

**Commonwealth of Massachusetts  
Department of Public Health**

## **Palliative Care Key Informant Interviews**

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**June 2015**

**Conducted for:  
MDPH Comprehensive Cancer Prevention and Control Program**



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**Massachusetts Department of Public Health**  
**Palliative Care Key Informant Interviews**  
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## **Massachusetts Department of Public Health**

### **Palliative Care Key Informant Interviews June 2015**

#### **Background and Purpose**

In April of 2015 the Massachusetts Department of Public Health (MDPH) commissioned Ulrich Research Services to conduct a series of personal interviews with “key informants” on the subject of palliative care. The general purpose of the research was to learn to what extent palliative care is currently being provided in Massachusetts and to obtain informed opinions on ways in which palliative care can be improved. The information from this study will be used to promote palliative care, guide regional forums, and advance the development of various resources which will help improve palliative care across the state.

#### **Objectives**

1. To understand how and to what extent palliative care is offered and defined in organizations throughout Massachusetts.
2. To identify the sources and areas of confusion in palliative care among patients, families, and providers.
3. To learn which types of organizations are most actively involved in palliative care in their communities.
4. To understand the palliative care referral process and determine ways in which it can be improved.
5. To understand the major barriers to providing higher quality palliative care, and learn what resources are most needed to help professionals improve their palliative care programs.

#### **Method**

The Palliative Care Working Group at MDPH provided Ulrich Research Services with a list of 69 possible key informants for this study. Some of the key informants had previously participated in online surveys conducted by MDPH and had agreed to participate in follow-up interviews on the subject. Others represented individuals suggested by members of the Working Group as likely prospects for the interviews.

During the week of June 1 we began to contact prospects by telephone and e-mail. Our goal was to obtain interviews from professionals in all six MDPH regions and in various types of organizations involved in palliative care. We completed 24 personal interviews by telephone between June 4 and June 26, 2015. Four executive interviewers collaborated on the interviews: Jim Flagg, Nancy Ulrich, Kimberly Maxwell, and Dr. Roger Cochran.

In most cases we e-mailed a copy of the questions to our respondents prior to the

interview. Twenty-one interviews were conducted with individuals and three were conducted with two persons simultaneously at the request of the respondent we initially contacted. In total, 27 professionals participated in the study. A complete list of the key informants is included at the end of this report.

The interviews ranged from 23 to 53 minutes in length, with an average length of 35 minutes. They were distributed by MDPH region and type of organization as follows:

<b>Region</b>	<b>Type of Organization</b>
Western = 5	Hospital = 4
Central = 2	Skilled Nursing Facility = 2
Metrowest = 2	Hospice = 8
Northeast = 7	VNA or Home Health Agency = 7
Southeast = 5	Area Health Education Center = 1
Boston = 3	Social Service Organization = 2

In several cases the individual we initially contacted was no longer working at the same organization or worked in a different capacity, and we interviewed the person who volunteered to take their place. We also accepted referrals and volunteers from other organizations who sincerely wanted to participate in the study.

It is important to note that the interviews focused on palliative care as viewed by professionals in the field. They did not include representatives from the patient or family perspective.

This report contains verbatim quotes from respondents that may have been edited or abbreviated for clarity. We promised our respondents that we would not attribute specific comments to individuals in our report. To protect their anonymity we show only the type of organization for which the respondent worked, and not the MDPH region.

## Summary of Findings by Objective

### 1. To understand how and to what extent palliative care is offered and defined in organizations throughout Massachusetts.

- Seventeen of the 24 organizations we interviewed had a palliative care “program” by their own definition of the term. The respondents who did not say they had a program were involved in palliative as referral sources, counselors, or educators.
- Those with palliative care programs represented all types of organizations, especially hospices (7 respondents), hospitals (4), Visiting Nurse Associations or home health agencies (3), and skilled nursing facilities (2). Because our “sample” leaned heavily toward hospices, many respondents defined palliative care as part of a hospice care program. In some cases palliative care was only distinguished from hospice because it had a different funding source. Some respondents defined palliative care as a “bridge” or “continuum” between home health or hospital care and hospice.
- When we asked how they defined palliative care, our key informants showed a consensus on several common points:
  - Providing comfort.
  - Managing pain.
  - Managing side effects of treatment and medication.
  - Supporting quality of life.
  - Incorporating psychological, social, and spiritual care.
  - Including the family in care.
  - Respecting cultures and values.
  - Supporting patients and families with interdisciplinary teams.
  - Defining and discussing the goals of care.
- Most of the informants liked the definition of palliative care used by MDPH. Several said that they did not like the word “operationalize” in the definition. Only a few made suggestions for adding to the definition, such as including the phrase “quality of life” and incorporating the idea of “changing goals over time.” Several noted that their own program did not include a chaplain or emphasis on spiritual care, and felt that it should.

### 2. To identify the sources and areas of confusion in palliative care among patients, families, and providers.

- While noting that progress has been made in recent years, our key informants agreed that confusion about palliative care exists on all sides among patients, families, and providers. The most common theme in nearly every interview was that the general public and health care providers need to be made more aware of palliative care and understand its role in the management of chronic disease.
- The respondents noted several common areas of confusion among patients and families, such as:
  - The idea that palliative care means the withdrawal of all treatment.
  - The idea that palliative care is inevitably the “bridge” to hospice.

- That palliative care is only concerned with pain management.
- That palliative care means the patient is dying.
- They also mentioned several areas of confusion on the provider side:
  - The question of who has the responsibility to refer a patient to palliative care, and when.
  - Confusion over who pays for palliative care, and how much. Many providers do not understand how insurance reimbursement will work if a patient is referred to a palliative care program.
  - Confusion introduced by providers who market palliative care programs without trained palliative care professionals, and what constitutes a trained palliative care professional.

**3. To learn which types of organizations are most actively involved in palliative care in their communities.**

- Many of our key informants were justified in considering their own organizations to be leaders in palliative care, including Tufts University Medical Center, Lawrence General Hospital, Cooley Dickinson VNA and Hospice, and Hebrew Senior Life.
- In general, our informants identified large teaching hospitals, multi-unit organizations that provide home care and hospice services, cancer centers and oncologists, hospices, and some Visiting Nurse Associations and home health agencies as leaders in palliative care. We found that there are leading organizations in every region of the state.
- Our respondents had varying opinions on the types of organizations that are “lagging behind” in palliative care. Organization types that were mentioned as leaders by some were mentioned as laggards by others. They most often mentioned smaller community hospitals, primary care physicians, specialists outside of oncology, assisted living and independent living facilities, some Accountable Care Organizations, some of the medical schools, and insurance companies.
- Only three of the key informants could say that they were “very satisfied” with the state of palliative care in their community or service area. Eleven were “somewhat satisfied” and five were “not satisfied.” When we asked them to describe the state of palliative care in their community, we heard phrases like “not optimal,” “not consistent,” and “just scratching the surface.”
- The respondents noted the following areas of weakness for palliative care in their communities:
  - A lack of trained specialists in palliative care.
  - A shortage of specialists leading to infrequent visits with patients.
  - Lack of palliative care for patients with chronic diseases other than cancer, such as Parkinson’s Disease.
  - Lack of education for primary care physicians and hospitalists.
  - No insurance reimbursement for psychosocial and spiritual care.
  - The need for a body of “best practices” in palliative care.

**4. To understand the palliative care referral process and determine ways in which it can be improved.**

- Our key informants agreed that in most cases a referral is made too late for the patient and family to fully benefit from palliative care. In general, they would like health care providers to recognize the need for palliative care in a more systematic and consistent manner.
- They identified the following major reasons for referral to palliative care programs:
  - End of life care for patients and families who do not want to hear the word “hospice” (“the H word,” as one respondent said).
  - To address high hospital re-admission rates.
  - For pain management at home.
  - Care planning for patients who have resisted a “goals of care” discussion.
  - To help families cope with chronic disease, especially in cases of pediatric palliative care.
- The major sources of palliative care referrals included hospitals, oncologists, primary care physicians, and hospices. Our respondents also noted that a growing number of referrals were “self-referrals,” often made by word of mouth or from familiarity with other family members or friends who received palliative care.
- Our key informants made the following suggestions for improving the palliative care referral process:
  - Earlier intervention and referral to palliative care, such as when someone has been diagnosed with an advanced illness or when there has been a change of condition.
  - Education for all parties in the chain of referral: patients, families, physicians, nurses, and medical staff.
  - Make palliative care consults a more systematic part of treatment for chronic illness.
  - Allow payments to be made for palliative care when referrals are made by non-physicians.

