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I. EXECUTIVE SUMMARY

Background
Palliative care as a specialized form of medical care for people with serious and chronic medical conditions has seen exponential growth. This has been due to a number of factors, primarily a rapidly aging population, many with complex and costly care needs, and emerging evidence citing the benefits of palliative care. Numerous studies have cited the value and benefits of palliative care, from improved quality of life for patients and caregivers to reduced medical costs. In addition, palliative care reduces hospitalizations, readmissions, emergency visits, and overall costs. Home based care has been found to improve patient satisfaction and outcomes, as well as reduce medical costs.

Community-based palliative care has been of increasing interest in recent years, due in large part to patient needs and preferences the potential for additional cost savings and to increase access in areas with few hospital-based palliative care programs. Many patients with serious illness prefer to be in their own environment. Additionally, many patients do not meet criteria for hospital admission but can still benefit from support, including patients who are homebound and/or with unpredictable prognoses.

In order to increase the awareness and education of timely palliative care in cancer care and other chronic diseases, the Massachusetts Comprehensive Cancer Prevention and Control Network (MCCPCN) formed a Palliative Care Workgroup made up of partners from home health care, skilled nursing, pediatric palliative care, research and hospice in April 2014. The workgroup implemented a statewide survey (November-December, 2014) and key informant interviews (June, 2015) assessing the accessibility and quality of palliative care in various settings.

JSI Research & Training Institute, Inc. (JSI) was contracted in August 2016 to support MCCPCN and its Palliative Care Work Group to:

● Conduct regional assessments and mapping of community-based palliative care in order to identify gaps in access.
● Participate in regional subgroups meetings.
● Document lessons learned and recommendations for partnership development across the state that would promote access of palliative care services to members of cultural and geographically disparate populations.
● Review concurrent activities regarding palliative care and end of life activities in the state.

Regional Assessment and Key Informant Interview Process
A total of 38 interviews were completed with 44 key stakeholders across four regions in the state. Of the 44, 11 were from the Western MA region, another 10 were from the Northeast/Metrowest region, 12 were from Central MA, and six were from the southeast. Interview participants included hospital, healthcare organizations, and hospice administrators and medical directors, palliative care clinicians (physicians, nurse/nurse practitioners, medical assistant), social service providers, nutritionist and clergy. In addition, five other stakeholders were interviewed to offer a “state level” perspective on palliative care in Massachusetts.
Summary of Key Findings
The following highlights findings from across all regions in the state:

1. **Palliative Care in the community is provided under a variety of provider structures.**
The growing movement out of the hospital setting into the community has seen health delivery systems adapting to match this need. Major hospital systems such as Hallmark Health, Lahey Health, Baystate Medical Center, Cooley Dickinson, Southcoast Hospital have incorporated home health (VNA)/hospice service within their own system. This facilitates a continuum of care for patients from in-patient to home care/hospice services. Hospitals that do not have their own home health/hospice such as Tufts Medical Center refer to a variety of agencies to meet their patients’ palliation and hospice needs. The consultative model has been an effective way to provide in-home palliative care for patients that do not meet the eligibility criteria of being “homebound”. While there is overlap and good coverage in most of the state, some stakeholders expressed concern over gaps in services and ensuring services provided meet the criteria to be classified as palliative care.

2. **Reimbursement for palliative care drives type of care and ability to provide quality services.**
The lack of or limited reimbursement for palliative care services and the fee for service model was universally mentioned as the biggest barriers to providing increased, comprehensive, and high quality services. These aspects become burdens for providers and healthcare organizations who want to include or expand services in their practice. Additionally, the complexity and lack of understanding of insurance coverage contributes to gaps in services or patients not receiving any services. Despite these complexities, case managers and discharge planners can play a large role in navigating insurance complexities.

3. **Provider misconceptions about palliative care can delay referrals and impact quality of life for patients.**
Demand for palliative care is growing due to an aging population. Providers need to have knowledge about how to direct patients/facilitate access to these services. Across regions participants expressed that palliative care services need to be delivered early to clients in order to be most effective in improving the quality of their lives.

4. **Increasing public awareness must be met with increased provider capacity.**
All stakeholders interviewed agreed that efforts to increase public awareness need to be balanced with increasing provider knowledge and capacity in palliative care. Interviews revealed that for both patients and providers, the most common misunderstanding is the distinction between palliative care and hospice. This is even important for some cultural groups where “palliative care” does not have a direct translation.

5. **Importance of managing transitions to avoid gaps in services.**
Coordination is an essential component of community-based palliative care. Some type of case manager or patient navigator is essential to ensuring that access to palliative care is not disrupted as patients transition between care settings.

Summary of Next Steps
Based on these findings, the following next steps are recommended:

1. **Continue Regional Strategic Planning.** Each region should continue to advance its own strategic plan that addresses their informal assessments of the gaps between needs and services, leverages multi-sector teams and partnerships, and avails their subgroup of important and timely opportunities.
2. **Foster Clinical-Community Linkages.** Deeper collaborations can be built to extend palliative care both across staff and departments within institutions and beyond out into community settings.

3. **Extend Partnerships and Collaborations.** Greater capacity and leveraging of resources arise as regions work to even more fully strengthen their partnerships and collaborative efforts. A number of organizations and individuals can be brought into this process.

4. **Strengthen Statewide Partnerships.** Statewide progress in promoting palliative care and establishing a supportive context is also poised to be advanced. Next steps include: linking and collaborating with other state aging, healthcare and anti-poverty agencies; deepening relationships with statewide initiatives and organizations (such as the MA Coalition for Serious Illness, Honoring Choices) to work around common goals and decrease replication of efforts; centralizing provider education requirements as a means of enhancing competencies.

In addition to these next steps, the full report contains region specific processes and assessment findings, maps of palliative care delivery sites by region, recommendations, and successful strategies to help the initiative keep moving forward.

More information regarding this report can be obtained by contacting Stewart Landers (Stewart_Landers@jsi.com).
II. BACKGROUND AND INTRODUCTION

Palliative care as a specialized form of medical care for people with serious and chronic medical conditions has seen exponential growth. This has been due to a number of factors, primarily a rapidly aging population, many with complex and costly care needs, and emerging evidence citing the benefits of palliative care. This type of care is focused on providing relief from symptoms with the goal of improving quality of life for both the patient and their family. According to the National Consensus Project for Quality Palliative Care (2013), palliative care refers to patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice.¹

Numerous studies have cited the value and benefits of palliative care, from improved quality of life for patients and caregivers to reduced medical costs. Multiple randomized clinical trials have shown that palliative care improves quality of life, reduces pain and depressive symptoms, and increases patient survival (length of life).²,³,⁴,⁵,⁶,⁷ Palliative care has been also been shown to improve health and quality of life for caregivers of deceased patients.⁸ In addition, palliative care reduces hospitalizations, readmissions, emergency visits, and overall costs.⁹,¹⁰ Home based care has been found to improve patient satisfaction and outcomes, as well as reduce medical costs. A randomized controlled trial assessing the impact of home-based palliative care found that it improved patient satisfaction and outcomes as well as reduced medical costs.¹⁰

Community-based palliative care has been of increasing interest in recent years, due in large part to patient needs and preferences the potential for additional cost savings and to increase access in areas with few hospital-based palliative care programs. Many patients with serious illness prefer to be in their own environment. While almost 60% of deaths occur in hospitals, studies show that most patients prefer to die at home.¹⁰ Additionally, many patients do not meet criteria for hospital admission but can still benefit from support, including patients who are homebound and/or with unpredictable prognoses. Community-based palliative care can fill these service gaps. Furthermore, a significant portion of medical spending in the United States is dedicated to end-of-life care and treatment of chronic diseases, both of which characterize patients who could benefit from palliative care.

There are many models of community-based palliative care. Through an initiative called the Palliative Care Action Community, the California HealthCare Foundation documented several different structures for community-based palliative care (defined as non-hospital, non-hospice palliative care). Some organizations offering palliative care were embedded in clinics or small community hospitals, often connecting with other specialties directly or traveling with the patient across visits to different specialists. Other organizations provided care in the patient’s home or assisted living facility. Some home-based palliative care providers reported accompanying patients to clinic visits, while others coordinated with other providers separately. Finally, some organizations provided palliative care consultation through a phone-based service. Embedded and mobile providers were cited as promoting coordination among specialty and palliative care providers, making scheduling easier for patients, and creating consistent messaging for patients across settings. Mobile providers in particular facilitated access during transitions in care.

Massachusetts State Assessment (2014-2015)
The Massachusetts Comprehensive Cancer Prevention and Control Network (MCCPCN) formed a Palliative Care Workgroup made up of partners from home health care, skilled nursing, pediatric
palliative care, research and hospice in April, 2014 to increase the awareness and education of the importance of timely palliative care in cancer care and other chronic diseases. The workgroup implemented a statewide survey (November-December, 2014) and key informant interviews (June, 2015) assessing the accessibility and quality of palliative care in various settings. The survey results demonstrated that access to palliative care services across the state is fragmented. Certain types of medical facilities offered palliative care services more frequently than others. For instance, 84% of home health programs reported offering palliative care, while 68%, 48%, and 35% of hospitals, community health centers, and skilled nursing facilities did, respectively. This difference in access to palliative care has a racial and ethnic impact, as hospitals and community health centers serve populations with greater proportions of patients of color. Rural areas, which often have higher populations of low income residents, also lack accessibility. Beyond availability, there were differing perceptions on the state of palliative care in Massachusetts, although most organizations identified a shortage of trained staff and opportunities for education. As a result, the workgroup held seven regional palliative care forums (end of 2015-mid 2016) to disseminate the findings from the previous assessments and to bring stakeholders together to share ideas and develop an action plan to increase access to palliation in these regions.

**JSI Scope of Work**

JSI Research & Training Institute, Inc. (JSI) was contracted in August 2016 to support the MCCPCN and its Palliative Care Work Group to:

- Conduct regional assessments and mapping of community-based palliative care in order to identify gaps in access
- Participate in regional subgroups meetings
- Document lessons learned and recommendations for partnership development across the state that would promote access of palliative care services to members of cultural and geographically disparate populations
- Review concurrent activities regarding palliative care and end of life activities in the state

The following report describes activities undertaken by JSI to fulfill this scope of work. This included conducting:

1. an environmental scan of concurrent initiatives and groups in the state engaged in advance care planning, serious illness and end of life issues,
2. a literature review of advance care planning tools,
3. a series of key informant interviews with stakeholders in four regions, and
4. mapping palliative care service locations.

At the start of JSI’s contract (August 2016), palliative care provider organizations in different regions of the state had begun to coalesce as a result of regional presentations and discussions of the state’s findings. JSI staff members attended regional subgroup meetings to engage in the local discussions and identify stakeholders to participate in interviews.
III. THE MASSACHUSETTS CONTEXT

A. Introduction and Methodology

While JSI was contracted to provide support and strengthen community-based palliative care networks in all Massachusetts regions, there have been past and concurrent activities across the Commonwealth that relate to efforts to improve treatment of serious illness as well as end of life care.

In the context of Health Care Reform in Massachusetts, an expert panel was convened to address end of life issues. Chapter 305 of the MA Acts of 2008 included several provisions regarding end of life care. These efforts resulted in reports in both 2010 and an update version in 2014. More recently, House Bill 2104 established a “State Palliative Care and Quality of Life Interdisciplinary Advisory Council”. The Council consists of interdisciplinary palliative care medical, nursing, social work, pharmacy and spiritual professional expertise and patient and family caregivers. The role of the Council is to advise the Massachusetts Department of Public Health on ways to maximize the effectiveness of palliative care initiatives within the state.

Other statewide advanced care initiatives such as The Conversation Project and Honoring Choices Massachusetts provide tools to encourage and facilitate conversations both within families and between families or individuals with medical providers regarding advance care planning. Specifically, Honoring Choices Massachusetts has worked with the Massachusetts Department of Public Health (MDPH) -organized Northeast Region Work Group to adopt its “Five Questions” card regarding advance care planning specifically for palliative care.

