



University of  
Massachusetts  
UMASS Medical School

# MA Expert Panel on End of Life Report

Looking Forward: 2014 and Beyond



Presented by: **UMass Medical School**  
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## Table of Contents

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|  |            |
|--|------------|
| 1. <b>Executive Summary</b> .....  | page 2     |
| 2. <b>Introduction</b> .....   | page 4     |
| 3. <b>Massachusetts 2014 End of Life Summit Action Plan</b> .....                                    | page 6     |
| 4. <b>Massachusetts End of Life Expert Panel Report 2014 Update:</b><br>Recommended Next Steps ..... | page 17    |
| 5. <b>Appendices</b> .....   | page 18-34 |
| a. MA End of Life Summit Participants .....  | page 18    |
| b. Description of Process to Update 2010 Expert Panel Report .....                                   | page 19    |
| c. Results of Process to Update 2010 Expert Panel Report .....                                       | page 21    |
| d. MOLST Statewide Expansion .....   | page 26    |
| e. MOLST Evaluation Report Executive Summary .....   | page 27    |
| f. MOLST Committee Membership .....  | page 28    |
| g. End of Life/Palliative Care Policy-Related Activities in Massachusetts and Other States . . . .   | page 30    |

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## Executive Summary

**As part of the Commonwealth's overall effort at health care reform, Chapter 305 of the MA Acts of 2008 included several provisions regarding end of life care. Specifically, Section 41 of Chapter 305 mandated the convening of an expert panel on end of life care to:**

- investigate and study health care delivery for patients with serious chronic illness and variations in delivery of care among health care providers in MA;
- identify best practices for end of life care, including those that minimize disparities; and
- present recommendations for any legislative, regulatory, or other policy changes necessary to implement its recommendations. (M.G.L. Chapter 305 of the Acts of 2008, Section 41)

In 2010, a panel of forty-three Massachusetts end of life and palliative care experts and advocates produced the Massachusetts Expert Panel on End of Life Care Report *"Patient-Centered Care and Human Mortality: The Urgency of Health System Reforms to Ensure Respect for Patients' Wishes and Accountability for Excellence in Care."* (See Panel Report: <http://molst-ma.org/sites/molst-ma.org/files/2010ExpPanRep.pdf>.)

Section 103 of Chapter 224 of the Acts of 2012 continued the focus to improve care at the end of life. In 2014 the MA Department of Public Health (DPH) requested that Commonwealth Medicine at the University of Massachusetts Medical School update the 2010 Expert Panel Report and re-establish priorities for end of life care.

### 2010 Report Recommendations

**The 2010 Report issued six major recommendations to address deficiencies and inconsistencies in end of life care identified in Massachusetts:**

1. Inform and Empower Residents of Massachusetts.
2. Support a Health Care System that Ensures High Quality Patient-Centered Care.
3. Ensure a Knowledgeable, Competent, and Compassionate Workforce.
4. Create Financing Structures that Promote Patient-Centered Care.
5. Create a Responsible Entity to Ensure Excellence and Accountability.
6. Employ Quality Indicators and Performance Measurement.

### 2014 Report Update

**To update the report, the following approach was implemented:**

1. Conduct a brief survey among MA end of life and palliative care experts regarding the status of the six major recommendations in the 2010 Report.
2. Conduct key informant interviews with a smaller group of end of life and palliative care experts regarding the 2010 recommendations.
3. Use findings from the survey and interviews to inform a discussion for creating an action plan at the 2014 MA End of Life Summit held on April 9, 2014.
4. Submit to MA DPH an updated report incorporating findings from these activities and a suggested action plan.

This report provides a brief snapshot of end of life care activity in Massachusetts since the 2010 report, identifies related themes and trends in MA health care institutions, and conveys current concerns and priorities for improving end of life care in the Commonwealth.

## 2014 Plan for Action

**An action plan was developed for each of the 2010 recommendations. To summarize, the action plan for:**

- **Recommendation 1** seeks to secure organizational and funding resources as soon as possible to develop and implement a public awareness campaign in MA about advance care planning, palliative care, and end of life options.
- **Recommendation 2** seeks to ensure that patients are engaged in advance care planning, and that health care professionals have access to tools and processes that will prepare them to communicate competently and compassionately with patients in the health care setting.
- **Recommendation 3** seeks to identify professional palliative care and end of life care educational resources in MA institutions; and to establish core competencies and build capacity and accountability for – communication between patients, families, and health care providers.
- **Recommendation 4** seeks to develop and disseminate among MA health care institutions and other stakeholders billing and financial system modifications to support and optimize patient-centered palliative care and end of life care in MA.
- **Recommendation 5** seeks to create and secure funding for a recognized entity with broad stakeholder support responsible for ensuring excellence and accountability in palliative care and end of life care in MA.
- **Recommendation 6** seeks to determine and define relevant measures for palliative care and end of life care in various clinical care settings, and to establish state benchmarks for high quality care.