**5. To understand the major barriers to providing higher quality palliative care, and learn what resources are most needed to help professionals improve their palliative programs.**

- Our key informants identified three major barriers to palliative care on the patient side:
  - A lack of access to palliative care services.
  - A lack of understanding of palliative care.
  - The fear of “giving up” on the hope for improvement or a cure.
- Out of all their recommendations for removing barriers on the patient side, the key informants most consistently called for educating the public about palliative care. They also recommended:
  - Making the goals of care conversation a systematic part of the plan for

- chronic disease.
  - Promoting educational materials such as the MDPH *Know Your Choices* guide, books like Dr. Atul Gawande's *Being Mortal* and *The Conversation Project's* "Starter Kit."
  - Working with insurance carriers to expand coverage of palliative care services.
- The respondents identified the following barriers on the provider side:
  - Not recognizing or admitting the need for palliative care.
  - Waiting too long to refer the patient to palliative care.
  - Avoiding a difficult conversation with the patient or family.
  - Not wanting to share their patients with other professionals.
  - Fear that recommending palliative care is an admission of defeat in treatment.
  - Legal issues with guardians of patients that may require time-consuming court processes.
- As with patients, the key informants called for improved communication, education, and awareness of palliative care among providers.
- Because it is difficult to sustain palliative care programs financially, our respondents naturally mentioned money as a needed resource for palliative care. They also mentioned several other resource needs:
  - Support groups and volunteers to relieve the social isolation, loneliness, and depression from dealing with chronic disease.
  - Access to education through training materials and websites.
  - Community outreach events.
  - More professional support, such as home health aides and chaplains.
  - A structured model for palliative care programs.
  - Reimbursement solutions that help palliative care pay for itself.
- Our key informants suggested several topics for regional forums:
  - Advance directives, healthcare proxies, and the MOLST.
  - Symptom management.
  - Guidance to information that is available online.
  - How to navigate a patient to palliative care.
  - Legal issues, such as guardianship.
  - Mentoring to help with difficult conversations.
  - A model of palliative care with examples of programs.
  - The curriculum of basic through advanced training for staff.
  - Best practices in culture change.
  - Differentiating palliative care from hospice care.
- Thirteen of the 24 respondents were familiar with the MDPH *Know Your Choices* guide. Those who were familiar with it thought it was an excellent educational tool, and many had made efforts to distribute it. Several asked us to e-mail a PDF of the guide.
- Sixteen of the informants had heard of the 2014 Massachusetts palliative care legislation. Those who were familiar with it expected and hoped it would have a "big impact" on palliative care in the state.



## Discussion of Findings

### Palliative Care Programs in Organizations

#### Existence of a palliative care program

When we asked about the existence of a palliative care program in their organization, seventeen of twenty-four participants answered affirmatively. Three participants indicated that no official palliative program was in operation. Four of the participants did not clearly indicate an answer because they viewed their palliative care services as part of their hospice care program.

Because we interviewed representatives of hospitals, hospices, visiting nurse associations, skilled nursing facilities, and home health agencies, all of the palliative care programs existed within the context of other services. In some cases the respondents would only say that they had a palliative care “program” if that program had a dedicated staff or separate funding source.

The following comments illustrate the participants’ responses to their organization’s approach to palliative care programming.

- *“We have a hospice program. We have a palliative care program. We have pediatric hospice and pediatric palliative care. And we have a bereavement program.” (Hospice)*
- *“We are, I would say, a hospice and a palliative care organization. We do care across the continuum. We have a pretty unique palliative care program, by the fact that we are the inpatient palliative care in five different hospitals.” (Hospice)*
- *“Hospice is more of a comfort. I would say that I do palliative care.” (Home Health Agency)*
- *“So my hospice actually specifically is part of an umbrella agency called Home Health Foundation, so it’s affiliated with a VNA...And we have a palliative care service that I supervise. It’s nurse practitioner run.” (Hospice)*
- *“Specifically there’s been an evolution. We’ve been doing palliative care through our agency. It’s mostly a home-based program...Some nursing home.” (Hospice)*
- *“We have a couple of things that are sort of separate. We have the DPH-funded pediatric palliative care program, which is separate from hospice but has to be administered by a hospice. And then because we’re part of the hospital I do the in-patient palliative care here, which is mostly physician consult but palliative care consults within the hospital and the outpatient cancer center.”(Hospice)*
- *“We have a hospice and we have a VNA. We also have a bridge program between our hospice and VNA. We do have a palliative care program, which is comprised primarily of myself and one palliative care and nurse practitioner.” (Hospice)*
- *“There’s two ways to answer that. One is that hospice is palliative care. Hospice was the first palliative care program ever created in this country and it is the gold standard palliative care. Usually when people are asking about palliative care they mean non-hospice palliative care...So hospice care is what we would*

*consider the full gold standard of palliative care. So it contains every aspect, every component of palliative care and by regulation must do that. Palliative care programs that are not hospice are not regulated so programmatically they can be doing a little bit of this, a little bit of that. But hospice is probably the most comprehensive palliative care program.” (Hospice)*

## **Definition of Palliative Care**

The participants offered a range of definitions when they discussed palliative care, but they centered on a few common points. Many respondents mentioned the importance of supporting physical comfort while managing pain. Additionally, most participants noted the importance of interdisciplinary or holistic approaches when pursuing palliative care, and incorporating emotional support for the patient and their families.

They often interchanged the terms “hospice” and “palliative care.” Many participants discussed the relationship between palliative care and hospice care as one of overlapping priorities yet distinct purposes. For example, one participant discussed the supportive aspect of palliative care for pain management in-home as a better fit for patients not yet at the hospice level of care.

The following comments illustrate the participants’ responses regarding the defining and operationalizing of palliative care.

- *“I define palliative care as somebody who is not ready for hospice.” (Hospice)*
- *“Palliative care is something that can occur across the lifetime, and not just at the end of life...its main realm is the control of pain.” (Social Service Organization)*
- *“We’re kind of defining it as a type of care in that supporting quality of life through pain, system management, as well as spiritual and psychosocial support, so a holistic process aimed at improving systems and quality of life.” (Hospital)*
- *“We define it in our organization as a specialized healthcare program dedicated to providing excellent physical, psychological, social, and spiritual care for persons with life threatening illness in their families.” (Hospice)*
- *“What we usually do is meet with the family and go through...again, it's symptom management. It's trying to find out again where the family is in the process, and where the resident or patient themselves are in the process.” (Skilled Nursing Facility)*
- *“Palliative care incorporates both spiritual and psychological care as well, and it deals with the whole family and their values and their cultures.” (Home Health Agency)*
- *“Palliative care is a program that helps people who are maybe having challenges with pain or symptom management in their home. They may be taking medication that has a lot of side effects. Some patients are undergoing treatments that have a lot of side effects. Patients may be declining and not quite fit a hospice criteria in which they would need hospice services, but we would help support them at home and make them as comfortable as possible.” (Home Health Agency)*

- *"It is pain and symptom management and goals of care are the objectives. It is an interdisciplinary approach to palliative care, to managing those issues. In its truest form, it should be interdisciplinary and it should include ultimately or ideally the model that hospice is, which is with social work, chaplain, medicine, nursing, and we do that in fact." (Hospital)*

## **Responses to the Definition of Palliative Care Used by MDPH**

We asked the key informants to comment on the definition of palliative care that is used by MDPH:

*"Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care with consideration of patient and family needs, preferences, values, beliefs, and culture. A formal program has dedicated palliative care team members including a physician, nurse, social worker, and chaplain."*

Many participants agreed with and supported the definition of palliative care used by MDPH. A few suggested small modifications such as: change the word "operationalized," incorporate an aspect of "changing goals over time," or "take a broader view in overall support of the patient." One participant felt everyone should use the definition from the Center to Advance Palliative Care ([www.capc.org](http://www.capc.org)). Some participants indicated that a consistent definition and structure for palliative care might help reduce some of the confusion surrounding it.

The reference to a chaplain as part of the palliative care team sparked some discussion. Some participants indicated that a chaplain was more often seen in hospice programs rather than palliative care programs. Several participants reported that their approach to palliative care did not currently include a chaplain. The definition reminded them that spiritual counsel could be an important part of palliative care.

The following comments illustrate the range of participants' reactions to MDPH's formal definition of palliative care.

- *"I think 'quality of life' kind of sums up the goal of palliative care. So I kind of would like to see that phrase stuck in there somewhere." (Hospital)*
- *"I don't love that definition. Well for one thing, I think we probably should all be using the CAPC definition. CAPC is an acronym for the Center to Advance Palliative Care, so we probably should mostly be using that. And theirs is that palliative care is specialized medical care for people living with serious illness, and it focuses on providing relief from the symptoms and stress of a serious illness, whatever the diagnosis, with the goal to improve quality of life for both patient and family." (Hospice)*
- *"I think that palliative care also is a precursor to hospice care. I think it's providing to people who may be in the stages prior to requiring hospice care." (Home Health Agency)*
- *"I think the definition doesn't necessarily speak to chronic disease management or serious illness in that definition. And I think the word 'operationalize' feels cold to me. It should be something like 'comfort care' maybe, but yes I agree that basically we're on the same page." (Home Health Agency)*

- *“So I feel that palliative care is about supporting patients with advanced illness, regardless of what their goals of care are, whereas hospice is more narrowly defined as, you know, providing symptom and psychosocial support for patients whose goals are no longer curative. So I guess I have a bit of a broader definition, and in terms of a formal program, I don't think that Massachusetts or anyone else has really defined a formal program in terms of creating a program that is paid for.” (Home Health Agency)*
- *“I think the MDPH definition corresponds to palliative care. I think it is missing a little bit of addressing the goals changing over time. I think that's really an important aspect. I do have the belief that we often substitute the word palliative care for hospice, just because we're afraid to mention hospice care. Patients whose goals match hospice would benefit from hospice care as well as the whole palliative care continuum and it is all just one piece.” (Hospice)*
- *“I would define palliative care as care that helps alleviate symptoms. The focus of our program is to focus on patients who have acute pain and symptom management needs as well as may require discussion regarding goals of care decisions. Our role is to help patients, sometimes we go in to just do strictly goals of care discussion, sometimes we go in to do pain and symptom as well as goals of care.” (Home Health Agency)*
- *“People talk a great deal about effective management of pain, and quite often they're talking about physical pain. There's also a spiritual, psychic piece so I would love to see that bubble out a little bit more.” (Social Service Organization)*

### **Confusion About Palliative Care**

Although some participants indicated that they have seen progress in the understanding of palliative care over recent years, most of the respondents confirmed that there continues to be confusion on what palliative care is, what role it plays, and when it is appropriate to refer someone to palliative care. Confusion is found among patients and their families, as well as among providers across the medical community.