The Massachusetts Coalition for Serious Illness Care (the “Coalition”) is bringing together diverse stakeholders to raise awareness of the variety of efforts, learn from and inspire one another, and coordinate efforts as makes sense. The Coalition had its inaugural meeting on May 12, 2016. It’s co-chairs are Maureen Bisognano, Institute for Healthcare Improvement and Dr. Atul Gawande, Brigham and Women’s Hospital and its founding members include Andrew Dreyfus, Blue Cross Blue Shield of Massachusetts and Ellen Goodman, The Conversation Project. The Coalition conducts surveys and events to further its mission which is “to ensure that health care for everyone in Massachusetts is in accordance with their goals, values and preferences at all stages of life and in all steps of their care.”

Other organizations and initiatives related to palliative care were identified across the state of Massachusetts with the goal of facilitating meaningful coordination and the avoidance of duplicative efforts. Through attendance at regional working group meetings and discussions with individuals connected to various advance care planning and end of life initiatives, a list of organizations working in the state and their core activities was developed. Each organization’s mission and relevant activities were further detailed through discussion and web searches.

B. Summary of Findings

Three broad categories of initiatives were identified: statewide organizations promoting palliative care, advance care planning, and issues related to seniors in general; initiatives originating from the Massachusetts state government; and other advance care planning organizations. These initiatives are summarized in Table 1. The full summary is found in Appendix 1.

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Two key themes were identified from this activity: networking amongst organizations and service providers and the facilitation of care and care planning. The Hospice and Palliative Care Federation of Massachusetts coordinates among and supports service providers in the state, while the Pediatric Palliative Care Network, sponsored by the MA DPH, links hospitals providing pediatric palliative care. Other organizations focus instead on promoting individuals’ access to information and ability to have conversations about end of life care.

IV. LITERATURE REVIEW

A. Methodology

In discussions with the subgroups, JSI was asked to conduct a literature review on the effectiveness of the major advance care planning (ACP) tools in use with the public, including The Serious Illness Conversation Guide, The Conversation Project, Honoring Choices, Respecting Choices, and articles written by Angelo Volandes and about his intervention videos. Additionally, JSI included search terms relevant to racial disparities and differences in the effectiveness of these tools by ethnic/racial group to answer the research question: “What are the most effective outcomes of using these tools for advance care planning purposes?”

In total, JSI identified more than 100 articles matching the search criteria and analyzed the abstracts of every article for its relevance in answering the research question. JSI’s researcher determined some articles did not list expressly the outcomes from using these interventions and thus were not useful to this literature review. In the end, 17 article abstracts were curated in a table titled “Effectiveness of Advance Care Planning Interventions.” The final table (see Appendix 2) represents the most up-to-date evidence of the effectiveness of using advance care planning tools with various populations from multiple countries around the world.

B. Summary of Key Findings

Information on effectiveness of advance care planning tools with multicultural patient populations is limited. Across the 17 articles, the research populations varied and focused on:
- Patients with specific disease processes (for example, patients with heart failure, on dialysis, and advanced cancer),
- Patients in a specific age group (for example, outpatients 75 years or older, patients 18 years or older, and low-income adults 60 or older),
- Staff at medical organizations (for example, nurses and medical assistants), and
- Patient caretakers and surrogates

Several research studies did include African Americans (in addition to Whites) as a specific population for research.

**Advance Care Planning Tools**

Videos were commonly used as an ACP tool with patients and proven to be effective in a range of settings. The majority of the videos were developed for the research that was conducted and targeted to a specific population group; however one video was developed based on a video originally created by Angelo Volandes, MD (Department of Medicine at Harvard Medical School and Massachusetts General Hospital).

Videos combined with another tool (e.g., ACP checklist, ACP brochure) were also found to be effective with patients. Additionally specific programs (including those that used a combination of tools) such as Sharing Patient’s Illness Representations to Increase Trust (SPIRIT), PREPARE, the Conversation Starter Kit, Let Me Decide, and Respecting Choices were proven to be effective. Key findings across the 17 articles demonstrated a range of outcomes. These included:
- Increased ACP knowledge, confidence with decision making, and documentation
- Increase patient-family conversation
- Less intensive curative treatment (for example, patients less likely to choose CPR and intubation)
- Increased use of hospice
- Decreased cost to insurance

One study found the Sharing Patient’s Illness Representation to Increase Trust (SPIRIT) intervention to be particularly effective in promoting preparedness and peace of mind among African Americans, a group often documented as being underserved in advance care planning.

**V. REGIONAL ASSESSMENT & KEY INFORMANT INTERVIEWS**

**A. Methodology**

**Regional subgroup and workgroup meetings**

As a result of the regional forums, participants began to coalesce by region to take action steps in improving access to palliative care. These groups were organized by MCCCPN in with partnership with the American Cancer Society (ACS). ACS staff provided administrative and logistical support to the subgroups that started to meet.

In order to build on the existing knowledge base about palliative care delivery in Massachusetts, JSI began by reviewing reports and presentations of the statewide survey and key informant interviews conducted by MDPH/MCCPCN (2014-15). JSI assigned one staff member to each of the four regions to attend subgroup meetings and gain a deeper understanding of the priorities as well as action steps in each region. Subgroups were at various stages of organization and engagement. For example, the Northeast/Metrowest group had met four times and had identified a set of action steps, while the Southeastern group was only beginning to be formed. Therefore, JSI’s participation
and role on these subgroups varied depending on the support that was requested by the subgroup and MDPH. JSI also attended Palliative Care Workgroup meetings to gain an understanding of the broader context in which Palliative Care is situated and introduce and update on our scope of work which included key informant interviews and mapping of palliative care delivery.

**Interview guide development**

JSI worked with MDPH/MCCPCN staff to refine the goals of the assessment at the regional level to describe:

1. The nature and extent of palliative care services in the region, in particular, how “community-based” palliative care is defined and delivered.
2. How community-based models of palliative care function within the different regions in order to provide recommendations for partnership development statewide.

Key informant interviews with stakeholders in each region were planned as the first phase of the regional assessment. JSI developed the interview guide by first reviewing two interview guides that had been used for prior assessments – (1) the State’s Palliative Care Key Informant Interview Guide and (2) the interview guide developed by Signe Flieger, PhD, Tufts Medical School to create a directory of palliative care services for the Northeast regional subgroup. Questions from these guides that were related to the goals of our assessment were identified for further adaptation.

Based on the selected questions from previous assessments, a new set of questions were developed by the JSI team that focused on community-based palliative care services in the region to learn about underlying sources of gaps in access within the region and recommendations for improving access to palliative care. For the purpose of the interviews, *community-based* palliative care include services offered to a patient within their local area which includes a patient’s residence (senior housing, group housing and assisted living facilities), a clinic or long term care facility (skilled facility or nursing home). The draft version of the guide was reviewed by MDPH staff and the Workgroup co-chair. Comments and edits were received and incorporated into the final version of the guide (see Appendix 3).

**Recruitment of interview participants**

A recruitment letter (see Appendix 3) was developed to introduce the purpose of the interviews and identify key stakeholders in each region to participate in the interviews. JSI staff attended regional subgroup meetings starting in September 2016 to describe the interview process and share the introductory letter and interview guide. In partnership with regional subgroup members and subgroup coordinators from ACS, a list of key stakeholders for each region was identified. JSI emailed potential participants to schedule telephone interviews. As interviews progressed, MDPH and subgroup members made further recommendations on whom else to contact to ensure a balanced and broad perspective from different parts of each region. Interviews were between 45-60 minutes in length and were conducted over the phone between November, 2016 and April, 2017.

**B. Description of Key Informants**

A total of 38 interviews were completed with 44 key stakeholders across four regions. Of the 44, 11 were from the Western MA region, another 10 were from the Northeast/Metrowest region, 12 were from Central MA, and six were from the southeast. Interview participants included hospital, healthcare organizations, and hospice administrators and medical directors, palliative care clinicians (physicians, nurse/nurse practitioners, medical assistant), social service providers, nutritionist and clergy. In addition, five other stakeholders were interviewed to offer a “state level”
perspective on palliative care in Massachusetts. All organizations that participated in the interviews are listed in Appendix 4.

C. Data Analysis

A total of four JSI staff members conducted the phone interviews with regional and state level stakeholders. An interviewer and a note taker were assigned for each interview. A template was developed to facilitate uniform note taking and subsequent analysis process. The interviews were also audio-recorded with the participant’s permission to ensure accuracy of information.

Analysis of the notes followed an iterative process. Each JSI staff member reviewed his/her interview notes for emergent themes. Staff then met on several occasions to discuss and revise the organization of themes, providing quotes to convey the ideas behind the themes. Themes illustrated observations, patterns and ideas that were consistent across more than one region.

D. Summary of Key Themes Across Regions

1. Palliative Care in the community is provided under a variety of provider structures

Interviews with key stakeholders revealed a variety of provider structures in the provision of palliative care. The growing movement out of the hospital setting into the community has seen health delivery systems adapting to match this need. Major hospital systems such as Hallmark Health, Lahey Health, Baystate Medical Center, Cooley Dickinson, Southcoast Hospital have incorporated home health (VNA)/hospice service within their own system. This facilitates a continuum of care for patients from in-patient to home care/hospice services. Palliative care is typically provided by a nurse and home health aides under the home health insurance benefit where patients must meet the “homebound” criteria. Hospitals that do not have their own home health/hospice such as Tufts Medical Center refer to a variety of agencies to meet their patients’ palliation and hospice needs. These consultative models are provided by hospices with staff certified in palliative care, such as VNA Care’s VNA Hospice and Palliative Care, Care Dimensions, Merrimack Valley Hospice and Home Health, and Hospice of Franklin County. Care is primarily provided by a nurse practitioner who assesses the patient’s goals of care and works with the patient’s primary care provider to coordinate care among an interdisciplinary team that can include doctors, nurses, hospice aides, social workers, chaplains and nutritionists. The consultative model has been an effective way to provide in-home palliative care for patients that do not meet the eligibility criteria of being “homebound”.

The service areas of these larger VNA/Hospice/Home Health organizations often cut across state and/or regional boundaries. This is more evident in the eastern part of the state where there is greater overlap in service area among providers, especially in high population areas such as northeast, metro Boston and southeastern MA. Merrimack Valley Hospice and Home Health provide services as far north as New Hampshire and Maine. Care Dimensions based in Danvers serves almost all of the eastern/southeastern part of the state from the New Hampshire border, south to Canton, Randolph, Braintree, east to Lowell, and west to Littleton. Hope Hospice and Palliative Care based in Rhode Island has recognized the potential across state lines and is looking to expand its services in Southeastern MA.

While there is overlap and good coverage in most of the state, some stakeholders expressed concern over gaps in services and ensuring services provided meet the criteria to be classified as palliative care.
“Right now, there is a patchwork of services and there are access gaps. And it’s not really team-based...a big belief of mine is you must meet certain requirements to say you offer palliative care services.” (Palliative Care Nurse/Educator, Western MA)

Another concern was related to the limitations of communication flow between palliative care clinicians and VNA/stand-alone hospice services that are not affiliated with a health system. As one hospital-based palliative care physician pointed out, “I worry that when it’s a community service and not affiliated with a health system, palliative care will become a road to hospice and a road to decreasing readmissions”.

While key informants emphasized that palliative care exists in the larger health care context of hospital mergers and emphasis on cost savings, they offer this reminder:

“Part of what palliative care is, is not having an agenda. We’re all focused on readmissions and how palliative care is looked at as something that can help that...it absolutely can do that, but it does it by doing the right things, by understanding who is the patient and what’s important to them” (Palliative Care Physician, Northeast Region)

2. Reimbursement for palliative care drives type of care and ability to provide quality services

The lack of or limited reimbursement for palliative care services and the fee for service model was universally mentioned as the biggest barriers to providing increased, comprehensive, and high quality services. These aspects become burdens for providers and healthcare organizations who want to include or expand services in their practice. Coverage for community services is often through a home health insurance benefit that is fairly limited due to patients needing to fit criteria for being home bound, not always interdisciplinary and comprehensive, and is often a stepping stone to hospice. (Palliative care patients need medical and non-medical services.) Additionally, the complexity and lack of understanding of insurance coverage contributes to gaps in services or patients not receiving any services. Despite these complexities, case managers and discharge planners can play a large role in navigating insurance complexities.