## Next Steps

It is crucial that the public become aware of available options for palliative care and end of life care as stated in Recommendation 1. Care and treatment decisions made by an informed and empowered public will result in greater concordance between the expressed preferences of patients and the care that is actually provided. This was identified as the highest priority by survey respondents.

Steps toward ensuring improvements in end of life care in Massachusetts must be addressed interdependently. To accomplish this, a coordinating mechanism needs to be in place that has both the authority and the resources to promote implementation of the recommendations, disseminate best practices, and support efforts to measure performance improvements. Creating a responsible entity to ensure excellence and accountability is a matter of urgency because without it, the other recommendations are not likely to be successfully navigated and coordinated throughout the Commonwealth. For this reason, the implementation of Recommendation 5 deserves prompt attention, which will allow other improvements to follow.

## Introduction

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### Background

**In 2008 the Massachusetts Legislature passed Chapter 305 of the Acts of 2008, which included several provisions regarding end of life care in the Commonwealth. Section 41 of Chapter 305 mandated the convening of an expert panel on end of life care to:**

- Investigate and study health care delivery for patients with serious chronic illness and the variations in delivery of care among health care providers in MA;
- Identify best practices for end of life care, including those that minimize disparities; and
- Present recommendations for any legislative, regulatory, or other policy changes necessary to implement its recommendations. (M.G.L. Chapter 305 of the Acts of 2008, Section 41)

To that end, a panel of forty-three Massachusetts end of life and palliative care experts and advocates met during 2009. The outcome of these efforts was the 2010 Massachusetts Expert Panel on End-of-Life Care Report *“Patient-Centered Care and Human Mortality: The Urgency of Health System Reforms to Ensure Respect for Patients’ Wishes and Accountability for Excellence in Care.”* (See Panel Report: <http://molst-ma.org/sites/molst-ma.org/files/2010ExpPanRep.pdf>.)

**The report issued six major recommendations and numerous specific steps to address deficiencies and inconsistencies in end of life care identified in Massachusetts. The recommendations included:**

- **Recommendation 1:** *Inform and Empower Residents of Massachusetts*
- **Recommendation 2:** *Support a Health Care System that Ensures High Quality Patient-Centered Care*
- **Recommendation 3:** *Ensure a Knowledgeable, Competent, and Compassionate Workforce*
- **Recommendation 4:** *Create Financing Structures that Promote Patient-Centered Care*
- **Recommendation 5:** *Create a Responsible Entity to Ensure Excellence and Accountability*
- **Recommendation 6:** *Employ Quality Indicators and Performance Measurement*

Concurrent with this effort, the Medical Orders for Life-Sustaining Treatment (MOLST) Demonstration Project, also mandated by Chapter 305 in Section 43, was conducted in the Greater Worcester area through collaboration among the MA Executive Office of Elder Affairs, the MA Department of Public Health (DPH), and Commonwealth Medicine at UMass Medical School. MOLST is a standardized medical order form for use by clinicians caring for patients with serious advancing illnesses. (See MOLST website: [www.molst-ma.org](http://www.molst-ma.org).) After a successful pilot, the MOLST Steering Committee recommended that MOLST be expanded throughout Massachusetts. (See MOLST Demonstration Report: <http://molst-ma.org/sites/molst-ma.org/files/MOLSTDemoRep.pdf>.) The Expert Panel agreed with this conclusion, calling for state-wide expansion of MOLST by January 2014, which was achieved.

## Today's Imperative

In early 2014, the MA DPH requested that Commonwealth Medicine update the 2010 Expert Panel Report and re-establish priorities for end of life care. The process used to accomplish this is described in Appendix B, and the results of those processes follow in Appendix C. The purpose of this report is to provide a brief snapshot of end of life activity in Massachusetts since the 2010 report, to identify related themes and trends in health care institutions, and to convey current concerns and priorities for improving end of life care in the Commonwealth.

Improving end of life care in the age of health care reform in both Massachusetts and on the national front requires that careful consideration be given to several crucial factors: **patient choice, patient engagement, quality, and cost.** The 2010 Expert Panel Report has already pointed Massachusetts in this direction by issuing strong recommendations that address these factors. The importance of **patient choice** and **patient engagement** are acknowledged in Recommendation 1 by pointing out the need to hear the patient's voice regarding preferences for care at the end of life, and by issuing a mandate to ensure that those preferences are honored. **Quality** is addressed in Recommendations 2, 3, and 6 through prescribing changes in the Massachusetts health care system and in the education of competent and compassionate health care providers, and also by highlighting the need to monitor and measure the performance of health care institutions as they provide care to the sickest and most vulnerable of patients. **Cost** factors are emphasized in Recommendation 4, which proposes the creation of financing structures that promote patient-centered care; while in some cases this may mean that more medical treatment is provided, in many cases this will also mean that unwanted medical treatment is not provided.

To ensure that the proposed end of life improvements occur in Massachusetts, these compelling recommendations must be addressed interdependently. To achieve this, a coordinating mechanism needs to be in place that will have both the authority and the resources to promote the implementation of these recommendations, disseminate best practices, and support efforts to measure performance improvements. Creating a responsible entity to ensure excellence and accountability is a matter of urgency because without it, the other recommendations are not likely to be successfully navigated and coordinated throughout the Commonwealth. For this reason, the implementation of Recommendation 5 deserves prompt attention.