The wide range of services included in palliative care and a lack of consensus on what makes up a structured palliative care program adds to the confusion for both providers and patients alike. Some common misunderstandings include the following:

- Palliative care is gap care.
- Palliative care is hospice.
- Palliative care means withdrawal of all care.
- Palliative care is confused with pure pain service.
- There is no defined benefit for palliative care.
- Palliative care provides custodial care.
- Patients must stop treatments such as chemotherapy to get palliative care.
- Palliative care means the patient is dying.

The key informants noted some common areas of confusion about palliative care, such as:

- Confusion over the appropriate timing to refer patients to palliative care.
- Confusion about insurance reimbursement if providers refer their patients to palliative care.

- Confusion over whose responsibility it is to refer patients to palliative care.
- Confusion created by providers who market their services as palliative care programs without having any trained palliative care professionals.

The following comments illustrate key areas of confusion or disagreement among providers, patients and their families as to the purpose of palliative care.

- *“There's definitely so much confusion. I find sometimes that the bulk of my role is describing what my role is, defining palliative care versus hospice, and the differentiation between them. A lot of people say ‘we're not ready for palliative care yet,’ but what they're saying is they just don't want hospice yet. I find I have to explain the difference with both clinicians and with the public.” (Hospital)*
- *“To explain something so broad, people are going to get lost. The key is to really educate people about what is hospice and what is palliative care.” (Hospital)*
- *“I think there is confusion among people who think they're providing palliative care about what palliative care is. And I have some real biases about some of the programs I see touting themselves as palliative care because they do not really have a formalized structure. They don't have trained folks. It's no more than some kind of really slick marketing from a lot of organizations that say they have palliative care since it's a big “in” word right now. I think it's very confusing to people.” (Hospice)*
- *“People hear it and they think that ‘no treatment’ means ‘withdrawal of all care.’ So there's a fear of being given up on, or that people won't be able to receive the treatment that they need and want. Sometimes people use the word interchangeably, palliative care and hospice care. The word hospice often has many fearful, negative connotations to it. Yet, I just think that the word palliative care includes all sorts of aspects. I think there's a lot of misunderstanding about it, even among providers.” (Social Service Organization)*
- *“There's confusion with all of the above [referring to providers, patients, and families], but it'll take a lot of years for everybody to sort of get it and for the palliative care community to define itself better.” (Hospice)*
- *“There's a basic ‘what is it?’ It's a funny word; people don't understand it. Our biggest challenge is often that it's confused with a pure pain service. And a lot of palliative care programs have this problem where we need to screen out kind of chronic pain issues, people who are better treated in a pain clinic. There are ethical or legal dilemmas; that's something different. So sort of that Venn diagram of how all those things overlap - ethics consultation, pain consultation, palliative care - can be blurry.” (Hospice)*
- *“On the provider side, it's that fear of giving up and fear of, oh, it's not yet time for palliative care. And on the patient side, it's also a misunderstanding of the word, palliative care, so that people are then afraid...‘Oh my god, is my physician wanting me to talk about hospice?’ On the other hand, the major issue for patients on the patient side is not being aware of it. And so I don't think they're as aware of what it is and how it can help them. Consults are requested sometimes by families, especially for patients that are elderly or very ill, so that the families are actually the ones needing it, and really having to advocate for it. Not knowing, ‘do we talk to someone from palliative care,’ ‘would that be helpful [for cancer,*

dementia, etc. Sometimes the families are not aware if that is an appropriate avenue.” (Hospital)

- “I can safely say that I believe the biggest confusion is that we come in and provide custodial care, that we are hands on, that we do the daily baths, that we are going to come out once a week, that we are going to be the care provider if the patient no longer needs VNA Services. That’s from a family perspective. From a case management or a professional perspective, I feel almost the same in that they feel as though we are providing “gap care” in a sense, if they’re going to discharge patients and they don’t want to see the patient after discharge, let’s get palliative in there, because they can continue to see the patient and if they change, we can put them back on our services. Well, that’s not what we do. I think that’s a huge misleading bit of information.” (Home Health Agency)
- “If you ask me to sort of define how to conceptualize the barriers, I would say there are patient and family barriers. There are institutional barriers, and there are professional or clinician based barriers. And when I say institutional barriers, I don’t mean academic settings or hospital settings, I mean our general culture at large, too, it’s not just the institution itself.” (Hospital)
- “The way I like to try to explain that misinformation is to say that palliative care is broader than hospice care.” (Hospital)
- “I think that people generally don’t know what palliative care means, patients and families, and I think that among providers, there’s confusion mainly because there isn’t really a defined benefit. So in many organizations, a palliative care program is viewed as a bridge program, a bridge to hospice for instance.” (Home Health Agency)
- “So we’ve done a lot of work and now people don’t dread us. Palliative care is a very important part of hospice care. We were viewed as ‘uh-oh, you’re the hospice team’.” (Skilled Nursing Facility)
- “Many of them think it’s the same as hospice. Many of them think that you have to wait until a patient is very close to end of life to consult palliative care. There’s just sort of general confusion about what we do. They don’t understand that we’re specialists in symptom management.” (Hospice)
- “The way I explain it to lay people is all hospice is palliative, but not all palliative is hospice. But the reimbursement piece still prohibits a crossover of palliative and hospice.” (Hospice)
- “I think maybe one way to characterize some of the ‘issues’ that I’ve seen within the private practice community may be the result of confusion around what it is and when it’s most appropriate to refer or give patients that type of service. But I also think that there may also be some issues that result from, you know, practitioners in clinical areas basically just doing what they do. And making sure that they exhaust all possibilities for the areas of service that they can provide” (Hospital)
- “I do think that there’s a bit of confusion because there’s no programmatic definition.” (Home Health Agency)
- “I think a lot of clinicians have not been trained or mentored in having difficult conversations. So they avoid it. They’re not comfortable, they don’t know the words, they don’t know how to respond to emotion, so when patients start crying

*or are upset or angry they want to run out of the room and just call the social worker.” (Hospital)*

- *“I think physicians in general need better education with regard to home care, palliative care, and hospice care, and when to refer. I don't think that they have a good handle on that, at least the majority of them don't. I think the confusion is that they just don't take the time to understand it, that they don't feel it's part of their role to understand that.” (Home Health Agency)*
- *“Doctors stay in their bubble. Not all doctors, but I think that's where there is the problem.” (Home Health Agency)*

## Views on Palliative Care in the Community

### Organizations Leading in Palliative Care within the Community

Many of our key informants believed that their own organization was leading the way in palliative care. Some felt that the larger hospitals and hospice organizations had the most advanced programs.

The following list identifies most of the organizations noted by participants to be “leading the way” in palliative care:

- Central Massachusetts Area Health Education Center
- Lawrence General Hospital
- Cooley Dickinson and VNA and Hospice
- Care Dimensions, Danvers
- Merrimack Valley Hospice
- Hospice & Palliative Care Federation for Massachusetts
- Mass General Palliative Care, Boston
- Beth Israel Deaconess, Boston
- Hebrew Senior Life, Boston
- Boston Medical Center
- Tufts University Medical Center
- Brigham and Women’s Hospital
- North Shore Medical Center
- Massachusetts Palliative Care Coalition
- Saint Anne’s Hospital, Fall River
- Charlton Memorial Hospital
- Center to Advance Palliative Care
- Nantucket Hospice
- Facilities linked with the American Cancer Society
- Larger, multi-unit organizations that provide both certified home care and hospice services
- Cancer centers
- Non-profit palliative care
- Most of the big Boston hospitals
- Larger teaching hospitals
- Healthcare hospice agencies
- Home health and hospice agencies
- Acute care hospitals
- Hospice organizations
- Certain specialists (“primarily the oncologists – they know where to direct people”)

The following comments further illustrate the variance in opinions regarding leading palliative care programming and related efforts within participants’ communities.