“Our payment structure is the single biggest barrier to PC care in the country. You can’t run a program on measly reimbursement.” (Hospital Administrator and Provider, Western MA)

"Until we switch away from fee for service, it’s going to be really hard for PC to bring in their own money and get buy in from physicians to start offering." (Hospice Manager, Western MA)

“Money is the biggest obstacle. It impedes everything else. Our need to provide services is great. Our obstacles are financial resources. We’ve been talking about expanding for years, and no one has moved it to the front burner, including myself.” (Hospice Provider, Western MA)

“There is a huge gap in reimbursement for the service - it’s often not recognized by the insurers. It’s hard to build programs with significant impact if we can’t fund them.” (Home Health/Hospice Administrator, Northeast MA)

"Once we get their pain under control, they want to keep us in because we’re a good support system, and we have to step out because their bridge services are no longer
covered, and they are not interested in hospice/eligible at this time. And that’s most cases unless their insurance isn’t Medicare.” (VNA, Central MA)

Additionally different models of care (e.g., consultative home care agencies, complementary supportive care centers) have their own unique challenges. Travel time for example to more remote locations for homecare providers isn’t always reimbursable and thus some agencies and providers can’t find staff who are willing to travel for these visits.

“There are financial stability issues of a consultative model – we are paid per visit, it is time consuming and have to cover great distances... we experience limited staffing capacity, backlog of patients waiting to be seen.” (Free-standing palliative care/hospice, Northeast Region)

There are efforts in the state to address reimbursement issues. Tufts Health Plan, for example, has developed unique insurance codes to reimburse palliative care services for private payer patients. Analyzing these data will provide a mechanism to understand utilization of palliative care by their members.

3. Provider misconceptions about palliative care can delay referrals and impact quality of life for patients

Demand for palliative care is growing due to an aging population. Providers need to have knowledge about how to direct patients/facilitate access to these services. Across regions participants expressed that palliative care services need to be delivered early to clients in order to be most effective in improving the quality of their lives. Yet early referrals were said to be rare, as recounted below:

“Palliative Care should begin at diagnosis of a serious illness, but I tend to get people at end stage.” (Palliative Care Nurse, Western MA)

The Central MA subgroup devoted one of its meetings to this topic concluding that it is the lack of full awareness and understanding of palliative care among providers that presents the greatest barrier to early referrals for all those with serious chronic conditions who might benefit. This arose in previous assessments and was confirmed by a number of our key informants and regional subgroups members. Their observations included lack of provider education, coupled with stigma associated with palliative care, in which providers view the services as linked to hospice and giving up on the possibility of successfully treating patients:

“Palliative care is seen as a bridge to hospice [by providers], which it is not. No one wants to cross that bridge which makes palliative care hard.” (Hospital Administrator, Northeast Region)

“The cardiologists and oncologists are somewhat resistant to it – don’t understand what it is. They will talk about cases and when I suggest Pal Care, I get the ‘evil eye.’” (Nurse, Southeast Region)

Physician champions were seen as key in advancing palliative care referrals among providers and are needed across many hospital departments and not just oncology where the initial focus on palliative care services started.
Patients and their families may also hold misconceptions about palliative care that impedes acceptance of services. Some providers noted that family members may be even more reticent than the patients themselves due to their fears of it meaning treatment will be stopped or that it implies continued decline.

“Patients, families, and public aren’t aware – don’t look [for community-based palliative care] until they need it. When a crisis occurs then they go to the hospital.” (Community Service Agency, Central MA)

4. Increasing public awareness must be met with increased provider capacity

All stakeholders interviewed agreed that efforts to increase public awareness need to be balanced with increasing provider knowledge and capacity in palliative care. Interviews revealed that for both patients and providers, the most common misunderstanding is the distinction between palliative care and hospice. This is even important for some cultural groups where “palliative care” does not have a direct translation.

“Palliative care is still a scary term for people. It’s getting back to semantics and meaning. I think the other thing is language or if you don’t have the cultural understanding, this can lead to misunderstanding by the patient.” (Palliative Care Provider, Metro Boston)

“Public education is a huge part [of facilitating access] – a lot of people don’t know what to ask for. There is still a knowledge gap – palliative care is not hospice.” (Palliative Care Program Manager, Northeast MA)

“Many folks still think of palliative care as hospice and they don’t have hope...it’s not always the patients, sometimes it’s the family. The family dynamic can bring a lot of barriers”. (Oncology Services, Northeast MA)

For some providers, not knowing how early they can refer or how to refer and not understanding the scope of palliative care services were related to the confusion about palliative care versus hospice.

“The gaps are in other care providers understanding of what the service line can do for their patients and how palliative care can help other providers manage patients.” (Home Health Administrator, Northeast MA)

For others, conversations with a patient and his/her family about treatment of life limiting disease and chronic illness are a time-consuming process. In order to meet the demand, the greatest resource that providers cited was time.

“It’s hard to explain palliative care to patients and we have 15 minutes visits and we’re often double booked. We have huge time constraints” (Primary Care Provider, Northeast Region)

“If we don’t take the time to understand them, we can’t help these people and that’s what palliative care is” (Palliative Care Physician, Northeast Region)
5. Importance of managing transitions to avoid gaps in services

Coordination is an essential component of community-based palliative care. Some type of case manager or patient navigator is essential to ensuring that access to palliative care is not disrupted as patients transition between care settings.

“Where we fall apart would be the smooth transitions from one site of care to another. From the patients at home, I hear there are gaps in the care and gaps in-between visits. This is one of our metrics - to tighten up the time from referral to actually getting someone in the home.” (Program Director, Southeast Region)

While some of this may be related to insurance coverage or identification of a service provider to provide palliative care services in the new setting, some of it has to do simply with system. It is extremely complicated to manage all of the services needed in a new location. As one physician put it:

“The referral system is extremely complicated.” (Physician and Director of PC Services, Southeast Region)

E. Regional Subgroups: Process and Interview Findings

WESTERN MA

The Western MA subgroup has been meeting since September 2015. There are approximately 20 members on the distribution list for this subgroup with 3-8 members who attended each meeting. A representative from ACS organized and facilitated meetings. Member representation includes but is not limited to providers and administrators from hospitals (Cooley Dickinson Hospital, Baystate Medical Center), hospice (Hospice of Franklin County, Mercy Hospice), and healthcare organizations (Commonwealth Care Alliance, Berkshire Healthcare Services, and academia (University of Massachusetts-Amherst).

Subgroup Meetings

The subgroup has met five times. At the first meeting, discussion focused on what is working well and what is not working well in the region MA for three priority areas:

- Education
- Access and availability
- Reimbursement.

For education, a variety of ongoing educational events to increase awareness and education about palliative care targeted to both providers and the public were discussed (e.g., grand rounds at Franklin Medical Center, UMass curriculum for nursing students, Cooley Dickinson-organized community events, Brightwood Health Center forums). Tracking education that is implemented and connecting the people who present was discussed as a need. A more centralized approach and/or connecting everyone could lead to a more cohesive and coordinated approach. MA Medical Society was mentioned as a potential partner that could assist with a centralized regional or statewide approach for provider education.

Regarding access and availability, discussion focused on the need for mapping palliative care providers in the region and the services of each. Regarding reimbursement, discussion focused on the challenges, the need for up-to-date and correct information, and the need for comprehensive...
Palliative care reimbursement legislation. The subgroup decided that they were going to focus on education for consumers as the main activity.

At subsequent meetings discussion focused on the content and key messages for increasing awareness and education and distribution mechanisms. A decision was made to start with the development of an op-ed piece that could be sent to a variety of newspapers in the region. JSI participated in subgroup meetings and to share about the regional assessments around community-based palliative care and present preliminary findings from the interviews. Additionally, subgroup members were instrumental in recommending partners and stakeholders for the key informant interviews for the regional assessment.

Key Stakeholder Interviews
A total of 10 interviews were conducted as part of the Western MA regional assessment (see Appendix 4 for a list of organizations). Interview participants were primarily palliative care providers and hospital/hospice/healthcare organization administrators. Efforts to recruit participation of a social worker in the field of palliative care and additional representation from Berkshire and Franklin counties were unsuccessful.

In addition to the summary of key themes across the state described above, interviewees revealed the following information:

1. Palliative care services are expanding however the focus is more in the inpatient setting.
2. The very rural nature of the Western MA region makes access to palliative care services challenging. Outpatient services are very limited. Thus there can be long distances for patients to travel. For certain patients who are homebound and can’t travel, and for patients who don’t have their own car and can’t find a ride, transportation is a real barrier.
3. More innovation with technology could be utilized, such as face-to-face palliative care consults via computer.
4. The Program for All-Inclusive Care for the Elderly (PACE), found in Hampden and Hampshire counties and other counties in the state and Commonwealth Care Alliance (CCA) provide models of care to ensure that those who need palliative care receive it.
5. There is a recognized need for more diverse caregivers and a better understanding of how different cultures perceive, understand, and use palliative care services. Language barriers were frequently mentioned during interviews.
6. Education is a large need, and there is a commitment to continuing the educational efforts for consumers and providers. Increased consumer education may increase demand for services which could pose a challenge.

Priorities Moving Forward
The subgroup has identified public education as the area to make the biggest impact. At the Quality of Life in Massachusetts: Building Community-Based Palliative Care Meeting on June 1, 2017, the Western MA breakout group discussed the following in relation to public education:

1. Materials need to be consistent, culturally competent, and provided in other languages to meet the diverse needs of the region.
2. Target education to patients who are not yet very sick. Use an upstream approach.
3. Include churches and clergy leadership as partners in public education. Consider engaging the Council of Churches and/or the Greater Boston Interfaith Organization.
4. Consider the educational approach, for example, a centralized location for presentations versus person to person/individual education by faith-based entities and healthcare providers. (Note: The region is large, and travel poses significant challenges for a centralized approach.)
5. Coordinate resources through an online calendar or other system to post slides and to ensure educational messages are consistent.
6. Consider the use of PSAs, billboards, local cable, radio, and local theater as additional ways to reach the public.

CENTRAL MA

The Central MA subgroup has been meeting since November 2016. There are approximately 20 members on the distribution for this subgroup, with varying participation depending upon the location. The northwestern portion of the region has been identified as an area of particular need and members have started congregating in that locale more frequently in order to facilitate engagement of area stakeholders. The core members comprise administrators and providers from major hospitals in the region, including Heywood and Athol Hospital Group, UMass Memorial, and St. Francis. Other subgroup members include specialists from Montachusetts Healthcare and the Simonds-Sinon Regional Cancer Center.

Subgroup Meetings
The subgroup has met three times, with a fourth session planned for June. Large distances to travel and poor conditions due to snow and ice hampered several planned meetings, which is emblematic of some of the key transportation barriers identified as making it difficult for patients and home visiting providers to advance palliative care services.

During the first meeting of the Central MA palliative care subgroup raised the twinned issues of lack of awareness of the availability and nature of palliative care services, and stigma that accompanies misunderstandings of these services so that palliative care is equated solely with end of life. These issues rose to prominence as a priority for the subgroup to address. Subgroup participants had started to conduct educational initiatives for both providers and the general public and they decided as a group to focus their efforts on a shared approach and potential campaign. Issues of branding were discussed; i.e., should they work around the term “palliative care?” St Vincent’s was employing that strategy by creating a Patient Wellness and Support Center. Yet the group decided it was best to work towards de-stigmatizing the term palliative care in order to feed into national momentum.

Key Stakeholder Interviews
Eight sets of interviews were conducted (see Appendix 4 for list of organizations). The following key themes emerged from meetings and interviews:

1. Inpatient palliative care is strengthening and serves diverse patients
2. Community-based care is predominantly VNA, homecare, and hospice services
3. Community-based care does not extend to many populations; especially those without insurance coverage (undocumented) and those not as well connected culturally to be aware of services. Coverage gaps exist between initial home-based services (VNA) and hospice eligibility
4. Provider reticence to make early referrals is key barrier
5. Education of providers and community-based outreach to residents is starting to take hold (more slowly in multicultural settings)
6. Community health centers are not engaged/linked
7. Access determined by payer, geographic location, information in one’s own language. North Central region has unique disparities driven by rural poverty, lack of transportation, and limited reimbursement for needed services.
Priorities Moving Forward

Participants in the Central MA Palliative Care Subgroup posed the dilemma of whether to raise awareness of palliative care services more broadly in the community prior to having adequate capacity at the health organizations. The Subgroup decided to proceed with broad community outreach hoping that increased demand would be needed prior to increased administrative buy-in to expand availability of services. As this effort is advanced, it will be an opportunity for MDPH and the statewide Palliative Care Workgroup to build on efforts to ensure that outreach extends to more geographically, economically, linguistically, and culturally isolated populations in the region.

