but not limited to physicians, nurses, social workers and chaplains.

## SCORECARD FOR SUCCESS

One of the goals of the first annual Louisiana Palliative Care Summit was to create a metric to determine the success of the summit and the success of palliative care programs statewide. Three categories were adopted that allow for measurement of palliative care development throughout the state. Education was seen as the forefront for palliative care in the years to come. Increasing the number of certified palliative care workers, expanding palliative care education in health professional schools, and measuring professional/ community education class by palliative care facilities are the metrics used to assess education. With the large gap in the capacity of our current palliative care programs compared to the need for palliative care in the state

there needs to be an increase in total programs and program size. This will be measured by the number of programs in each region, having at least one advanced level facility in each region, and the CAPC grade of our state for inpatient quality. Finally addressing utilization of resources throughout the state will allow us to better manage palliative care. Measuring the number of full resuscitation attempts in the intensive care unit (ICU), the number of LaPOST registrants, and evidence of a change in the goals of care in an emergency department setting. Over time shifts in these metrics will help to inform palliative care practitioners, healthcare administrators, and state policy makers on the changing status of palliative care in the state.

## COMMUNITY RESOURCE: PARTNERSHIPS/GAPS

### **What is available for patients in the community?**

Those who might benefit from palliative care are ubiquitous in our communities. They attend church on Sundays, go to clinic appointments, receive services from area agencies on aging, engage skilled home health and home and community-based services, receive meals on wheels, and are engaged in family activities. *Through some of these activities in the community potential palliative care beneficiaries receive education, participate in grief focused and other support groups, benefit from adult day health, PACE, and other available services.*

**What are other groups/ organizations are doing that can be leveraged by this summit?** *Veterans programs are progressive and might inform the work of this community of palliative care evangelists. Medically fragile children benefit from Families Helping Families, the Make a Wish program, Children's Miracle Network, child life experts, and other groups who aim to help children in need. Universities have expertise in many conventional and*

*unconventional areas of expertise, with our imaginations being the only limit in possible connections. Music therapists, grief support programs, family caregiving specialists, AARP, and chaplains are a few other important professionals who perform tasks that could be leveraged.*

### **Our group aims to address:**

- keys to assuring outpatient follow-up, enhancing access/availability/and ease of obtaining care
- building a broader, more robust stakeholder community through networking software
- accessing literature and data via a research librarian to support an active speakers' bureau
- use the California tool kit as a community resource  
<https://www.chcf.org/resource-center/community-based-palliative-care/>

## ADVOCACY, LEGISLATIVE, REGULATORY

With regards to **Advocacy, Legislative, Regulatory** by 2020, the Summit Action Plan calls for a clearer vision of palliative care in Louisiana, united by a common definition - as proscribed by the National Consensus Project. Over the coming 2 years this newly formed coalition of palliative care providers will identify and work with state healthcare associates sharing a common interest in the evolution of palliative care in Louisiana. Our goal will be to craft united messages for patients

and families, advocates, legislators and regulators. In doing so, this coalition will provide leadership, grassroots education and organizational support to providers, patients and caregivers, as well as work with the Louisiana Department of Health (state licensure directory for hospice, home health, hospitals, home & community based service, nursing homes and pain clinics among others) to implement these changes into state law and regulation.

## BEST PRACTICES SHARING / NETWORKING

Everyone agreed that Social Media is the quickest and easiest way to connect. Facebook and LinkedIn were mentioned the most. Although there may be some privacy concerns, most attendees felt that having a Facebook Group Page would be useful. Attendees also suggested giving consideration to expanding LMHPCO's area code meetings to include those who attended the summit as well as those interested in palliative care education and networking. Identifying volunteers who might be interested in championing the networking for each region was felt to be an important step to ensure responsibility is shared and does not only fall on the shoulders of the current staff of LMHPCO.

Most felt it was worth sharing the list of attendees and have this resource on the LMHPCO website so that

there can be a quick reference of those that attended, where they are from and what their interests and focus are, and who are interested in collaborating and brainstorming.

Acknowledging that in the past LMHPCO has been primarily a hospice education and networking resource, most felt that the creation of a **palliative care task force** would be vital to ensure the future work begun at the summit continues.

A long term goal that was mentioned was to create a mentor/mentee program by continuing the networking effort throughout the state. This would allow budding programs to lean on and learn from more advanced programs to ensure patients get the best palliative care throughout the state.

## ROADMAP

In preparation for the Palliative Care Summit, the planning committee created a **Roadmap** as a tool to summarize the information presented. The roadmap was created with a two-part approach: **resources needed and strategic focus**. The roadmap had categories based on critical elements of delivering Palliative Care. The categories consisted of **beginning, basic, intermediate and integrated**. During the Summit, we had participants assess their current position on the roadmap. The goal is that over the next five years, we will see shifting along the roadmap for the participants and increase the level of palliative service that is being provided to patients.

The next steps are to refine the roadmap based on feedback from the groups including creating a legend

that enables understanding of the two approaches. The first pass of participants aligning with the categories has been completed and has created an initial view of how palliative care is being offered in Louisiana. We feel that this roadmap would be beneficial to other states in understanding how palliative care is being offered in their state. The internal team will work on publishing the roadmap, via a white paper, and sharing best practices to other states. The white paper will be written and published by December 2018. As part of future summits, the committee will use the roadmap as an assessment tool which will have the same voting format that was create in the first summit.