- *“I mean we have Mass General. We have Beth Israel Deaconess. We have the Brigham. We have Tufts. We have Boston Medical Center.” (Skilled Nursing Facility)*



- *"Lawrence General has the only dedicated palliative care service with real board certified physicians and a dedicated social worker chaplain team." (Hospice)*
- *"I would say that's probably us. I think the hospital and the hospice and the ACO and geriatric teams, I think we're leading the way." (Hospice)*
- *"Mass General is probably head of the pack." (Hospital)*
- *"The Center to Advance Palliative Care has worked miracles in having hospitals grow and get there." (Hospital)*
- *"I will tell you for 15 years I've been trying to get palliative care established here at Tufts, and it wasn't until there was a groundswell that demanded this as an expectation that it really kind of came to the forefront." (Hospital)*
- *"We are definitely one of the leaders in palliative care. There is another agency that is a hospice agency that is providing free standing palliative care like we are and they're doing a great job north of Boston. I would probably say there are two or three. There are great inpatient programs like the city of Boston has a Mass General Palliative Care Program which is outstanding." (Home Health Agency)*
- *"There really is no real community palliative care available north of Boston other than our program." (Home Health Agency)*
- *"Our organization is. A lot of the hospitals in the Boston area either have a dedicated palliative care team, so they have their own program or are developing their own program, or are bringing in outside organizations to provide palliative care to their inpatient population. So, it's growing." (Hospice)*
- *"Teaching programs, medical schools, nursing schools, I think are really the ones establishing palliative care." (Hospital)*
- *"I think that large physician group practices are very interested in palliative, whether they're developing their own, or they're contracting for it. They are definitely advancing the development of palliative care." (Home Health Agency)*
- *"We have three major hospitals in our area, and each one of them has had palliative or have a palliative physician on staff, and they have really developed their program both inpatient and for the community programs as well as the VNAs and hospice associated with them or they work with. Yeah, I think homecare and hospice are leading the way as well." (Home Health Agency)*
- *"I always think about bigger hospitals as having basically the Cadillac of palliative care teams. And they also feel like they own the patients in a way that a lot of hospitalists don't feel that they own the patients. So they are more comfortable having these very complex and intimate discussions about what they do and do not want for treatment. And they don't worry about alienating their friend who's a PCP that's working with his patients." (Hospital)*
- *"ACOs and the Integrative Managed Care systems that are doing a much better job." (Hospital)*
- *"I think homecare agencies are truly leading the way." (Hospice)*
- *"Hospitals are doing it because it's cheaper to provide a palliative care M.D. than to keep somebody in the ICU." (Home Health Agency)*

## Organizations Lagging in Palliative Care within the Community

The participants had varying views on organizations lagging in palliative care. Accountable Care Organizations (ACOs) were most frequently mentioned among the types of organizations believed to be lagging in the area of palliative care, but a few also felt that ACOs were leading the way. Skilled nursing facilities, PCPs, community hospitals, academia, and non-oncology specialists (such as pulmonary and cardiac specialists), all were also noted multiple times. This list includes entities identified by participants as lagging in palliative care:

- Accountable Care Organizations
- Community hospitals
- Physician offices/PCPs
- Community based organizations
- Assisted living facilities
- Skilled nursing facilities
- Insurance companies
- Independent living facilities
- Some medical schools
- Specialist groups such as cardiology or pulmonary clinics
- Some hospice organizations
- Some homecare agencies

The following comments illustrate the wide range of opinions our informants had on the types of organizations that are lagging behind in developing palliative care programs.

### *Hospitals*

- *“Community hospitals, physician offices, community based organizations, assisted living facilities have a tougher time with it. Large provider network organizations, primary care physicians in the community, certain primary care offices maybe.” (Hospital)*
- *“Our medical director had been working for a number of years, well over a decade, to try to establish a palliative care program in those hospitals, and has yet to be successful.” (Hospice)*
- *“Very few community hospitals are...I mean you’ll look on a website where a hospital swears they’ve got a palliative care service; and they don’t. They have a case manager who is doing some palliative care screening. Maybe they have some local hospices coming in providing either NP consultation, maybe MD consultation, but it’s not a palliative care service.” (Hospice)*
- *“Small community hospitals. And for good reason; it’s expensive. No one can do the cost shifting calculations. I don’t know why; the data exists, but they can’t. I think once we are all truly accountable care organizations that will change and everybody will suddenly then maybe have a good palliative care service. And again that’s why we’ve run away from doing this in the hospital because everybody kind of wants it on the cheap. It doesn’t pay my staff salary.” (Hospice)*
- *“The smaller hospitals often don’t have a real palliative care program or are struggling with them.” (Hospital)*

- *“Small hospitals definitely don't have the same resources. The private and for-profit hospitals, I think, also struggle making an argument for palliative care, despite the fact that there's a lot of research about the cost savings when you do have a palliative care team.” (Hospital)*

#### *Skilled Nursing Facilities*

- *“Skilled Nursing facilities, I think they probably are least able to do palliative care programs just because of the lack of trained physician presence, I guess I would say.” (Hospice)*
- *“I think skilled nursing facilities are sometimes hesitant to use palliative care appropriately. And I think we get very late palliative care consults as far as patients would have benefited from this discussion before this third or fourth hospitalization.” (Hospice)*

#### *Accountable Care Organizations*

- *“You can't successfully have ACOs without integration of palliative care as a critical component to manage patients and to manage care and costs. To my way of thinking, this is a no-brainer and it's not happening. Again, with the development of ACOs, they would be leading the charge and they're not.” (Hospice)*
- *“Certainly the accountable care organizations are interested, but they haven't taken that step yet. Primary care offices or primary care practices as well are lagging. Certain specialty groups, for example cardiology or pulmonary clinics where there's a high burden of diseases that are affiliated with some of those that require management throughout the course of that disease.” (Hospital)*

#### *Insurance Companies*

- *“I think the insurers should be pushing for it more, because that would create more of an incentive to providers that would give us more guidance about exactly what sorts of resources should we put into place that would be reimbursable.” (Home Health Agency)*

#### *Physician Practices*

- *“I think the physician practice is lagging behind.” (Home Health Agency)*
- *“There's still a pretty big need for it among the primary care outpatient setting.” (Hospice)*

#### *Medical Schools*

- *“I wish that more and more of the medical schools would start right there, the nursing schools with this is what palliative care is and what it really means not just what the words are. I know the geriatric fellows get this education but I'm not sure everybody else does or how well they get it.” (Skilled Nursing Facility)*

#### *Medical Specialists*

- *“There needs to be a lot more access for patients in the pulmonary and cardiac populations.” (Hospice)*

## Home Health Agencies

- *“Any homecare agency that doesn’t have a palliative care program in place. I think anybody who is taking care of patients in the community or seeing them at home sicker and sicker, I think it’s a disservice to any patient that they take on board if they haven’t had education with their staff on end stage illness.” (Hospice)*

## Satisfaction with Palliative Care Services in the Community

Only three of our key informants said they were “very satisfied” with the palliative care services in their community. Eleven were “somewhat satisfied,” and five indicated that they were “not satisfied.” Two participants did not clearly indicate their level of satisfaction.

The respondents commented that there are still many areas in which improvements need to be made, such as education for the general public and providers, better communication and relationships with referral sources, easier access to palliative care, more trained personnel, and consistency in payment structures. One participant succinctly described the current state of palliative care as “just scratching the surface.”

The following comments illustrate the range of respondent satisfaction with palliative care services in their community.

- *“I’d love for us to have a palliative care physician on the island who would be an expert in palliative care. That being said, we’re little so we can’t have specialists in everything out here.” (Hospice)*
- *“I think we really do pretty good down here for palliative care and end of life.” (Skilled Nursing Facility)*
- *“I would say they meet them pretty well, but not optimally yet. The thing about palliative care is it could be so wide open. We meet the needs of our patients with cancer in the community quite well, but there are a lot of other illnesses that we haven’t really done too much with yet. People with Parkinson’s disease have some real palliative care needs.” (Hospice)*
- *“I’m pretty satisfied. Most of our specialists come in once a month or something, or sometimes once every couple of weeks. So it would be great to have that, but I’m not sure that that’s realistic for us. In general, I’m pretty happy with what we’ve been able to do.” (Hospice)*
- *“I would say satisfied. There’s always more that we can improve upon as a community as a whole, such as educating some of the hospitalists. It’s not our primary care physicians for the most part that have issues, I think it’s the hospitalists.” (Skilled Nursing Facility)*
- *“Somewhat satisfied because I don’t think that there’s a consistent approach in our community.” (Home Health Agency)*
- *“It’s just very difficult to get these hospitalists for education. It’s difficult enough to get some of our PCPs to go to education, and luckily our medical directors are very good. They’ve focused in on this.” (Skilled Nursing Facility)*

- *“There are huge opportunities for improving how we communicate and how we support palliative care in our larger extended community.” (Hospital)*
- *“We're still an early program, we're not well established yet, it's sort of building on successes and getting the word out, and the best way to do that is to take on the biggest challenges and win friends and allies.” (Hospital)*
- *“Spiritual care is not addressed in terms of an insurance model. More education or more public health dollars could go towards educating older adults about palliative care.” (Home Health Agency)*
- *“I would say not satisfied just because I don't think we're even scratching the surface of need.” (Home Health Agency)*
- *“So the insurance company will pay us to go out and provide the IV chemotherapy, but they won't pay us to send out a specialist to help someone work through their feelings.” (Home Health Agency)*
- *“You're talking about the greater Boston area, which is one of the epicenters in the world of medical care. Massachusetts, that it's as poorly developed as it is and given all that is going on, it is mind-boggling to me...They can't meet the needs of the community.” (Hospital)*
- *“Those [Parkinson's] patients need really good palliative care, but I don't really know that we have great palliative care people looking at that yet.” (Hospice)*

## **Ways to Improve Palliative Care Programs**

One participant pointed out about palliative care, “It's not in addition to good medicine, it is good medicine.” Our respondents identified several key ways to create significant improvement in palliative care programs.