Southeastern MA

The Southeast subgroup has a mailing list of approximately 25 members. Typically 5-10 attend any individual meeting. Attendance varies by location, and meetings have been held in Brockton, Fall River, and Fairhaven (outside New Bedford). Representatives of the following organizations have attended at least one meeting: HopeHealth, St. Anne’s Hospital, Community VNA, Cape Cod VNA, Southcoast Hospital, Good Samaritan Hospital, Beth Israel Deaconess Plymouth, Brookhaven Hospice, and Seasons Hospice. A call-in line has been made available at meetings due to the long travel distances within the region.

Subgroup Meetings

In the Southeast Region, meetings began in December, 2016. Since then, there have been 6 meetings in total held by the group, including one held at the annual MCCPCN state cancer meeting on June 1, 2017. The Southeast is a large geographic region, with sub-areas (north, south, and east) that vary greatly in population density, age distribution, and racial/ethnic/linguistic diversity. In addition, it was decided that Cape Cod (and the Islands) would be considered a separate region, given its current and robust activities in the area of advance care planning.

Both clinical and support staff attended meetings held in Brockton and Fairhaven (outside New Bedford). No meetings have been held to date from the Plymouth region, though representatives from that area attended the annual MCCPCN state cancer meeting.

Each of the meetings of the Southeast Region had rich discussion regarding the challenges and successes in developing, managing, and maintaining palliative care programs. One participating organization, Southcoast Cancer Center, talked about its success using community health workers, in conjunction with other area organizations, to conduct outreach to encourage cancer screening tests, in this particular case, colonoscopies. The strategy was used to address health disparities in colonoscopy rates between the white and non-white population.

Other discussion topics included the challenges of hiring and maintaining staff with specific training in palliative care. Another focused on how the planned use of EMRs to prompt providers to speak to patients about advance care planning.

Key Stakeholder Interviews

There were six key informant interviews conducted with representatives from the Southeast Region (see Appendix 4 for list of organizations). The main themes of these interviews were:

1. Difficulty of maintaining providers with specific training in palliative care;
2. Value of embedding palliative care providers within provider organizations, when possible;
3. Importance of introducing palliative care as early as possible after a qualifying diagnosis;
4. Need for continued education of both providers and patients regarding what palliative care
5. Working with some diverse communities raises specific challenges regarding cultural perceptions of palliative care.

Priorities Moving Forward
The main activity the group decided upon as its priority area is provider education. The group will continue to meet to develop an educational intervention for providers in this area. In addition, these concerns were articulated moving forward:
1. Develop ways to support further training for providers that will “stick” i.e. not have to be repeated in six months when the next palliative care patient comes along;
2. Build greater rapport between providers in northern, southern, and eastern areas of region such as use of tele-conferencing;
3. Identify structure for self-sustaining efforts post-June 30.

NORTHEAST/METROWEST
The Northeast/Metrowest subgroup has been meeting since March, 2016. There are approximately 50 members on the distribution list for this subgroup, with 8-10 members who attend consistently. The core members comprise administrators and providers from the major health care delivery systems and hospitals in the region, including Lahey Medical Center, Tufts Medical Center, Winchester Hospital and Hallmark Health. Hospice and palliative care providers, including VNA Care and Care Dimensions, and home health agencies such as VNA of Middlesex East, are key members in the subgroup.

Other subgroup members include Tufts Health Plan and Atrius. The subgroup is facilitated by the American Cancer Society (ACS) who has been instrumental in convening the subgroup, setting concrete action steps and following up with resources to move the agenda forward. Another strong partner in the subgroup has been Dr. Signe Flieger, faculty member at Tufts University School of Medicine. Along with two graduate students, Dr. Flieger has conducted interviews and web research to create a directory for the Northeast region that details service type and staffing at of palliative care service locations.

Subgroup Meetings
Over the past year, the subgroup has met monthly. In order to facilitate broad participation across the region, meeting locations rotated between different facilities. The rotation of meeting venues may present potential challenges in engaging a consistent group and unified action steps. However, a committed core group and strong facilitation by ACS has enabled this arrangement to be possible. The focus of the subgroup has been consumer and provider education. The group has partnered with Honoring Choices’ Ellen DiPaola to create a discussion tool for providers and consumers focused on palliative care. JSI participated in subgroup meetings to share about the regional assessment around community-based palliative care and present preliminary findings from the interviews and regional maps.

Key Stakeholder Interviews
A total of 10 interviews were conducted as part of the Northeast/Metrowest regional assessment (see Appendix 4 for list of organizations). Interview participants were mainly hospital/hospice administrators and palliative care clinicians. Efforts to recruit participation of social workers in the field of palliative care and other community-based agencies were unsuccessful. We were however able to interview a primary care provider to learn about the perceptions of community health center patients around end of life care. Interviews with participants revealed the following:
1. The demand for community-based palliative care are related to factors such as the prevalence of chronic illness in the aging population, the desire to receive care in one’s own home, and pressures on health systems to reduce readmissions.

2. The growing demand will need to be met with providers who are knowledgeable in how to engage patients in conversations about quality of life and palliative care, and to facilitate its timely access.

3. The financial viability of community-based models such as free-standing, consultative hospice/palliative care agencies are challenged with payment arrangements that do not account for the time consuming nature of the service. Free standing hospices rely on referrals, are paid per visit and have to cover great distances. At the same time, they are constrained by shortage of staff and accumulate a backlog of patients.

4. For patients, access to seamless care is challenged by having to meet eligibility criteria, type of insurance, one’s geographic location and information in one’s own language about palliative care.

Priorities Moving Forward
The subgroup has identified the following priorities/goals for the next six months:

1. Train the trainer, train middle tier staff (i.e. nurses, social workers, etc.)
2. Develop a standardized assessment tool for palliative care referrals.
3. Provide training/education for billing and coding for palliative care consults.
4. Create an online directory of Massachusetts palliative care providers and the specific services they provide—not all palliative care providers offer the same services.
VI. MAPPING PALLIATIVE CARE SERVICES

A. Mapping Overview

One focus of our work was to better understand the geographic scope of palliative care services in the state and to visualize accessibility to geographically disparate populations. To achieve this we used geographic systems (GIS) to map palliative care service or office locations statewide. The point locations were then overlaid on a map with population level demographics, such as population density and linguistic isolation, for city and towns across the state to provide context to the geographic distribution of palliative care services and to visualize potential demand and barriers to service. Additionally, other related community resources, such as community health centers and senior centers were mapped. We prepared static report maps both at the statewide level and maps focused on each regional sub-group area. JSI also prepared an interactive web map that can be accessed through a web link. The map contains all of the data created for static maps and allows the user to pan and zoom, address search, the ability to turn map layers on and off and the identification of results at by clicking on any service location.

B. Methodology and Limitations

Mapping Palliative Care Office/Service Locations

JSI identified and gathered palliative care locations in Massachusetts from multiple sources and through an iterative review process using information gathered from key informant interviews and local knowledge. Sources for the final list of palliative care locations include:

- Contact list of palliative care providers from the Massachusetts Department of Public Health (DPH)
- Home Care Alliance list of home health agencies providing palliative care
- Massachusetts Executive Office of Elder database, keyword “palliative”
- Site identification from Key Informant Interviews
- JSI staff input

We geocoded service location addresses in desktop GIS software. This is the process of converting a list of addresses to points on a map or to latitude/longitude (xy) values in the database. We used an iterative process to ensure that service sites are located as accurately as possible. The locator services we used can locate facilities accurate to a point address or to a street address range. Addresses are often not uniform and a final additional step is a google search to find a facility by name or community. The mapped point locations contain all of the attributes of the gathered tabular data. Essentially the table is linked to the mapped points and the points can be symbolized based on these attributes.

For the purposes of mapping we classified palliative care locations by facility type or service type. Many locations will offer multiple/overlapping services. The classification categories below were used in all maps and are based first on facility type (i.e. Hospital) and second on an organizational type or name (i.e. VNA)

- Hospital
- Hospice
- Home Health / VNA
- Elder Care, Assisted Living, Nursing Home, SNF
- Medical Center, Primary Care, Family Health
Limitations - Mapped Palliative Care Office/Service Locations

The mapped locations of palliative care services and the table from which the map was created have two important limitations. First, there is not a definitive list of locations offering palliative care services in Massachusetts. The list of sites created and the map represent a best-effort to identify as many locations as possible at the time of the delivery of the final report. The map should not be considered complete or comprehensive. In addition to the potential for missed sites, many organizations with multiple locations will offer palliative care but it was unclear whether only some or all sites offer the services. Second, unlike other healthcare services such as primary care or dental, palliative care services are not always provided in a medical office setting but may be provided in other locations such as hospice or in the patient’s home. Many of the points on the map represent offices or dispatch centers and not service locations. We did not have information on service areas or catchment areas for locations. The points on the map show the geographic distribution of palliative care office/service locations but do not show the direct geographic accessibility for services.

C. Report Maps

For each sub-group region there are 5 report maps: The full collection of maps can be found in Appendix 5.

1. Palliative Care Sites
2. Palliative Care sites with Population Density

3. Palliative Care sites with Limited English Proficiency
4. Palliative Care sites with % Age 65+

5. Other related community resources
All demographic data is from the American Community Survey (ACS) 2011-2015 5-year estimates at the county subdivision level. This is equivalent to the city and town level in Massachusetts. A definition for each demographic is below:

- **Population Density**: Persons per Square Mile, ACS table source = B01001 for population, geo table for land area.
- **Limited English Proficiency**: % Population 5 years and over in households in which no one 14 and over speaks English only or speaks a language other than English at home and speaks English "very well" ACS table source = B16003
- **Percent Age 65+**: Percent of the population age 55 years or older of the entire population, ACS table source = B01001

Sources for other related community resources:

- **PACE**: Program of All-inclusive Care for the Elderly, Massachusetts Executive Office of Elder Affairs, MA HHS, [http://www.mass.gov/eohhs/consumer/insurance/pace/](http://www.mass.gov/eohhs/consumer/insurance/pace/)
- **Senior Centers**: Massachusetts Care Planning Council (MaCPC), [http://www.caremassachusetts.org/list11_MA_senior_centers.htm](http://www.caremassachusetts.org/list11_MA_senior_centers.htm)
- **Long Term Care Residences**: Mass GIS, March 2007, [Nursing Homes and Rest Homes: Division of Health Care Quality (DHCQ), Massachusetts Department of Public Health.](http://www.mass.gov/eohhs/healthcare/longtermcare/)
- **Assisted Living Facilities**: Massachusetts Executive Office of Elder Affairs.

**D. Interactive Web Map**

In addition to the static maps, we have created a live-linked interactive web map containing all of the same map layers, with the same symbology, that are presented in the report maps. The web map was created in and is stored in the Environmental Systems Research Institute (ESRI) ArcGIS online mapping platform. Functionality in the web map allows for panning and zooming into an area of interest and the ability to turn demographic context layers and other community resource layers on and off. The map also provides multiple options for background layers showing streets and administrative boundaries. The most important functionality is the ability to identify or click on any point location on the map and see a pop window with organizational name address and other gathered information on that specific service or office location (see graphic below). Link to the interactive map is here: [https://tinyurl.com/y8bczldc](https://tinyurl.com/y8bczldc)
VII. DISCUSSION & RECOMMENDATIONS

A. State of community-based palliative care in Massachusetts

Palliative care services are available in each of the regions where palliative care workgroups were established. However, there were many issues affecting access to and the delivery of palliative care services including varying models of service delivery, the comprehensiveness of services, referral patterns, staffing, finance (including insurance coverage), cultural competence, and geographic access.

Models vary based on the host agency for the services. As health care service delivery systems become more integrated, palliative care programs may be structured in multiple ways. Models include a consultative structure, centered on an individual provider licensed in the field, hospital-based, VNA based (which may be embedded in a hospital setting and others).