# ROADMAP FOR PALLIATIVE CARE STRATEGIC PLAN

## RESOURCE ALIGNMENT

SUMMARY DESCRIPTION	0 BEGINNING	1 BASIC	2 INTERMEDIATE	3 INTEGRATED
	Any organization that is starting a Palliative Care Model in their hospital, clinic, or home based program. Typically have 1 resource who is nominated to build the program	Palliative care programs that offer "Basic" services are defined as using borrowed clinicians to support patient care within a hospital and/or within the community	Palliative care programs offering full spectrum of patient palliative care services with dedicated resources and the ability hand-off patient care to community clinicians.	This model features fully dedicated Palliative Care clinicians dedicated to patient care. Staffing for this approach requires fully-dedicated physicians, highly-trained nurses, Chaplains, as well as social workers and spiritual care resources. The team is in partnerships with community clinicians, research programs, and various disease management clinicians.
a) Hospital Based Palliative Care		Basic centers have a borrowed members (spiritual guide/ chaplain, etc) on the team that assist as needed. They have a provider (NP, RN, Social Worker) that is assigned to the program, and a collaborative MD. Basic programs offer some level of Inpatient Consultative Services  The same definition exists for pediatric hospitals	Intermediate centers have at least 1 dedicated MD.  Additional staff would be 1 Social Worker, 1 RN. The inpatient would have a collaboration with the Outpatient Clinic. The same definition exists for pediatric hospitals	Integrated centers would have a full, comprehensive team with greater than 1 Interdisciplinary team member including a Chaplain. A spiritual provider might also be part of the team. The team would consist of fully dedicated MD/ clinicians (could include APP's). The inpatient teams would provide all palliative services for the hospital and would be consulted as part of the patient care.  The same definition exists for pediatric hospitals
b) Outpatient/ Clinic Based		Basic service provided is awareness of the resources for patients to access. Minimal affiliations exist with larger hospitals/ health systems.	Multi-disciplinary clinic space is available for collaborative and patient-centered clinics; e.g. Survivorship care, nutritional needs, and community palliative clinicians. Space is available within the institution for team meetings and case reviews. The clinic is typically in a strong collaboration with a hospital/ system – with possible collaboration agreements.	Engage in complicated and complex follow up care. These clinics are built around robust multidisciplinary teams that work together across the entire continuum of patient needs. Visits are patient-centric with teams coming to the patient versus the patient moving; physicians and support teams collaborate on approach and care delivery for seamless patient experience. Space is available onsite for team meetings and case reviews. The clinic is typically owned by the hospital
c) Community Based Palliative Care		Community provider is several lists for referrals.  Typically an NP making house calls with collaborative agreement with a palliative care MD that is providing care to patients in their homes	The community providers are typically Home Health or Hospice agencies. They are may be using CAPC (or similar model) as a starting point to their Palliative model.  They have 1-2 RN and a shared MD for oversight. The agency has a basic collaboration with hospitals/ clinics.	These centers are distinct service lines that are based around the CAPC model and meet all of the criteria as defined by the model; including Board Certified MD's/ NP/ clinicians. They ensure CAPC competency models are met, using evidence –based orientation to include didactic and mentoring from an experienced provider. These centers can bill as a provider and have strong partnerships with hospitals, other healthcare entities, LTCF, and ALF; supporting the ability for clinicians to see patients in their own home setting. There is involvement/access to multiple disciplines to create a MDT approach. Patient experience consists of 24/7 access and medical notes that are communicated between all clinicians (hospital/ clinic). Program has ability to recommend/ orchestrate referral to Home Health/ Hospice if needed, working as a consultant partner with all healthcare clinicians. The goal is to discuss treatment goals, advance care planning, pain, and symptom management and interpret clinical data that supports education/understanding of their disease process.
d) Research Alignment		Data tracking of who is enrolled	Research Quality Improvement Person	Research alignment and community outreach

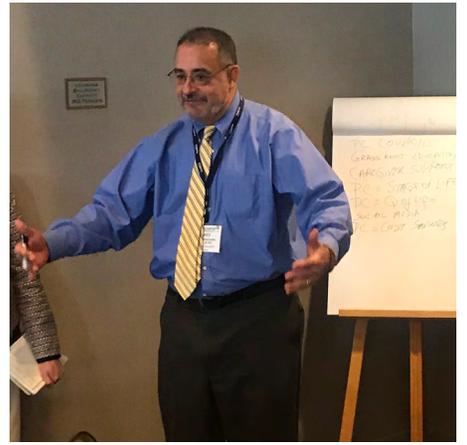
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a) Hospice/ End of Life/ Comfort Care		✔	✔	✔
b) Survivorship			✔	✔
c) Alignment with Cancer Services/ Disease		✔	✔	✔
d) Chronic / Complex Disease Management		✔	✔	✔
e) Survivorship Resources		Resources are minimal or limited; literature and educational resources used in the clinic are produced by partner or national organizations; run by volunteers or grant funded positions and not paid permanent positions	Employ part time support teams offering programming related to nutritional services, survivorship, and palliative care; resources have dedicated space in the Clinics and provide a one-stop approach for patients	Support full service teams dedicated to patient care: nutrition, survivorship, palliative care in dedicated space in the cancer center to provide a one-stop approach for patients; medical center is a regional or national sponsor and leader in production of these offerings as well
f) Patient Advocate/ Navigators/ Social Worker/ Chaplain		✔	✔	✔ Highly integrated into the team and being patients advocate
g) Patient and Family Alignment				

**LEGEND:** ✔ = fully implemented      ✔ = partially implemented

**For more information on Palliative Care contact**  
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*phone: 888-546-1500, ext. 7*



Thanks to all Partners who made  
the 2018 Summit possible

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