The main improvement opportunities listed by participants included the following:

- Specialized palliative care for specific disease processes.
- Improvements in education and understanding of palliative care.
- Consistent program structures across providers and organizations.
- Financial support, adequate reimbursement, and expanded Medicare guidelines.
- Earlier access and referrals to palliative care.
- Financial resources for hiring qualified palliative care professionals.

The following comments are grouped in the categories of improvement suggested by the respondents.

### *Specialized Palliative Care*

- *“I think in the long run what you're going to need to see are people who are sort of specializing within palliative care for certain disease processes.” (Hospice)*
- *“Well, I think that we need to have a body of information for what is best practice for that kind of patient. And then I don't know because I think we're all going to have to figure out how that really could be provided for. Are you going to have one palliative care generalist who is going to know cancer care, cardiology, respiratory disease, dementia, all of that? Because just the same way as you*

*don't have one person knowing all of that in earlier stages of disease, I think that the same thing is going to be true for late stages of diseases. It's tricky." (Hospice)*

#### *Improvements in Education and Understanding*

- *"I think just a general improvement in understanding of what palliative care is and accessing it earlier, having an earlier referral to a palliative care program." (Home Health Agency)*
- *"Awareness of palliative care across the state may not be as high as I would like it to be. I think that the resources are clearly there. So at whatever point the awareness can adjust to the resources..." (Hospice)*
- *"Palliative care programs are usually value-added services, not money makers. But I would say that value added service is critical to your mission as a hospital. It really is about creating a culture that says this is best medical care. It's not in addition to good medicine, it is good medicine." (Hospital)*

#### *Consistent Program Structures and Continuity Across Functions*

- *"They're all structured so differently. It is one of the challenges that we have. I will often get a referral from another agency that doesn't quite practice it the way that we do." (Home Health Agency)*
- *"The ones that understand it I think have taken the time to look at post-acute services in general, and the continuum of care from acute to chronic care, and I think palliative care has a lot of chronic care components to it, and I don't think that all places are out of their silos yet." (Home Health Agency)*
- *"I think we need to do a better job of supporting both in-home care and skilled nursing facility care. When we look at end of life care, 25% of families that are providing in-home end of life care suffer tremendous financial burden from doing that. In some cases we actually impoverish families by doing that. I think as a society we haven't worked that out yet." (Hospital)*
- *"We really need some national organizations to take the lead. I actually think that we've been ahead of most national organizations because we've been doing this for a lot of years." (Hospice)*
- *"And even some of the big medical centers really are just trying to get palliative care programs going. What will be helpful is when national programs start to look at the needs of people with advanced cardiac disease and advanced respiratory disease and advanced neurological diseases like Parkinson's and dementia and some things like that and start to say these are best practices for taking care of these." (Hospice)*

#### *Financial Support, Reimbursement and Medicare Guidelines*

- *"I think we're moving from that acute care model to the fact that people are suffering from chronic disease. Survey after survey says patients want to die at home, and yet that's still not the case for the majority of Americans. And so when you look at the Medicare financing, the largest part of the Medicare budget is spent in the last six months of life. We're doing something wrong, I think." (Hospital)*
- *"The cost. We're trying to do a joint position with them that will do both hospice*

*and palliative because the one doctor there is stretched. I mean I think every palliative and hospice doctor in the world is stretched now because organizations can't afford us. It's labor intensive, it's time intensive, and while the results are there the pressures of the bottom line are huge nowadays." (Hospice)*

- *"I know that they're actively trying to put resources into a palliative care team. But they're mostly thinking about it from their standpoint of reducing re-admissions, possibly reducing the utilization cost of a DRG." (Hospital)*
- *"But I absolutely feel that what VNA programs are offering as palliative care for homebound patients and for patients that don't have access to outpatient palliative care programs is fabulous. I think Medicare guidelines are going to have to change so that that it can continue for patients beyond the limited time when they're going to be reimbursed for it." (Hospital)*

#### *Improved Referral Systems*

- *"We need a link system that could trigger an e-mail to me when a patient who meets certain criteria even comes into the hospital. We do need to work on having people recognize when they should be making a referral more quickly." (Hospice)*
- *"What needs to happen more is for the hospitals and physicians and referrers to get more used to identifying more people who could use that extra layer of support." (Hospice)*

## The Palliative Care Referral Process

### Major Reasons for Referrals

When we asked our respondents to describe the major reasons for patient referrals to palliative care, they distinguished between the reason or purpose of referral and the sources of referral. Sometimes they described the purpose of palliative care as bridging the gap between hospital care and hospice care. The participants identified the following major reasons for referral to palliative care

- End of life care
- Addressing high readmission rates
- Symptom and pain management
- Care planning
- Non-curative care
- Helping families cope

The following comments illustrate the major reasons for referral.

#### *End of Life Care*

- *“I think that's been the new push. A lot of our referrals are pushed initially by case management to the doctor, saying this person has a very advanced disease and they keep coming back. They tend to be those who are closer to the end of life, like in their last year, and they also are asking for a goals of care discussion.” (Hospital)*
- *“In our program, believe it or not, about 40% are for oncology patients, and I would say for the oncology patients they tend to be crisis driven, so an admission for an out of control symptom, or for clearly an end of life admission. For the 60%, I would say are cardiology service, particularly our cardiomyopathy service is probably the highest number.” (Hospital)*

#### *Address High Readmission Rates*

- *“Re-admission rates are cited most often as the reason behind it. They come in a few times, they have very advanced conditions. I think that's been the new push. A lot of our referrals are pushed initially by case management to the doctor, saying this person has a very advanced disease and they keep coming back. That's the type of person that we see most often. They tend to be those who are closer to the end of life, like in their last year, and they also are asking for goals of care discussion about how they want to handle the repeat hospitalizations.” (Hospital)*

#### *Pain Management at Home*

- *“Issues with dosing of pain medication. What physicians consider a high maintenance patient who has a lot of chronic conditions that there's no cure for, and a family who needs more support than the average patient.” (Home Health Agency)*
- *“Pain management, also cardiopulmonary symptoms, renal failure patients who are still having dialysis.” (Hospice)*



## Care Planning

- *“The other reason why a VNA nurse might make a referral to palliative is because they think the patient could be hospice eligible, and they haven't had much success in kind of guiding the conversation in that direction, or just to advanced care planning in general, so they make a referral to palliative care kind of for help in that area.” (Home Health Agency)*
- *“We would say about 70% of referrals are goals of care and 30% are symptom management, somewhere in that range. There is always a combination of both. It is very rare that you will see a patient who just has symptoms that you don't address goals of care.” (Hospice)*

## Non-Curative Care

- *“For us, it is symptom management, comfort care for end stage disease. In some cases, patients or families are not what you would call kind of in quotations “ready for hospice.” They're still seeking treatment or they're just not ready for that next step, so often they will accept palliative programs.” (Home Health Agency)*
- *“It's not necessarily the best or the right reason but often times providers will believe that there is a limit to the curative aspect of a disease. Yet failure patients haven't quite come to grips with that. And so providers will often refer to palliative care to assist with a difficult decision and utilize the palliative care expertise to help them with these difficult discussions that will then help patients make decisions about their care.” (Hospital)*
- *“The major reasons are unmanaged symptoms, the most common probably being of course pain. Second, goals of care, a really good referral. Thirdly, I'll say that I get palliative care referrals for people who are totally hospice appropriate because they are afraid to use the H word. I get asked to do a palliative care and I am told point blank, do not mention the H word, where clearly they are hospice appropriate, but didn't want to use the H word. I would say 95 plus percent of the time, when I'm done, they're on hospice.” (Hospital)*

## Helping Families to Cope

- *“In the pediatric world for us it is really about children and families that need something they can't get anywhere else. Because it's not so much medical, it's the social, emotional piece for the pediatrics. On the hospital side I think we get referrals a lot from folks who feel that patients are being over treated, which is not the goal that the patient has stated, so we get a lot of ‘can we intercede’ and really have a goals of care conversation.” (Hospice)*

## Improving the Referral Process

Our key informants identified four ways to improve the referral process:

- Make earlier consultations and referrals.
- Educate patients, families, and providers.
- Overcome financial constraints on palliative care.
- Create more systematic palliative care triggers.

The following comments illustrate their recommendations.