Part of this initiative is the promotion of “comprehensive” palliative care services which entails meeting the medical, mental health, social service, and spiritual needs. A number of providers have removed the name “palliative” from their services either due to the stigma associated with the word but, more often, due to lack of specialty-trained staff in one or more of the service areas. Given small numbers of specialty-trained staff, various healthcare organizations strive to provide palliative care despite these limitations.

Financial barriers, cultural barriers, and geographic barriers continue to limit access to community-based palliative care services. Many patients fall into the “gaps” in financing of palliative care. According to key informants, certain racial/ethnic/linguistic minorities are less familiar with palliative care and have less support for and knowledge about how to navigate the healthcare system. Providers in Central MA noted, for example: “African, Hmong, Laotian (in Winchendon) – often do not seek healthcare. Hmong go to their shamans.” Geographically remote areas will likely have more limited choices, especially for individuals able to receive palliative care services at home.

B. Successful strategies

There are a number of promising practices that regions are advancing, many of which could be shared with other regions and extended. These fall across a range of areas from education and outreach, to partnerships, and scope of services offered.

Provider/Consumer Tools

Among educational interventions, many regions are focused on effective provider, patient, and general education. Tools include use of Serious Illness Conversation Guide developed by Atrius Health and the simple, low-literacy Honoring Choices Palliative Care Questions that have been formatted and handout out to both providers and patients to help generate conversations regarding palliative care.

Provider Education/Workforce Development

A number of healthcare organizations and educational sites are trying to offer more consistent provider education. University of Massachusetts Medical School in Worcester, for example, offers a Dual Palliative Scholars program in which RNs can become certified in palliative care. Their nurse faculty champion is also working with the graduate nursing school to have a course offered to Nurse Practitioner students. UMass is also among several institutions that conduct teaching with
residents and fellows, and that offers grand rounds to the entire hospital over the course of the year. They go so far as to hire an actor as a patient in order to provide live teaching about how to have difficult conversations. Also aiding in provider awareness is the engagement of interdisciplinary members within palliative care teams, which often included a pastor and social worker alongside of a palliative care nurse and specialty provider (such as an oncologist).

**Holistic/Complimentary Therapies**

Many major hospitals now offer a range of complementary therapies to extend their services. In some locales there are also extensive community-based resources; although eligibility may be disease-specific. Among these, The Virginia Thurston Healing Garden in Harvard, MA, launched in 2000 was highlighted. As a non-profit organization with a sliding scale fee structure, their mission is to provide integrative therapeutic services, educational programs and a healing environment to people affected by breast cancer. A personalized care plan is offered for those who are just starting out with diagnosis, are pre-treatment or post-treatment. Treatment modalities offered include acupuncture, Core Movement Integration®, Reiki, reflexology, shiatsu, Therapeutic Touch®, massage, qigong, counseling, exercise/movement programs, expressive arts, nutrition counseling, horticultural therapy and a variety of support groups and workshops also open to the general public.

**Community Health Center Model**

Brightwood-Commonwealth Care Alliance offers an example of the potential that Community Health Centers can offer to the field. Their statewide Life Choices Palliative Care Program draws upon interdisciplinary teams that embed palliative care services into primary care in a flexible approach that change over time as needs change. Individualized care plans are tailored to patient and family wishes. They have capacity to work with a diversity of families, including Spanish-speaking and other immigrant populations in Springfield. Their continuum of care offered obviates the need to choose between aggressive care or hospice as palliative care can be provided to those who are still receiving treatment services. The types of palliative care services offered is extensive, and draws upon the leveraged resources of connected community palliative care, hospices, and other providers. Among important benefits are patients can stay under the care of the primary care provider they have established relationships rather than having to shift to other facilities.

**Community-Based Outreach**

Community-based outreach was also mentioned by several informants, including those from VNA, hospice, and homecare service organizations. Materials were being developed and events had been held that ranged from discussions at community meetings to local health fairs. Heywood/Athol Hospitals are starting to work on how to best extend their services to address health equity through both a Multicultural Department and participation in a Multicultural Taskforce in the North Central portion of the region. The Director of the Initiative on Palliative Care and Advanced Care Planning from the Boston Archdiocese also provided a more extensive outreach model, having worked extensively with regional Archdiocese to engage pastors and providers in Catholic Health Services to promote broader outreach. This has included outreach conducted on Catholic Media stations available online (see: http://www.catholictv.com/shows/inter-nos/mc-sullivan-end-life-care).

**C. Recommendations**

Based on the information we collected through our collaboration with the regional workgroups, key informant interviews, and mapping, JSI offers the following recommendations for consideration:
1. Build leadership support for palliative care services to enhance palliative care
Having a champion for palliative care within a given institution is necessary to have a successful palliative care program. A champion can be anyone with sufficient energy, enthusiasm, and knowledge to encourage and support the development of palliative care programs or services. Medical staff, administrators, social workers, patient advocates, and other types of individuals can all be champions. Champions help develop palliative care programs by making them a priority for the organization. In addition, they help by identifying resources that can be used to provide palliative care services. This includes recruiting staff with specialty training in palliative care, providing opportunities for education about palliative care, and supporting use of palliative care services by providers at all levels of care.

Having a champion for palliative care within a given institution is necessary to have a successful palliative care program. Champions help develop palliative care programs by making them a priority for the organization. In addition, they help by identifying resources that can be used to provide palliative care services. This includes recruiting staff with specialty training in palliative care, providing opportunities for education about palliative care, and supporting use of palliative care services by providers at all levels of care.

2. Address reimbursement for coverage gaps
Reimbursement for palliative care is essential to making provision of palliative care services available. Currently there is a patchwork of reimbursement available for this type of care, strongly tied to type of insurance held by individuals. Because palliative care is rarely its own billing code, sometimes certain type of services (such as nursing care) may be reimbursable while others, such as spiritual services, may not be.

Further, the type and extent of services billable for palliative care may change based on the facility where it is offered. So a patient receiving palliative care services as a hospital inpatient, may have difficulty maintaining those services when they transition back to home or from home health to hospice. Other services that may be difficult to support are outreach and education for palliative care or provision of home health aide services.

3. Support workforce expansion
Having appropriately trained providers, such as palliative care certified physicians or nurses, is needed for having a comprehensive, high quality, palliative care program. Hiring and retaining staff with those qualifications can be difficult, and frequently loss of specialty trained care provider can affect the ability to sustain a palliative care program. Supporting opportunities for staff to obtain specialty training in palliative care can help ensure a successful program.

4. Increase provider education and networks
While specialty training is ideal, integration of a palliative care “mindset” in patient treatment is important to support awareness of focusing on “what the patient wants”, pain management, advance care planning, etc. It’s expected that education initiatives can be expanded through centralized and/or regional training opportunities.

5. Encourage “best” provider practices
There are some relatively simple things that could make a huge difference for people with serious illnesses who could benefit from palliative care. Several “best” practices were heard repeatedly throughout our conversations with individuals and groups. A major one is to encourage earlier referrals to palliative care services. More than anything else, having the practices and strategies of
palliative care introduced to patients and family members was considered to be essential to improving decision-making about care.

Another important “best” practice is to have team-based approaches to working with patients. The very definition of a comprehensive palliative care program is to have a team of providers addressing medical, social, mental health, and spiritual needs.

6. Build consumer awareness
There were extensive discussions across regions regarding balancing development of the provider workforce with increasing patient awareness of palliative care services to create a “demand pull” for these services. While there are concerns about creating a service that may not always be available, there are several perceived upsides to patient education. For one, educated patients have been shown to more frequently initiate conversations with providers regarding palliative care/advance care planning. Patient awareness can also “spill over” to family members. Sometimes family members may be barriers to patient access and education can counter this.

In other instances, with education of family members, they can support the patient in seeking palliative care services or be the advocate for these services on behalf of the patient. To address stigma associated with palliative care among diverse populations, consumer (as well as provider) education among racial/ethnic/linguistic minorities can remove or reduce cultural barriers.

7. Expand/improve clinical-community linkages
Increasing communication and follow up between clinical and community providers can facilitate transitions between service providers, and enhance the availability of services for patients that may improve quality of life. This can include community services such as complementary therapies (e.g. mediation, spiritual counseling, acupuncture, etc.) that may improve quality of life.

In addition, case managers/navigators who are part of palliative care team can provide referrals to address social determinants of health such as housing, counseling, food access, financial services, and other quality of life-related services.

D. Next steps for strengthening community-based palliative care in MA

To move forward in implementing these recommendations and continue the growing momentum across the state, the following next steps are proposed:

1. Regional Strategic Planning
Each region should continue to advance its own strategic plan that addresses their informal assessments of the gaps between needs and services, leverages multi-sector teams and partnerships, and avails their subgroup important and timely opportunities.

   a. Set SMART goals and objectives - To guide and monitor future direction, strategic plans should incorporate specific, measurable, achievable (as well as appropriate in terms of equity and other values), realistic, and time-bound (SMART).

   b. Review data - Plans should be informed by data, including the demographics of service areas, extent of services provided, and the existing geographical coverage areas. Over time, data can be reviewed in concert with measurable objectives established as part of regional plans to monitor progress.
2. **Foster Clinical-Community Linkages**

   Deeper collaborations can be built to extend palliative care both across staff and departments within institutions and beyond out into community settings. As regions explore opportunities for strengthened clinical community linkages, the following next steps could be taken:

   a. **Provider networking** - Relationships can be built among providers as various specialties are connected with interdisciplinary palliative care specialists. Interdisciplinary teams that incorporate community-based providers, such as faith leaders and social workers, can advance this effort.

   b. **Provider and community education** - Both are vital. Synchronizing provider education with public outreach can help ensure that increased demand for palliative care services can be met.

   c. **Connect to Community Health Centers** - CHCs may offer opportunities to serve residents in community-based settings. Existing models can be adapted with guidance from and linkage to existing palliative care organizations.

3. **Extend Partnerships and Collaborations**

   Greater capacity and leveraging of resources arise as regions work to even more fully strengthen their partnerships and collaborative efforts. A number of organizations and individuals can be brought into this process.

   a. **Engage leaders from ethnically diverse groups** - Palliative care can be introduced into the agenda of health equity task forces and multicultural coalitions. Resident advisors and community health workers with connection to the populations being served can be excellent resources.

   b. **Tie in community-based organizations** - Among those working with priority populations that would be appropriate collaborators include senior centers, meals on wheels, housing and fuel assistance, councils on aging, and faith based organizations. Consider which partners are missing from the discussion and conduct listening sessions to explore their perspectives and interests.

4. **Strengthen Statewide Partnerships**

   Statewide progress in promoting palliative care and establishing a supportive context is also poised to be advanced. Next steps include:

   a. **Link agencies** - State aging, healthcare, and anti-poverty agencies are poised to collaborate on unified approaches and resource-sharing with public health organizations.

   b. **Advance partnerships** - Continued and deepened partnerships with statewide initiatives and organizations will reap many benefits as collaboration builds around common goals and results in building synergies, decreasing replication of efforts, and innovating to solve problems such as addressing gaps and overcoming barriers. Included are the MA Coalition Serious Illness, Honoring Choices, Conversation Project, American Cancer Society, Mass Palliative Care and Hospice Federation, Home Care Alliance of Massachusetts, MA Senior Care Foundation.

   a. **Extend service coverage** - As state and private payers exhibit growing interest in palliative care services that can advance the Triple AIM of healthcare reform (improved quality, better outcomes, and reduced costs), the state and its stakeholders can continue to provide advice and guidance. White papers on the importance and benefits, and/or models for implementation are examples.

   b. **Strengthen provider education** - Centralized provider education requirements and opportunities can be explored as a means of enhancing competencies.
VIII. REFERENCES