### *Earlier Referrals and Consultations*

- *“Referrals have to be improved, probably for people just to realize that their patients and families could benefit earlier. They don’t have to wait until things are falling apart.” (Hospice)*
- *“I would love to see more patients’ family initiation by the healthcare providers.” (Social Service Organization)*
- *“That’s a huge thing. How can we get an earlier type of consultation, you know?” (Hospital)*
- *“I think our quality of care and reputation will drive earlier palliative care consults.” (Hospice)*

### *Education for Patients and Providers*

- *“[We need] more public health education, more physician education. Reaching out to the community.” (Hospice)*
- *“Again, I think it goes both back to education, and more availability of more comprehensive palliative services.” (Hospice)*
- *“Educating staff, absolutely. And allowing nurses and physicians to drive the consult, not just physician driven.” (Hospital)*
- *“The way I think it probably could be improved is by educating patients and families of their ability to request it. Because even if a physician doesn’t think of it, and we have patients and families here in our hospital that say, “I hear you have palliative care. We’d like to have them involved.” (Hospital)*
- *“I think again it depends on how we are going to operationalize palliative care so that everyone understands it. I think that’s your biggest thing. People still don’t get what it is. They don’t get what it is, and depending on who the provider is.” (Hospice)*

### *Overcoming Financial Constraints*

- *“So from a physician, clinician perspective, for hospital based programs in order to bill for a palliative care visit, a physician or mid-level has to make the referral. So that is one difficult part, but of course, these days, we all have to make our revenue. So that is one barrier, oftentimes. I think a lot of places would probably have a more robust palliative care program if they could be referred by nurses, social workers, or just requested by families without having to have a physician, you know, put in the formal consult.” (Hospital)*

### More Systematic Palliative Care Triggers

- *“In an ideal world, everybody with non-curable cancer gets a palliative care consult. That it’s part of an oncology clinic practice; it’s part of a hospital practice. Everybody with certain chronic diseases and has been in the ICU three times gets a palliative care consultation at the very least.” (Hospice)*
- *“So one of the things that we did early on was we posted on our Intranet palliative care triggers, so that it’s readily accessible to all clinicians in in-patient services, and we encouraged them to use the trigger sheets for patients with chronic illness. So that they can do a better job of intervening early.” (Hospital)*
- *“For example the left ventricular assisted device patients by Medicare guidelines now are required to have a palliative care consult before they’re placed on an LVAD. So that’s driven a lot of the referral, and so our cardiologists are really very on board with getting palliative care involved. That has helped...getting that message out and making it clear that this shouldn’t happen when the patient’s on the way in-extremis, because that’s not the time to have that conversation with the patient.” (Hospital)*

### Major Sources of Referrals

Participants noted that the sources of palliative care referrals primarily follow one or more of five distinct paths. They are:

- Direct referrals from hospitals.
- Oncology related referrals.
- Referrals from Primary Care Physicians.
- Self-referral and word of mouth.
- Referrals from hospice programs.

The following comments are categorized according to the primary pathway of palliative referrals (from the list above).

#### *Direct Referrals from Hospitals*

- *“The major ones are that we are in inpatient hospital settings, so it would probably be the hospitalists. Many of those palliative care consults are driven by the case managers in the hospital, social workers and case manager RNs.” (Hospice)*
- *“Our best partner hospital is Lawrence General, because they have a palliative care service and they don’t have an outpatient service. We have a pretty nice linkage with getting referrals from them to follow patients that they’ve picked up in the hospital, so we can do the continuity better.” (Hospice)*
- *“So in my hospital, you know, it’s physicians, and you know, after ten years, we’re proud to say we are involved with every department in our hospital and you know, it’s still nurses who are often our biggest advocates.” (Hospital)*
- *“Our local hospitals know about our program as well, and the community. It’s kind of challenging in a homecare setting when you have bigger hospitals that have their own VNA programs, but our community asks for us.” (Hospice)*

### *Oncology-Related Referrals*

- *“Oncology is a big one. Primary care is another big one. Visiting nurses too. The visiting nurses are asking us to see their patients. We’re getting the okay from the primary care and then going out. So, oncology, visiting nurse, and then primary care offices. I’d say those are the big ones outside of hospitals. We’re doing inpatient palliative care as well, so the hospitals themselves are referring because we’re there. But out in the community it’s oncology, visiting nurse, and primary care.” (Hospice)*

### *Primary Care Physicians*

- *“It would have been the primary care physicians, when they really were running up against a wall managing symptoms of patients coming into their offices in the cancer center, whether it be medical oncology or radiation oncology. We didn’t tend to see referrals really from the pain centers, although you might think that it would.” (Hospice)*
- *“I guess I’m going to have to say physicians. Physicians and family.” (Hospice)*

### *Self-Referral and Word of Mouth*

- *“A lot of patients self-refer, and they sort of heard by word of mouth “you should go see Shelly. Go to the palliative care program.” Physicians, nurses like VNA nurses sometimes, or inpatient. The island home nurses. So nurses and physicians and the other thing is that patients self-refer.” (Hospice)*
- *“Outside of our hospital, I think our major referral source is word of mouth. Patients will talk to other family members or friends and they’ll hear that we have a palliative care program here, so we do get palliative care referrals from patients that are not even part of our program when they hear about it, and that doesn’t exist elsewhere.” (Hospital)*

### *Hospice Programs*

- *“I would probably say the two hospices that are associated with the hospitals.” (Skilled Nursing Facility)*

## **The Appropriate Time for Referral to Palliative Care**

Almost all participants indicated that patients tended to be referred too late or that they would have benefitted if they had been able to utilize palliative care services earlier. When we asked what was the appropriate time for a referral, participants indicated it should be at the point of diagnosis or as part of an initial care plan.

### *Patients Would Benefit from Earlier Referral*

- *“We need more timely referrals. Seeing them and then sending them to hospice doesn’t really give us a chance to do our job.” (Hospice)*
- *“In general they’re referred late. I think it’s part of that equating palliative care with end-of-life care. I think it’s often at a crossroad when we don’t know what else to do as opposed to working in conjunction with other therapies who are also going to involve the palliative care team. That doesn’t happen. So I think they’re referred late.” (Hospital)*

- *“Almost 50% of the palliative care patients that we see in our organization are getting referred to hospice after one or two visits from us, and there’s another portion of those who should be on hospice but aren’t for a variety of reasons. Patients are getting referred to palliative care when they really should be getting referred to hospice, so palliative care should be more upstream. Literally their physicians should be contacting us months earlier than they are.” (Hospice)*

#### *Referral Should Be at Diagnosis or as Part of Initial Care Plan*

- *“Sometimes it might be with that diagnosis. Other times, again, it's that change in condition. That's the thing, and it's so hard to say six months before. You can't figure out a time. And I think we're very good at seeing when there is that small change, or when the family is ready, because again sometimes that's the other thing.” (Skilled Nursing Facility)*
- *“I think any time somebody has been diagnosed with an advanced illness. There’s so many factors that go into it. Could it be age? Could it be the diagnosis? Probably a combination, but I think when somebody is diagnosed with an advanced illness, there needs to be professionals surrounding them who are able to walk them through that process again, have the right conversations with them.” (Hospice)*

## Barriers to Providing Palliative Care

### Patient Side Barriers

The respondents most frequently mentioned the following barriers to patients in obtaining or accepting palliative care:

- Lack of understanding and confusion about palliative care.
- The fear of “giving up” on their disease.
- Lack of access to palliative care programs.

The following comments are illustrative of patient side barriers and are categorized according to the barrier categories.

#### *Lack of Understanding and Confusion About Palliative Care*

- *“Confusion and lack of information, maybe the way the information has been presented is a problem.” (Social Service Organization)*
- *“I don't think they really understand how to access those services.” (Hospice)*
- *“I think patients and families really do not have a clear understanding of what palliative care is, or if they do, know how to assess a quality program.” (Home Health Agency)*
- *“I think one of the barriers is that the patients might not really understand what it is and they may even equate it with hospice or end-of-life. If they haven't come to grips with that aspect of the disease they might not embrace the palliative care part of the care.” (Hospital)*

#### *Fear of Giving Up*

- *“I think fear is a barrier.” (Hospice)*
- *“But I do think that there are barriers about fear that are the biggest ones we see. There's a fear of the unknown, a fear that saying 'palliative care' and talking about things is going to mean that they're not going to get as good of care.” (Hospital)*
- *“Is this hospice? Are you giving up? Are you not going to do anything for me?’ I think the word, ‘palliative,’ is synonymous with hospice for many patients.” (Hospital)*
- *“Still there are people who can't get over that stigma. There are a lot of people today who have religious barriers. They either don't practice a religion, or don't want to be involved with anything that has any kind of religious connotation or support attached to it. And I think a lot of people think too that once they go onto palliative care, for them it means that they're giving up hope, and that they're just resistant to that.” (Home Health Agency)*
- *“I think from the patient side, it's mostly concern that that must mean that they are dying or that nothing else could be done for them. Sometimes people feel as though they should be able to handle things on their own.” (Hospice)*
- *“I wish palliative care would become a normal, not a frightening word, become just a part of conversation. I know that the hope is that it will be.” (Skilled Nursing Facility)*