### Other State Initiatives/Activities

<table>
<thead>
<tr>
<th>Organization</th>
<th>Mission/About Us</th>
<th>Website</th>
<th>Geographic Area</th>
<th>Profit Status</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice &amp; Palliative Care Federation of Massachusetts</td>
<td>To advance and promote excellence in end of life care by: advocating for its members, patients, families and the end-of-life care giving community; providing education and enhancing awareness.</td>
<td><a href="http://www.hospicefed.org/">www.hospicefed.org/</a></td>
<td>State-wide</td>
<td>Non-Profit</td>
<td>Christine McMichael, Executive Director (781) 255-7077 <a href="mailto:info@hospicefed.org">info@hospicefed.org</a></td>
</tr>
<tr>
<td>Massachusetts Coalition for Serious Illness Care</td>
<td>More than sixty Massachusetts-based organizations have come together to form the Massachusetts Coalition for Serious Illness Care. Working at these groups are dedicated physicians, nurses, hospice workers, counselors, clergy, hospital and health plan administrators, social workers, attorneys, policymakers, researchers, and other health professionals. Ultimately, people need to be at the center of discussions with family and others concerning all aspects of their care; Coalition efforts are designed to support these important conversations. Our mission is to ensure that health care for everyone in Massachusetts is in accordance with their goals, values and preferences at all stages of life and in all steps of their care.</td>
<td><a href="http://www.maseriouscare.org/">www.maseriouscare.org/</a></td>
<td>State-wide</td>
<td>Unknown</td>
<td>(none)</td>
</tr>
<tr>
<td>Hospice of Western &amp; Central Massachusetts</td>
<td>To make a lasting difference in the lives of patients diagnosed with a life-limiting illness by enabling them and their loved ones to live each day as fully and comfortably as possible.</td>
<td><a href="http://www.hospiceservicesofma.com/">www.hospiceservicesofma.com/</a></td>
<td>Western &amp; Central Massachusetts</td>
<td>Non-Profit</td>
<td>Pittsfield 413-442-0045; Feeding Hills 413-786-4004</td>
</tr>
<tr>
<td>Mass League of Community Health Centers</td>
<td></td>
<td><a href="http://www.massleague.org/">www.massleague.org/</a></td>
<td>Boston</td>
<td>Non-Profit</td>
<td>617-426-2225 <a href="mailto:massleague@massleague.org">massleague@massleague.org</a></td>
</tr>
<tr>
<td>Home Care Alliance of Massachusetts</td>
<td>The Home Care Alliance of Massachusetts is a non-profit trade association of home care agencies that promotes home care as an integral part of the health care delivery system. Founded in 1969, our mission is to &quot;unite people and organizations to advance community health through care and services in the home.&quot;</td>
<td><a href="http://www.thinkhomecare.org/">www.thinkhomecare.org/</a></td>
<td>State-wide</td>
<td>Non-Profit</td>
<td>Patricia Kelleher, Executive Dir Tel: (617) 482-8830 <a href="mailto:info@thinkhomecare.org">info@thinkhomecare.org</a></td>
</tr>
<tr>
<td>Get Palliative Care</td>
<td>The site provides clear, comprehensive palliative care information for people coping with serious illness. Key features of the site include a Palliative Care Provider Directory of Hospitals, a definition of palliative care, and detailed descriptions of what palliative care does and how to get it. It also provides an interactive quiz to assist you in deciding whether palliative care might be right for you or a loved one. The site is provided by the Center to Advance Palliative Care (CAPC).</td>
<td><a href="http://getpalliativecare.org/">getpalliativecare.org/</a></td>
<td>Nation-wide</td>
<td>Non-Profit</td>
<td>(none)</td>
</tr>
<tr>
<td>Massachusetts Senior Care Foundation</td>
<td>To promote innovative tools, services, programs and research related to clinical and workforce quality across the continuum of care for older adults and people with disabilities</td>
<td><a href="http://www.maseniorcarefoundation.org/">www.maseniorcarefoundation.org/</a></td>
<td>State-wide</td>
<td>Non-Profit</td>
<td>Carolyn Blanks, Executive Director 617-558-0202, 1-800 CARE-FOR <a href="mailto:cblanks@maseniorcare.org">cblanks@maseniorcare.org</a></td>
</tr>
<tr>
<td>Pediatric Palliative Care Network</td>
<td>The goal of the Pediatric Palliative Care Network is to improve the quality of life for families caring for children with life-limiting illness. The Pediatric Palliative Care Network serves the unmet physical, emotional, social and spiritual needs of children in Massachusetts with life-limiting illnesses. Our services are provided at no cost to children 18 years old or younger who have a life-limiting illness.</td>
<td><a href="http://www.mass.gov/eohhs/gov/departments/dph/programs/childrens-health/palliative-care.html">www.mass.gov/eohhs/gov/departments/dph/programs/childrens-health/palliative-care.html</a></td>
<td>Springfield, Plymouth, Brockton/Hyannis, Greenfield, Newton, Pittsfield, Lawrence, Worcester</td>
<td>Non-Profit</td>
<td>1-800-882-1435; 617-624-6060; TTY 617-624-5992 <a href="mailto:Pediatric.palliative.care@state.ma.us">Pediatric.palliative.care@state.ma.us</a></td>
</tr>
<tr>
<td>Ariadne Labs Serious Illness Care Program</td>
<td>The Serious Illness Care program facilitates appropriate conversations between clinicians, seriously ill patients and their families. Drawn from best practices in palliative care, the intervention provides guidance for clinicians to initiate these difficult conversations in the right way, at the right time. Patients then have the opportunity to make informed choices that reflect their values, reduce suffering, enhance family well-being and improve quality of life.</td>
<td><a href="http://www.ariadnelabs.org/areas-of-work/serious-illness-care/">www.ariadnelabs.org/areas-of-work/serious-illness-care/</a></td>
<td>Boston; World-wide</td>
<td>Non-Profit</td>
<td>617-384-6555</td>
</tr>
<tr>
<td>Honoring Choices Project</td>
<td>Their mission is to improve access to health care planning and person-centered care throughout the Commonwealth. Honoring Choices empowers adults to make a personal health care plan and connect to the best possible care that honors their values and choices, all through their lives.</td>
<td><a href="http://www.honoringchoicesmass.com/">www.honoringchoicesmass.com/</a></td>
<td>Lincoln</td>
<td>Non-Profit</td>
<td>Ellen DiPloa, President &amp; CEO (781) 642-0454 <a href="mailto:ediploa@honoringchoicesmass.com">ediploa@honoringchoicesmass.com</a></td>
</tr>
<tr>
<td>Specialty Service Providers</td>
<td>Their mission is helping people talk about their wishes for end-of-life care.</td>
<td><a href="http://theconversationproject.org/">http://theconversationproject.org/</a></td>
<td>Nation-wide</td>
<td>Non-Profit</td>
<td>(617) 301-4868 <a href="mailto:conversationproject@IHI.org">conversationproject@IHI.org</a></td>
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<td>Salmon VNA &amp; Hospice</td>
<td>To help families achieve their best quality of life - senior living and healthcare communities.</td>
<td><a href="http://www.salmonhealth.com/home-care-and-hospice/">http://www.salmonhealth.com/home-care-and-hospice/</a></td>
<td>Central Massachusetts</td>
<td>For-Profit</td>
<td>1-800-446-8060; (508) 366-3662</td>
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<tr>
<td>SeniorLink / Caregiver Homes</td>
<td>Committed to continually pioneering solutions that bring together knowledge, human touch and innovation to transform the caregiving experience. At SeniorLink, they stand with the Caregiver Nation, honoring caregivers and their families and ensuring they will never be alone on their daily journey of providing compassionate care.</td>
<td><a href="http://www.seniorlink.com/">http://www.seniorlink.com/</a></td>
<td>State-wide; RI, CT, LA, IN, OH</td>
<td>For-Profit</td>
<td>866-797-2333 <a href="mailto:info@seniorlink.com">info@seniorlink.com</a></td>
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<td>VNA Hospice Care</td>
<td>Their mission to provide the right care with kindness and compassion every day for every person they serve.</td>
<td><a href="http://vnacare.org/">http://vnacare.org/</a></td>
<td>Hospice: Cambridge, Needham, Worcester; Clinical: multiple locations</td>
<td>Non-Profit</td>
<td>800-521-5399 <a href="mailto:info@vnab.org">info@vnab.org</a></td>
</tr>
<tr>
<td>Hebrew Senior Life (HSL)</td>
<td>Their mission is to honor our elders, by respecting and promoting their independence, spiritual vigor, dignity and choice, and by recognizing that they are a resource to be cherished. Non-profit, non-sectarian organization that has provided communities and health care for seniors, research into aging, and education for geriatric care providers since 1903. With nearly 2,600 employees aligned around a common mission, goals and cultural beliefs, they are one of the largest employers in Massachusetts. Cares for 3,000 seniors a day at our nine Boston area campuses and communities. They reach out to many more seniors, families, caregivers and senior care professionals around the U.S. and the world through our research and teaching mission.</td>
<td><a href="http://www.hebrewseniorlife.org/hospice">http://www.hebrewseniorlife.org/hospice</a></td>
<td>Roslindale, Canton, Dedham, Randolph, Brookline, and Revere</td>
<td>Non-Profit</td>
<td>617-363-8000; 781-234-9950</td>
</tr>
<tr>
<td>UMass Memorial Medical Center</td>
<td>UMass Memorial Medical Center is the region’s trusted academic medical center, part of the UMass Memorial Health Care system. They are committed to improving the health of people in Central Massachusetts through excellence in care, comprehensive health services, teaching and research. Pediatric Palliative Care: A life-limiting illness in a family is difficult for everyone involved. When it is your child who has one, you need support and care to help you through the challenges. To meet your needs, UMass Memorial Children’s Medical Center offers pediatric palliative care services. The program offers services to meet the physical, emotional and spiritual needs of children with life-limiting illnesses and their families.</td>
<td>ADULT: <a href="https://www.umassmemorialhealthcare.org/umassmemorial-medical-center/services-treatments/cancer-care/services-we-provide/palliative-care">https://www.umassmemorialhealthcare.org/umassmemorial-medical-center/services-treatments/cancer-care/services-we-provide/palliative-care</a>, PEDIATRIC: <a href="https://www.umassmemorialhealthcare.org/umassmemorial-medical-center/services-treatments/childrens-medical-center/2-list-pediatric-services/palliative-care">https://www.umassmemorialhealthcare.org/umassmemorial-medical-center/services-treatments/childrens-medical-center/2-list-pediatric-services/palliative-care</a></td>
<td>Central Massachusetts</td>
<td>Non-Profit</td>
<td>866-597-HOPE (4673); 855-UMASS-MD</td>
</tr>
<tr>
<td>Seasons Hospice &amp; Palliative Care of MA</td>
<td>Community-based organization on an ongoing mission to find creative solutions which add quality to life. They believe firmly in the patient/family focus of hospice care, recognizing that individuals and families are the experts in their own care. Counties Served: Essex, Middlesex, Norfolk, Plymouth, Suffolk.</td>
<td><a href="http://www.seasons.org/">http://www.seasons.org/</a></td>
<td>Counties: Essex, Middlesex, Norfolk, Plymouth, Suffolk</td>
<td>For-Profit</td>
<td>866-670-9449; 855-812-1136 <a href="mailto:info@seasons.org">info@seasons.org</a></td>
</tr>
<tr>
<td>Care Dimensions</td>
<td>Care Dimensions enriches quality of life for those affected by life-limiting illness, death and loss by providing exceptional care, support, education and consultation. At the essence of Care Dimensions is a set of core values that sustain our mission to serve and our commitment to evolve with the changing needs of the communities. These values are: Compassion, excellence, collaboration, integrity, responsiveness, and innovation.</td>
<td><a href="http://www.caredimensions.org/index.cfm">http://www.caredimensions.org/index.cfm</a></td>
<td>Eastern Massachusetts</td>
<td>Non-Profit</td>
<td>888-283-1722</td>
</tr>
<tr>
<td>HopeHealth</td>
<td>To enhance the quality of life for people experiencing serious illness and loss and to provide compassionate and high quality care to those diagnosed with a serious illness and their families.</td>
<td><a href="http://www.hopehealthco.org/">http://www.hopehealthco.org/</a></td>
<td>MA: Middlesex, Suffolk, Norfolk, Bristol, Plymouth, Dukes, Barnstable, Nantucket Counties; Rhode Island</td>
<td>Non-Profit</td>
<td>401-415-4200; 800-642-2423 <a href="mailto:Information@HopeHealthCo.org">Information@HopeHealthCo.org</a></td>
</tr>
<tr>
<td>Beacon Hospice</td>
<td>The mission is focused on our commitment to the cornerstone philosophies: (1) We will regard each team member professionally, respectfully and with sensitivity, (2) We will plan and provide care through the process of the interdiscipliary team, (3) We will develop and provide innovative, state of the art care, (4) We will provide care in a fiscally responsible manner, and (5) We will work to increase access to end-of-life care.</td>
<td><a href="http://www.beaconhospice.org/why_beacon/philosophy_mission.php">http://www.beaconhospice.org/why_beacon/philosophy_mission.php</a></td>
<td>MA: Boston, Beverly, Fall River, Hyannis, Leomoinster, Methuen, Plymouth, Springfield, CT, NH, RI, ME</td>
<td>For-Profit</td>
<td>877-242-8394</td>
</tr>
<tr>
<td>Hospice Services of Massachusetts</td>
<td>To make a lasting difference in the lives of patients diagnosed with a life-limiting illness by enabling them and their loved ones to live each day as fully and comfortably as possible.</td>
<td><a href="http://www.hospiceservicesofma.com/">http://www.hospiceservicesofma.com/</a></td>
<td>Eastern Massachusetts</td>
<td>Non-Profit</td>
<td>Everett: 617-881-7015, Wareham: 508-291-0049; Haverhill: 978-914-6312</td>
</tr>
</tbody>
</table>
**Background:** A literature search was conducted in January 2017 regarding the use of major advance care planning (ACP) tools, including *The Serious Illness Conversation Guide, The Conversation Project, Honoring Choices, Respecting Choices*, and articles authored by Angelo Volandes or about his intervention videos. Additional search terms included *advance care planning, outcomes, evaluation, and disparities*. The research question guiding the literature search was, “What is the outcomes evidence of the effectiveness of any of these tools (including by various ethnic/racial groups)?” The search returned more than 100 articles, but this final table represents 17 articles which addressed specific effectiveness from using advance care planning tools (e.g. increased ACP knowledge, lower medical costs, better/improved quality of life, decreased medical interventions).