- *“When palliative care broaches cultural aspects of care or preferences where you start talking about life prolonging versus death prolonging, I think religion has a role in how people think about this. I think certainly certain ethnic groups continue to believe that perhaps they are not being steered in the right direction when there's any hint of not proceeding aggressively with care.” (Hospital)*

#### *Lack of Access to Palliative Care Programs*

- *“I think it's really just the lack of access in communities across the state. The availability and then when they're available sometimes their own populations can't access them.” (Hospital)*
- *“I don't think they really understand how to access those services, and I think that's because they don't really exist.” (Hospice)*
- *“In hospital settings where you've got palliative care services there's usually more demand than there is capacity to provide those services. I think that another barrier is the size of the programs that are existing, so it's the access, the availability and the capacity that these programs have.” (Hospital)*

#### **Solutions to Patient-Related Barriers**

More than any other solution, our key informants consistently stressed the need to educate the public about palliative care. Many of their comments on the need for education have been listed earlier in this report. The informants mentioned several other tools or improvements that could help patients and families more easily accept the benefits of palliative care, such as:

- Training providers to developing a relationship of trust with the patient and family.
- Encouraging a culture of shared decision making for patients with chronic disease.
- Systematically having a goals of care conversation.
- Maintaining communication with the patient's PCP.
- Encouraging families to read books such as Dr. Atul Gawande's *Being Mortal* and to use resources like The Conversation Project's "Starter Kit" (<http://theconversationproject.org/starter-kit/intro/>).
- Working with insurance carriers to expand coverage for palliative care.

## Provider Side Barriers

The respondents identified several barriers to palliative care on the provider side, including:

- Not admitting the need or appropriate time for palliative care.
- Poor communication among providers, the patient, and family members.
- Legal issues associated with guardianship.

The following comments illustrate their thoughts on provider-side barriers.

### *Not Admitting the Need for Palliative Care*

- *“Some doctors feel like it’s not the appropriate time, and they delay the consult.” (Hospital)*
- *“You see their paternalistic side pop up when it’s a younger patient.” (Hospital)*
- *“The medical community on Cape Cod has not really embraced or had the need to really invest itself up to this point in a structured palliative care program.” (Home Health Agency)*
- *“I feel like we need to be more proactive, not reactive in that sense.” (Home Health Agency)*
- *“Occasionally we’ll see a barrier with the physicians, occasionally. I can think of one physician in mind who really has a hard time with residents that are at the end of life.” (Skilled Nursing Facility)*
- *“Physicians and nurse practitioners and nurses, we can’t be afraid to say the truth and look at the big picture. I think that’s a big barrier.” (Hospice)*
- *“They’re not recognizing the decline in the patient. Studies have shown that primary care providers who have seen patients for 30 years don’t see their decline as much as someone walking in saying, oh my gosh, you can’t get out of bed. They often don’t recognize that it’s time to maybe have conversations with patients about what’s going on and what they want for their end of life.” (Hospice)*

### *Poor Communication Among Providers, Patients, and Families*

- *“I think part of the problem with palliative care is if we’re not all on the same page in discussing where patients really are in their disease course, then they will hold onto the best prognosis that they get or just hear positive things.” (Hospice)*
- *“I don’t think they make it as much of a shared decision making between the provider and the patient.” (Hospital)*
- *“Not wanting to talk about the things, like end of life, when it’s a younger person. I do not get a lot of consults for young folks because the doctors don’t feel like they can talk about it. They don’t want to give up on this person.” (Hospital)*
- *“Some providers don’t really want to share their patients.” (Hospice)*
- *“Just generally, there’s not good care coordination between providers.” (Home Health Agency)*
- *“Fear of failure, fear of, “Oh my God, I didn’t fix them. I didn’t cure the cancer. They’re probably not used to working in conjunction with another team that is*



*going to be communicating with their patients about a lot of these things, addressing and recommending different treatments for symptoms.” (Hospital)*

#### *Legal Issues Associated with Guardianship*

- *“A guardian cannot change the code status, so I've seen some very horrible deaths because they have to go through the court systems which cost money to the guardian, so they drag their heels on that and they don't do it, so I've seen really bad end of life care for folks who have guardians making their medical decisions. Other barriers I've seen that are perhaps unique to Massachusetts is when DDS is involved for somebody who's got a developmental disability, it is a much longer process, which I appreciate, because it shouldn't be something that's done rashly.” (Hospital)*

#### **Solutions to Provider-Side Barriers**

Most participants favored solutions to provider side barriers that enhanced communication and common goals among medical professionals. Other notable suggestions included:

- Increasing awareness of palliative care across medical services (nursing homes, primary care, etc.).
- Increasing exposure to palliative care in medical school programs.

#### **Resources to Help Effect Solutions**

Participants offered a variety of comments concerning what resources would help to further develop palliative care. The following quotations illustrate the array of suggested resources:

- *“A volunteer corps. Extra people around to just sit with somebody, for that spiritual and emotional, psycho-social part.” (Skilled Nursing Facility)*
- *“It could be the referrals, to be honest with you. Not having enough awareness in the community.” (Hospice)*
- *“I think I would have to say money. Funding. It's difficult for these programs. It's difficult to sustain them financially.” (Hospital)*

## Resources Needed for Palliative Care

### Resources Needed

The final section of our interviews with key informants focused on resources their organizations may need to support and develop their palliative care programs. We assumed that most organizations could always use more money, and therefore we asked the respondents to consider resources “other than money.” The respondents identified the following types of resources that would help them increase palliative care services:

- Volunteers and more support in the community
- Transportation
- Education and community outreach events
- More personnel (such as Chaplains and health aides)
- More frequent contacts and communication among members of the palliative care team, PCPs, and the patient
- More consistent structure or model for palliative care for palliative care programs
- Reimbursement solutions and options

The following comments describe resources that would help develop palliative care programs.

#### *Volunteers and Support in the Community*

- *“I think there definitely could be more support groups in the community to provide support for not only the patients but the family as well with people who are dealing with end stage illness.” (Hospice)*
- *“Social isolation has been a big piece of loneliness and depression in our population.” (Hospital)*

#### *Education and Community Outreach Events*

- *“I think education is the biggest resource there could be, and that's for families. I think smaller groups of people...more interactive. Having people that have experienced end of life and being in palliative care, having a family member in it. Making it more like that, just an open discussion session.” (Skilled Nursing Facility)*
- *“Presenters and having events, having outreach is really the way to go. Having the face with what's being presented, and really feeling the passion and the compassion behind all of that is important.” (Hospital)*
- *“Access to education and training for our staff. That would be cost effective, even a train the trainer type of a course. I just think that having a facilitator for care who is knowledgeable. That could be a help.” (Home Health Agency)*
- *“I would love to be able to tell my patient ‘go to this website, please. I want you to watch this and then we're going to talk about it’ or even with a social worker. Dr. Volandes' videos. There are so many wonderful tools out there that I'd love to be able to give to our staff. When you show a patient a video of what dementia looks like, suddenly it becomes more real and relatable versus me just talking about feeding tubes and dementia.” (Hospital)*

### *Increased Personnel and Access to Consulting Specialists*

- *“More support, chaplains, home health aides, it’s all financial, educating the community and homecare professionals.” (Hospice)*
- *“Contacts between doctor’s offices and providers to insure that the patient knows what is going on in palliative care.” (Social Service Organization)*
- *“Contact with a physician specialist. That would be great. Someone available to help us when things are tricky. Specialists for specific health issues.” (Hospice)*

### *Mandated Structure for Palliative Care*

- *“I think that actually breaking us away from hospice would be beneficial for our team to realize our full potential. Having a mandate for what palliative care is in Massachusetts and saying that all hospitals must offer palliative care and have a palliative care team might also be a way to step forward and actually realize its full potential.” (Hospital)*
- *“I think a model of care, additional clinical training. A plan for how to get it off the ground, like a business plan.” (Home Health Agency)*
- *“Some sort of trigger, like it would be great if there was some sort of automatic trigger like that. Then they could say, oh yeah, my patient does have a lot going on and, oh yeah, they have been coming into the office a lot lately. That would be great.” (Hospice)*

### *Reimbursement Options*

- *“Money is I think the number one thing, because honest, I’m not going to tell you anything hopefully you don’t know, there is not money to be made in palliative care. If anything, in general, the way things are structured in our system for reimbursement, no one rolls out a palliative care program and expects that it is going to even pay for itself.” (Hospital)*
- *“Unfortunately, because there isn’t really adequate reimbursement for anything other than doctors and nurse practitioners.” (Hospice)*
- *“If the insurance companies are most invested in expanding their benefits, that will school the industry into being able to provide it more.” (Hospice)*

## Topics for Regional Forums on Palliative Care

The respondents' suggested topics for regional forums spanned a spectrum of areas in palliative care from how to educate providers and the general public to examples of successful palliative care programs. Advanced directives and symptom management were also frequently mentioned, along with the following suggestions:

- How to navigate the patient from the doctor's office to palliative care
- Advanced directives and the MOLST form
- Healthcare proxies
- How to address the needs of patients
- Symptom management
- Information available online
- Legal issues (such as guardianship)
- The "whole continuum of care"
- Mentoring to help with difficult conversations
- Present a model of palliative care (discuss how others are doing it)
- Solutions to transportation issues
- Basic through advanced training for staff
- Continued culture change
- Differentiating hospice and palliative care

## Awareness of the MDPH *Know Your Choices* Guide

Thirteen out of twenty-four participants indicated that they were familiar with the 2014 MDPH guide to palliative care titled *Know Your Choices*. Eleven indicated they had not heard of it or did not know much about it, and several asked us to send them a copy. The hospices and home health agencies seemed to be most aware of and interested in using the guide.

- *"The Know Your Choices brochure is very useful. And we certainly, as a hospice organization, really push that now and talk to doctor's offices about 'you really need this in your waiting room and we can help you talk about this'." (Hospice)*
- *"I sadly wasn't aware of it but I printed it up. It looks like a wonderful resource. I wonder where do you find that other than going on the site? What's the Massachusetts Department of Public Health doing with it? And I mean that very respectfully. Is that going out to physicians' offices? Who knows about this? Who would be sharing this wonderful knowledge? It's a great tool. I don't know who sees it." (Skilled Nursing Facility)*
- *"Yes, I've seen it. And I think it's good information. Great resource. The only question I have is if the average family would be able to navigate through it, through everything. It has some great resources online, links. I was just going to say I think it would potentially be helpful to have a discussion incited from the PCP's office and potentially hand out the Know Your Choices guide. I think a discussion guide and not just handing somebody a pamphlet." (Home Health Agency)*
- *"It's a great tool to walk into a doctor's office with and say 'you're supposed to have this available, so here it is and let us talk to you more about it.' Yeah, we've been out there with it." (Hospice)*

- *"It's a little tricky to try to figure out how to implement it. I think the idea is great. I think that the implementation is a little tricky and they're not very clear on it. We've come up with sort of a list for disease states that we think should trigger patients getting one of the guides, and so we've put a process into our electronic medical system that says if a patient comes in with advanced cardiac disease or metastatic cancer or some things like this, they should get one of these guides. So hopefully we'll start to use it." (Hospice)*

### **Awareness of the 2014 Massachusetts Palliative Care Legislation**

Sixteen out of twenty-four participants had heard about the 2014 palliative care legislation, while six had not known of it and two participants did not give a clear response as to their prior knowledge of the law. Those who were familiar with the legislation generally had high hopes that the law will increase public awareness of palliative care and promote growth in palliative care programs.

Here are some of their comments:

- *"I think it's only because of the new legislations, things like penalizing re-admission rates that they are potentially going to start increasing palliative care." (Hospital)*
- *"I think it would have a big impact. Again, every part of Massachusetts is a little bit different, like I said. Again, being a Catholic facility we've been dealing with this for a while, and doing this for a while. I think to me I think it's great that more people would be educated on this, more people would have to be able to have those resources available for people, and have that referral source available for people. So I just think that's great." (Skilled Nursing Facility)*
- *"What I understand it to be is legislation that says that we have to be able to offer palliative care to all of the residents who live, any patients that are at that point in their disease process." (Home Health Agency)*
- *"That's where the rubber meets the road. It's very nice and an advisory committee is very nice depending on what we come up with. It needs more teeth because it certainly talks about consequences, but that's where I feel really strongly that we need standards for people to rise up to." (Hospice)*
- *"It was relatively recently that I became aware of this new regulation. Even though I would like to say I'm really at the cutting edge, but it's not something that has been widely made available to the medical community in Massachusetts to this point." (Hospital)*
- *"I think it's going to definitely increase referrals to palliative care programs. I think it's going to improve end of life care for all folks in Massachusetts. I think it's also going to increase referrals to hospice, since those conversations are supposed to happen for all hospice-eligible patients. I think there could be backlash that we'll see. It's possible that there will be some backlash from the community, just like we saw with the backlash from the "death panels" with the Affordable Care Act when it first was being proposed." (Hospital)*

- *"I would love to say huge (impact). I think it's going to be slow, but I think in terms of culture change I think it's a good pillar to begin culture change. I think it will be slow because you're talking about impacting physician practice, and that's never going to be quick." (Hospice)*
- *"What I understand it to be is legislation that says that we have to be able to offer palliative care to any patients that are at that point in their disease process. If they're going through an SNF, if they're having treatment that requires ongoing assessment, that they have to be offered palliative care, both at the SNF, assisted living, all of the different types of facilities in Massachusetts. I do expect that there will be much more discussion around what is palliative care. If a family was offered the option or had the access to palliative care, one of their questions might be, what is it and how could we access it and is my loved one appropriate. That would really help it grow, if they even know that we're out there." (Home Health Agency)*

## Our Key Informants

The respondents included professionals working within or familiar with palliative care in their regions. All but one of the respondents gave us permission to list their name as a key informant.

### *Western Region*

- Holly Chaffee, RN, BSN, MSN, Porchlight Home Care, Lee
- Jean Zaleski, Mercy Home Care
- Dr. Sandra Bellantonio, Berkshire Health Systems, Pittsfield
- Nancy Ferguson, Cancer House of Hope
- Mary Stanton, MSW, Cooley Dickinson, VNA, & Hospice

### *Central Region*

- Joanne Calista & Jana Bowman Adams, Central Massachusetts Area Health Education Center, Inc
- Robin Wilson, RN, Med, VNA Care Network & Hospice

### *Metrowest*

- Timothy Boon, RN, BS, CEO, Good Shepherd Community Care
- One respondent from a hospice agency who wished to remain anonymous

### *Northeast*

- Karen Gomes, Chief Clinical Officer, Home Health VNA, Lawrence
- Dr. Lewis Hays, All Care VNA
- Catherine Duffy, NP, Care Dimensions, Danvers
- Dr. Robert Warren, Care Dimensions, Danvers
- Dr. Elizabeth Collins, Lahey Hospital & Medical Center
- Dr. Joanne Nowak, Merrimack Valley Hospice
- Dr. Rafel Bloise, Director Palliative and Supportive Care, & Maureen Couture, LICSW, Lawrence General Hospital

### *Southeast*

- Charlene Thurston, RN, ANP, Nantucket Hospice
- Sandy Dompierre, Community Nurse and Hospice
- Sherrie Souza, RN BC, CDP, Catholic Memorial Home, Fall River
- Jamie Nunes, Clinical Services Director & David Maloney, Hospice Administrator, Broad Reach Hospice
- Deborah Dolaway, Cranberry Hospice, Plymouth

### *Boston*

- Marybeth Singer, NP, Tufts University Medical Center, Boston
- Anne Mahler, CNS, Hebrew Senior Life, Boston
- Mark Kennedy, Executive Director, Massachusetts Prostate Cancer Coalition

## **Palliative Care Key Informant Interview Questions**

### **Palliative Care in Your Organization**

1. Does your organization have a palliative care program or provide access to a palliative care program?
2. (If the organization does not have a program) Are you developing a palliative care program or plan to develop one in the future?
  - a. If not, why not?
  - b. If yes, why are you developing a program?
3. How do you define palliative care in your organization?
4. I'm going to read you a formal definition of palliative care used by the Massachusetts Department of Public Health, and ask you to comment on it:

*“Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care with consideration of patient and family needs, preferences, values, beliefs, and culture. A formal program has dedicated palliative care team members including a physician, nurse, social worker, and chaplain.”*

- a. Does that correspond to your view of palliative care?
5. Is there confusion among providers, patients, or families about what palliative care is?
  - a. How do you explain it to patients and their families?

### **Views on Palliative Care in Your Community**

6. What types of organizations are leading the way in providing palliative care in your community?
7. What types of organizations are lagging behind in developing palliative care programs?
8. Overall how satisfied are you with palliative care services in your community? Very satisfied, somewhat satisfied, or not satisfied?
  - a. Why do you feel that way?
9. In your opinion, do the palliative care services in your program meet the needs of your community?
  - a. How could those services be improved?
  - b. How can palliative care services in your community as a whole be improved?



### **The Referral Process**

10. The next few questions are about the referral process for palliative care. In your opinion, what are the major reasons for referrals to palliative care in your program?
11. What is your opinion regarding the palliative care referral process?
  - a. How can the palliative care referral system be improved?
12. What are the major referral sources for palliative care services in your community?
13. Do you think patients are being referred to palliative care at the appropriate time?
  - a. What is the appropriate time?

### **Barriers to Providing Palliative Care**

14. Thinking about the patient side, what are the major patient-related barriers to providing high quality palliative care in your community?
  - a. How would you address these patient-related palliative care barriers?
15. On the provider side, what are the major provider-related barriers to providing high quality palliative care in your community?
  - a. How would you address these provider-related palliative care barriers?

### **Resources for Palliative Care**

16. Other than money, what type of support does your organization need in order to increase palliative care services?
17. What resources would be most helpful to you in developing or improving your palliative care program?
18. The Palliative Care Workgroup is planning regional forums to address palliative care issues in Massachusetts. What palliative care topics would you like to be included in the regional forums?
19. In 2014 MDPH published a guide to palliative care titled *Know Your Choices*. Are you familiar with this guide?
20. Are you familiar with the 2014 Massachusetts palliative care legislation?
  - a. What impact do you expect the law to have going forward?