<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
<th>Journal &amp; Year</th>
<th>Main Points (organized by patient population, method, and key findings)</th>
<th>Tool</th>
</tr>
</thead>
</table>
| 1 Randomized, Controlled Trial of an Advance Care Planning Video Decision Support Tool for Patients With Advanced Heart Failure | El-Jawahri A, Paasche-Orlow MK, Matlock D, et al. | Circulation (2016) | • English-speaking heart failure patients 64 or older, likelihood of death within 2 yrs  
• Randomized controlled trial comparing a video decision aid and checklist to verbal information only  
**Key Findings:**  
• Intervention group preferred less intensive curative treatment (p< 0.0001):  
  o 22% of controls vs. 41% of intervention group preferred life-prolonging care  
  o 25% vs. 22% limited care, 51% vs. 30% comfort care, 2% vs. 7% unsure  
• Intervention group  
  o less likely to choose CPR (68% vs. 35%, p < 0.001)  
  o less likely to choose intubation (77% vs. 48%, p < 0.001)  
  o higher mean knowledge score (4.1 vs. 3.0, p < 0.001) | Video Decision Aid, ACP Checklist |
| 2 Use of Video Decision Aids to Promote Advance Care Planning in Hilo, Hawai‘i | Volandes AE, Paasche-Orlow MK, Davis AD, et al. | The Journal of General Internal Medicine (2016) | • Racially, ethnically, and linguistically diverse population of adult hospital in-patients with late-stage disease; all adult outpatients 75 or older  
• Pre/post design and comparison to comparable health care markets for a multi-lingual video intervention designed to complement ACP patient-provider discussions  
**Key Findings:**  
• Increased ACP documentation (p < 0.001):  
  o Increased from 3.2% to 39.9% for late-stage disease adults in hospital  
  o PCPs had higher rates than control region for outpatients 75 or older (37.0% vs. 25.6%, p < 0.001)  
• Increased use of hospice (p < 0.001)  
  o Rate of discharge from hospital to hospice increased from 5.7% to 13.8%  
  o Rate of discharge to hospice grew faster than control region (p < 0.01)  
• Decreased cost to insurance compared to control region  
  o Average total insurance cost was $3,498 lower ($3,051 - $3,865 95% CI) | Video Decision Aid |
• Secondary analysis of data from a randomized trial comparing a SPIRIT intervention to care as usual for end-of-life (EOL) care  
**Key Findings:**  
• Improved EOL care outcomes 2-months post for African Americans only | Sharing Patient’s Illness Representations to Increase Trust (SPIRIT) |
| Surrogates | 4 Advance Care Planning Meets Group Medical Visits: The Feasibility of Promoting Conversations | Lum HD, Jones J, Matlock DD, et al. | Annals of Family Medicine (2016) | • Patients 65 or older in geriatric clinics, mostly white and female  
• Pre/post design and qualitative study of facilitated group visits about ACP, using the Conversation Starter Kit and PREPARE videos  
**Key Findings:**  
• Increased patient-family ACP discussions  
  o 75% reported having general or detailed ACP discussions with family  
  o Detailed ACP discussions increased after participating (19% to 41%, p = 0.02)  
• Patients found group visits to be comfortable and effective  
| Group Medical Visits, The Conversation Starter Kit, Videos from PREPARE website |  

| 5 Process and impact of an advance care planning intervention evaluated by bereaved surrogate decision-makers of dialysis patients. | Song MK, Metzger M, Ward SE. | Palliative Medicine (2016) | • 24 White and African American bereaved surrogates of dialysis outpatients  
• Qualitative interviews and thematic analysis to assess SPIRIT intervention  
**Key Findings:**  
• Patients felt SPIRIT facilitated EOL discussions  
• Effects:  
  o Surrogates gained understanding about patient and knowledge of ACP  
  o Strengthened relationships between patients and surrogates  
  o Surrogates felt prepared for EOL decisions  
  o Surrogates felt more peaceful during and after EOL decisions  
  o African Americans reported feeling prepared and peaceful more frequently  
| Sharing Patient's Illness Representations to Increase Trust (SPIRIT) |  

• Pooled data from 10 randomized clinical trials on video decision aids  
**Key Findings:**  
• Patients were less likely to want CPR  
  o Pooled risk ratio, 0.50 (95% CI 0.27 to 0.95); I²=65%, p = 0.01  
• Patients had improved knowledge of ACP  
  o Standardized mean difference, 0.58 (95% CI: 0.38 to 0.77); I² = 0%, p = 0.99  
| Video Decision Aid |  

| 7 Evaluation of an advance care planning education programme for nursing homes: A Longitudinal Study | Baron K, Hodgson A, Walshe C. | Nurse Education Today (2015) | • Nurses and medical assistants at 12 English nursing homes  
• Pre/post design for ACP staff education intervention  
**Key Findings:**  
• Staff knowledge improved  
<p>| Staff Training |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Authors</th>
<th>Journal/Publication Year</th>
<th>Key Findings</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 Evaluating the systematic Implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: staffs perspectives</td>
<td>Cornally N, McGlade C, Weathers E, et al.</td>
<td>BMC Palliative Care (2015)</td>
<td>• 17 staff interviewed from 3 nursing homes in Ireland</td>
<td>'Let Me Decide' ACP Program</td>
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<td>• Qualitative: 3 focus groups were conducted with 2-8 participants each, using a semi-structured topic guide and textual analysis to assess 'Let Me Decide' intervention</td>
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<td>Key Findings:</td>
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<td>• Effects:</td>
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<td></td>
<td>o Improved morale</td>
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<td>o Intervention facilitated conversation</td>
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<td>• Recommendations:</td>
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<td>o Involve junior staff</td>
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<td>o Apprise family about ACP upon admission</td>
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<td>• Barriers:</td>
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<td>o Time-consuming</td>
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<td>o Assessing residents' capacity to complete ACP</td>
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<td>• Pre/post prospective study assessing the effects of ADs, DPAs, and LWs on quality of last week of life</td>
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<td>Key Findings:</td>
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<td></td>
<td>• DNRs were associated with higher quality of life (ß = 0.75, p = 0.01)</td>
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<td>• DNRs were associated with $3,004 lower costs during last week of life (p = 0.005)</td>
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<td>• DNRs were associated with higher quality of life (ß = 0.75, p = 0.01)</td>
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<td>• Living wills and DPAs were not significantly associated with any outcomes</td>
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<tr>
<td>10 Evaluation of advance directives video education for patients</td>
<td>Toraya C.</td>
<td>Journal of Palliative Medicine (2014)</td>
<td>• 45 adult patients 18 or older, mostly outpatients</td>
<td>Video Decision Aid</td>
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<td></td>
<td>• Pre/post design for video intervention</td>
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<td>Key Findings:</td>
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<td>• Increased desire to complete an AD (78.6%, no significance testing reported)</td>
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<td>• Patients felt they had enough information to have discussions &amp; complete forms</td>
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<td>• Video was highly rated (8.8 of 10, no significance testing reported)</td>
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<td>• Pre/post retrospective study using medical records to test the effect of a physician order-to-withhold-care form and palliative care consult (2007 vs. 2010)</td>
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<td>Key Findings:</td>
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<td>• Decrease in burdensome interventions:</td>
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<td>o Decreased use of antibiotics (44.9% to 24.9%, p &lt; 0.05)</td>
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<td>o Increased orders to withhold CPR (66.2% to 80.0%, p &lt; 0.001)</td>
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<td>• Use of order form associated with</td>
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<td>Key Findings</td>
<td>Studies</td>
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<td>• Increased discussion of CPR</td>
<td>Lyon ME, Jacobs S, Briggs L, et al.</td>
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<td>• Palliative consult associated with</td>
<td>Journal of Adolescent Health (2014)</td>
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<td>o Less maintenance intravenous fluids (OR = 0.77)</td>
<td>• 30 adolescents, ages 14-20, with cancer and their families</td>
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<td>o Less tube feeding (OR = 0.45)</td>
<td>• Randomized controlled trial to test a pediatric ACP intervention, FACE-TC, on 3-month outcomes</td>
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<td>o Less antibiotics (OR = 0.46) ... in last 24 h of life</td>
<td>• Tools used to assess the intervention:</td>
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<td>• Palliative consult associated with</td>
<td>o Pediatric Quality of Life Inventory 4.0 Generic Core Scale</td>
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<tr>
<td>o Less maintenance intravenous fluids (OR = 0.54) ... in last 24 h of life</td>
<td>o Pediatric Quality of Life Inventory 4.0 Cancer-Specific Module</td>
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<td>• Increased discussion of CPR</td>
<td>o Beck Depression and Anxiety Inventories</td>
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<td>o With patients (4.6% to 10.2%, p = 0.002)</td>
<td>o Spiritual Well-Being Scale of the Functional Assessment of Chronic Illness Therapy-IV</td>
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<td>o With family (56.5% to 79.8%, p &lt; 0.001)</td>
<td>• AD completion</td>
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<td>12 A longitudinal, randomized, controlled trial of advance care planning for teens with cancer: anxiety, depression, quality of life, advance directives, spirituality</td>
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<td>13 A novel website to prepare diverse older adults for decision making and advance care planning: a pilot study.</td>
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<td>o DNR order (OR = 11.90)</td>
<td>• English-speaking, very diverse, low-income adults 60 or older</td>
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<td>o Less tube feeding (OR = 0.68)</td>
<td>• 1 week pre/post design to assess the effects of the website prepareforyourcare.org on thinking about and engaging in ACP</td>
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<td>o Less maintenance intravenous fluids (OR = 0.77)</td>
<td>• Thinking about ACP increased (p &lt; 0.001)</td>
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<td>• Palliative consult associated with</td>
<td>o More patients looked for, thought about, and remembered ACP information</td>
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<tr>
<td>o Less maintenance intravenous fluids (OR = 0.54) ... in last 24 h of life</td>
<td>o More patients reviewed their ACP documents (p = 0.008)</td>
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<td>• Increased discussion of CPR</td>
<td>o Patients felt more committed to doing ACP (p = 0.005)</td>
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<td>o With family (56.5% to 79.8%, p &lt; 0.001)</td>
<td>o More patients thought about or talked to their doctor (29% to 65%, p &lt; 0.003)</td>
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<tr>
<td>• Palliative consult associated with</td>
<td>• Website was well-received</td>
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</table>
Key Findings:

• ACP documentation increased
  o 40% video arm vs. 15% control arm (OR = 3.6, [95% CI: 0.9-18.0], p = 0.07)

Key Findings:

14 A randomized controlled trial of a cardiopulmonary resuscitation video in advance care planning for progressive pancreas and hepatobiliary cancer patients

Epstein AS, Volandes AE, Chen LY, et al.


- 56 patients with pancreas or hepatobiliary cancer
- Randomized control trial comparing educational CPR video to CPR verbal information and pre/post comparison

Key Findings:

- ACP documentation increased
  o 40% video arm vs. 15% control arm (OR = 3.6, [95% CI: 0.9-18.0], p = 0.07)
- Knowledge increased in both groups
- Preferences for CPR changed in the video group
- Preferences for mechanical ventilation did not change in either group
- More video group patients died in hospice settings
- Video was reported to be helpful and comfortable to discuss

Multimedia decision support intervention: a promising approach to enhance the intention to complete an advance directive among hospitalized adults

Hickman RL Jr, Lipson AR, Pinto MD, et al.

Journal of the American Association of Nurse Practitioners (2013)

- Convenience sample of English-speaking adult hospital patients 50 or older who had required acute mechanical ventilation for a brief period
- Comparative quasi-experimental posttest design comparing a multimedia intervention (video and interactive component) and brochure

Key Findings:

- Multimedia was more acceptable than the brochure (p = 0.03)
  o Multimedia helpfulness score of 8.11 vs. 5.80 for the brochure
- Multimedia patients were 24.7 times more likely to intend to complete an AD
- White patients were 7.28 times more likely to intend to complete an AD after adjusting for age and group assignment (p = 0.049)

The impact of advance care planning of place of death, a hospice retrospective cohort study


British Medical Journal Supportive and Palliative Care (2013)

- Adult patients with life-limiting disease in England, 57% having ACPs
- Retrospective observational cohort study looking at patients who died in a 2.5 year span to assess impact of having an ACP

Key Findings:

- 75% of patients with an ACP died in their chosen location (home, hospital, etc)
- ACP patients spent fewer days in hospital during last year of life (p < 0.001)
  o 18.1 days vs. 26.5 days for non-ACP patients
- Patients who died in hospital
  o Had more ER admissions (2.2 vs 1.7, p < 0.001)
  o Had higher medical costs (£11,299 vs £7,730, p < 0.001)

Augmenting Advance Care Planning in Poor Prognosis Cancer With a Video Decision Aid

Volandes AE, Levin TT, Slovin S, et al.

Cancer (2011)

- English-speaking adult patients with advanced terminal cancer
- Pre/post design to test the effects of an educational video on goals of care (life-prolonging care, basic care, comfort care)

Key Findings:
• Patients wanted fewer interventions after the video
  o Fewer patients wanted CPR (71% vs. 62%, p = 0.03)
  o Fewer patients wanted ventilation (80% vs. 67%, p = 0.008)
• Patient knowledge of goals of care increased (p < 0.001)
Appendix 3: Key Informant Interview Cover Letter and Guide
November, 2016

To: Regional Palliative Care Subgroup Members

JSI Research and Training Institute, Inc. (JSI) has been contracted by the Massachusetts Department of Public Health to assist the Massachusetts Comprehensive Cancer Prevention and Control Network’s Palliative Care Workgroup to identify gaps in palliative care across the state in order to promote collaborative partnerships that will increase the development of and access to palliative care services in the state, especially among members of cultural and geographic disparate populations. There is a special emphasis on community-based models of palliative care.

An initial assessment conducted by the state in 2014-2015 revealed a general lack of understanding of what palliative care is, who provides it, how and when to refer to palliative care, and how palliative care is reimbursed, especially for non-physician based services. These were among other findings presented at regional forums across the state in 2015-2016. As a result of the forums, several regional subgroups (Western MA, Central MA, Northeast/Metrowest, Southern MA and Cape and Islands) have started to meet to prioritize action steps for their particular region.

To further understand and support palliative care delivery networks at a regional level, JSI is conducting interviews with key stakeholders to identify:

1. The nature and extent of palliative care services (non-hospice services) in the region.
2. How “community-based” palliative care is defined and delivered; what local collaborations exist and how palliative care patients access local services in their community.
3. Promising community-based palliative care practices that offer examples and recommendations for partnership development statewide.

We are requesting recommendations of key stakeholders in your region who would be able to provide the information referenced above. We are aiming to conduct 8-10 interviews per region with an emphasis on learning more about provision of community-based palliative care. These stakeholders may be current regional subgroup members or those who are:
- Palliative care providers (community based providers such as home health agencies, hospices, clinics, or independent practices) or hospital based programs who serve the community
- Faith-based Organizations
- Nursing homes
- Adult day care
- Senior centers
- Community health centers
- Home health agencies
- Cancer Support Groups
- Visiting nurse organizations

Please contact Jocelyn Chu, Project Manager at 617-482-9485 or Jocelyn_Chu@jsi.com with your suggestions or any questions you may have.
**Introduction**

JSI Research and Training Institute, Inc. (JSI) has been contracted by the Massachusetts Department of Public Health to assist the Massachusetts Comprehensive Cancer Prevention and Control Network’s (MCCPCN) Palliative Care Workgroup to identify gaps in palliative care across the state in order to promote collaborative partnerships that will increase the development of and access to palliative care services in the state, especially among members of cultural and geographic disparate populations. There is a special emphasis on community-based models of palliative care.

An initial assessment conducted by the state in 2014-2015 revealed a general lack of understanding of what palliative care is, who provides it, how and when to refer, and how palliative care is reimbursed, especially for non-physician based services. These were among other findings presented at regional forums across the state in 2015-2016. As a result of the forums, several subgroups have started to meet to prioritize action steps for their region (Northeast/Metrowest, Western MA, Southern MA, Central MA, Cape and Islands).

To further understand and support community-based palliative care delivery networks at a *regional* level, JSI is conducting interviews with key stakeholders to identify:

1. The nature and extent of palliative care services (non-hospice services) in the region.
2. How “community-based” palliative care is defined and delivered; what local collaborations exist and how palliative care patients access local services in their community.
3. Promising community-based palliative care practices that offer examples and recommendations for partnership development statewide.

Your individual information and responses will be kept confidential and information will only be reported at an aggregate level, so please feel comfortable to give open and honest responses. Findings will go to the MCCPCN Palliative Care work group. The findings from these interviews will help to direct future activities and resources to support access throughout Massachusetts to palliative care programs.

This interview should take approximately 30 minutes to complete. We would like your permission to record this interview. Recording will be used to accurately report the information you provide throughout the interview and will not be shared with anyone beyond the JSI team responsible for these interviews.

If you have questions, please contact Jocelyn Chu at Jocelyn_chu@jsi.com. Thank you for your participation!

Are there any questions before we begin?
Questions

I. Background information – palliative care in your region
   a. Describe your organization and your role in the organization.

   b. What type of palliative care services, if any, are provided by your organization?
      
      Probe: Complex pain and symptom management, counseling, advance care planning, medication management, discharge planning, assumption of care

   c. What are the demographic characteristics of palliative care patients in your organization?
      
      Probe: Are the demographic characteristics of palliative care patients similar to those of other organizations in the region?

   d. What (other) organizations are providing palliative care in your region?

II. Community-based palliative care
   We are especially interested in learning more about community-based models of palliative care.
   a. How would you define “community-based palliative care”?

   Community-based palliative care has been defined as services offered to a patient within their local area which includes a patient’s residence (senior housing, group housing, and assisted living facilities), a clinic, or long term care facility (skilled facility or nursing home). It does not include services under the Medicare Hospice Benefit or the Medicare Home Health Benefit or hospital-based programs.

   b. Thinking about this definition of community-based palliative care, what are some examples of models of community-based palliative care in your region?
      
      i. Who are the community-based palliative care providers in your region?
      ii. Who are appropriate patients for community-based palliative care in your region?
         o How are patients identified?
         o How and when does palliative care begin for patients?
      iii. What types of services are offered?
      iv. How are services structured, where are patients seen?
      v. Describe the referral processes in this community-based network.
      vi. Describe how providers collaborate and partner with others.

   c. Stepping back from what you have just described, do you feel like it is working overall? Where are the gaps?
III. Reflections about Palliative Care in your region

Thinking about palliative care services in your region, in general:

a. What are some facilitators and barriers for people who seek palliative care services? In other words, what makes access to palliative care easy for some patients and more difficult for others?

Probe: How do care providers learn about palliative care services in your region?
Probe: How do patients, families, and the public learn about palliative care services in your region?

b. What is needed to reduce barriers to individuals in need of palliative care?

c. Are there particular groups of people for whom access tends to be more difficult based on insurance, location, culture or language needs?

d. What is being done, at your organization or by other groups or organizations that you’re aware of, to overcome these barriers?

Probe: Are you aware of any statewide advocacy groups working to reduce these barriers?
Probe: Are you aware of any government groups working to reduce these barriers?

IV. Next Steps

a. As you think about next steps in addressing access to quality palliative care for individuals in your area, who else should be included in the regional efforts to improve palliative care services in the region?

b. Are you involved with or have knowledge of current state initiatives/activities related to serious illness, advance care planning, end of life or palliative care? Please describe.

c. Can you recommend any helpful resources, tools or literature that has been helpful in your work?

d. Our next phase of the assessment is to conduct a survey of palliative care services in the region to learn about their needs/barriers. Can you provide recommendations for who we can send this survey to?
Appendix 4: List of Organizations of Key Informants

State Level
- Atrius Health
- Boston Archdiocese
- Home Care Alliance of Massachusetts
- MA Pediatric Palliative Care Network
- Tufts Health Plan

Western Massachusetts
- Baystate Medical Center
- Brightwood Health Center
- Commonwealth Care Alliance
- Cooley Dickinson Hospital
- Hospice Care in the Berkshires
- Hospice of Franklin County
- Mercy Hospice
- Mercy Hospital
- Mercy Life (part of the PACE program)

Central Massachusetts
- Central MA Area Aging Agency
- Community Action (Quabbin area; Franklin and Hampshire Counties)
- Gardner VNA
- Heywood and Athol Hospitals
- Montachusett Healthcare
- UMass Memorial Hospital
- VNA of Southern Worcester County

Southeastern Massachusetts
- Cape Cod QOL Coalition
- Good Samaritan Medical Center
- Hope Health
- Norwell VNA and Hospice
- Southcoast Hospital
- St. Anne’s (Steward Homecare)

Northeastern Massachusetts & Metrowest
- Care Dimensions
- Greater Lawrence Family Health Center
- Hallmark Health VNA and Hospice
- Lahey Hospital & Medical Center, Palliative Care Service
- Merrimack Valley Hospice and Palliative Care
- Tufts Medical Center, Palliative Care Service
- VNA and Hospice of Middlesex East
- VNA Care
- Winchester Hospital, Oncology Service
Appendix 5: Complete List of Maps
West Region Map of Identified Palliative Care Service/Office Locations

West Region Map of Other Community Resource Locations

*Note: Many Service locations will offer multiple overlapping services. Categories are based first on facility type (i.e. Hospital) and second on organizational name (i.e. VNA).

Date: 5/25/2017

Date: 3/20/2017
West Region Map of Palliative Care Locations and Percent of Population 65 or Older

Central Region Map of Identified Palliative Care Service/Office Locations
Central Region Map of Other Community Resource Locations

Central Region Map of Palliative Care Locations and Population Density

Date: 3/20/2017

Central Region Map of Palliative Care Locations and Population Density

Date: 5/25/2017
Southeast Region Map of Identified Palliative Care Service/Office Locations

Southeast Region Map of Other Community Resource Locations
Southeast Region Map of Palliative Care Locations and Population Density

Southeast Region Map of Palliative Care Locations and Limited English Proficiency
Southeast Region Map of Palliative Care Locations and Percent of Population 65 or Older

Northeast/Metrowest & Boston Map of Identified Palliative Care Service/Office Locations

*Note: Many Service locations will offer multiple/overlapping services. Categories are based
first on facility type (i.e. Hospital) and second on organizational name (i.e. VNA).

% Age 65+ Population**
- 9%
- 10% - 14%
- 15% - 19%
- 20% - 25%
- 30% - 41%


Date: 5/25/2017
Northeast/Metrowest & Boston Map of Other Community Resource Locations

Northeast/Metrowest & Boston Map of Palliative Care Locations and Population Density
Northeast/Metrowest & Boston Map of Palliative Care Locations and Population 65 or Older