### As members of the 2010 Expert Panel so compellingly state in their Report:

“Once the steps we recommend are implemented, we are convinced that when each of us confronts a serious advancing illness, and one day the inevitable fact of our own mortality, we and our loved ones can know that we will be cared for with the respect, the compassion, and the excellence that we will want, need, and deserve. Achieving this will require our united efforts.”

## Massachusetts End of Life 2014 Summit Action Plan

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Update to:

### **Recommendation 1 – *Inform and Empower Residents of Massachusetts, MA End of Life Expert Panel Report, 2010***

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#### **I. Summary Statement**

**Recommendation 1 should be achieved through the following initial steps:**

- a. Establish an ongoing group to explore Recommendation 1.
- b. Secure organizational and financial resources as soon as possible, to develop and implement a Massachusetts public awareness campaign.
- c. As a practical initial step, catalogue state-wide efforts of MA health care providers to share ideas, program resources and best practices for educating patients, families and communities about advance care planning and other end of life issues. These resources can be considered for use when a public awareness campaign is supported with resources.
- d. Collaborate with the Recommendation 6 Work Group to develop measures of progress.

#### **II. Discussion**

- a. This recommendation was ranked the highest priority of all the six major recommendations by responders to the March 2014 End Of Life Survey distributed to Massachusetts end of life experts and advocates before the End of Life Summit.
- b. Funding and the establishment of an institutional home for a Massachusetts advance care planning public awareness campaign were considered high priorities by Recommendation 1 Work Group participants, who expressed serious concern about conducting a sustained and significant campaign across the state without financial resources. The responsible entity proposed in Recommendation 5 of the MA End of Life Expert Panel Report could serve as the institutional home or, if funding were able to be achieved, an interested not-for-profit institution, or a collaboration of several institutions with a similar mission could serve in this role. Examples of entities which might be interested in funding an end of life public awareness campaign include Massachusetts health care insurers, accountable care organizations, and Massachusetts professional and trade associations.
- c. A statement of purpose for the campaign, as well as vision and mission statements, should be developed.
- d. Many members of the Recommendation 1 Work Group indicated that they would be willing to form an ongoing group to continue to explore Recommendation 1.

## Summit Action Plan: Recommendation 1 – (Update continued)

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### III. Key Milestones

#### a. Establish resources for MA End of Life Public Awareness Campaign.

- i. **What:** Identify institutional home for MA EOL Public Awareness Campaign.
  1. **By whom:** TBD (for discussion), with MA DPH.
  2. **Comments:** See Recommendation 5 for further information.
- ii. **What:** Identify potential funding sources and secure funds.
  1. **By whom:** Responsible entity or other interested organizations.
  2. **How:** Look to insurers, ACOs, AARP, MA professional and trade associations, other.

#### b. Build coalition of stakeholders:

- i. **What:** Identify and invite stakeholders to participate.
  1. **By whom:** Recommendation 1 Work Group.
- ii. **What:** Create vision and mission statements, structure, and schedule.
  1. **By whom:** Coalition of stakeholders.
- iii. **What:** Catalogue statewide efforts to educate the public to date.
  1. **By whom:** Recommendation 1 Work Group and coalition work groups.

Update to:

**Recommendation 2 – Support a Health Care System that Ensures High-Quality, Patient-Centered Care, MA End of Life Expert Panel Report, 2010**

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**I. Summary Statement**

**Recommendation 2 should be achieved through the following initial steps:**

- a. Ensure that patients are engaged in advance care planning by increasing general awareness of advance care planning tools within health care institutions.
- b. Develop tools and processes for practitioners and clinical teams to serve as triggers for engaging patients.
- c. Develop guidelines for how to communicate with patients and institutions in discharge planning.

**II. Discussion**

**a. Discussed key factors for consideration:**

- i. New MA end of life regulations, Chapter 224, Section 103.
- ii. Advance care planning (ACP) timeline across the lifespan. (See chart, **page 9**.)
- iii. The importance of appropriate timing; where/when ACP can be introduced safely.
- iv. Conversations should occur with transitions of care; follow the continuum of care model.
- v. Standard information should be provided on admission.
- vi. Sample models, resources and tools should be made available: how to engage the patient, triggers for health care providers, etc.

**b. Defined scope of ACP:** 3 D's, i.e. directives, discussions, decisions (See chart, **page 9**.)

**c. Discussed components of good practices:**

- i. Increase general awareness of ACP tools.
- ii. Provide information on basics; every patient should have ACP.
- iii. Identify and engage patients: Use trigger tools for when to engage in specific stages.
- iv. Use simple language.
- v. Develop processes for clinicians and core team, and use tools for each step.
- vi. Create guidelines for how to communicate in discharge planning and across the continuum.
- vii. Apply lessons learned from MOLST.
- viii. Need repository, like all the MOLST resources.

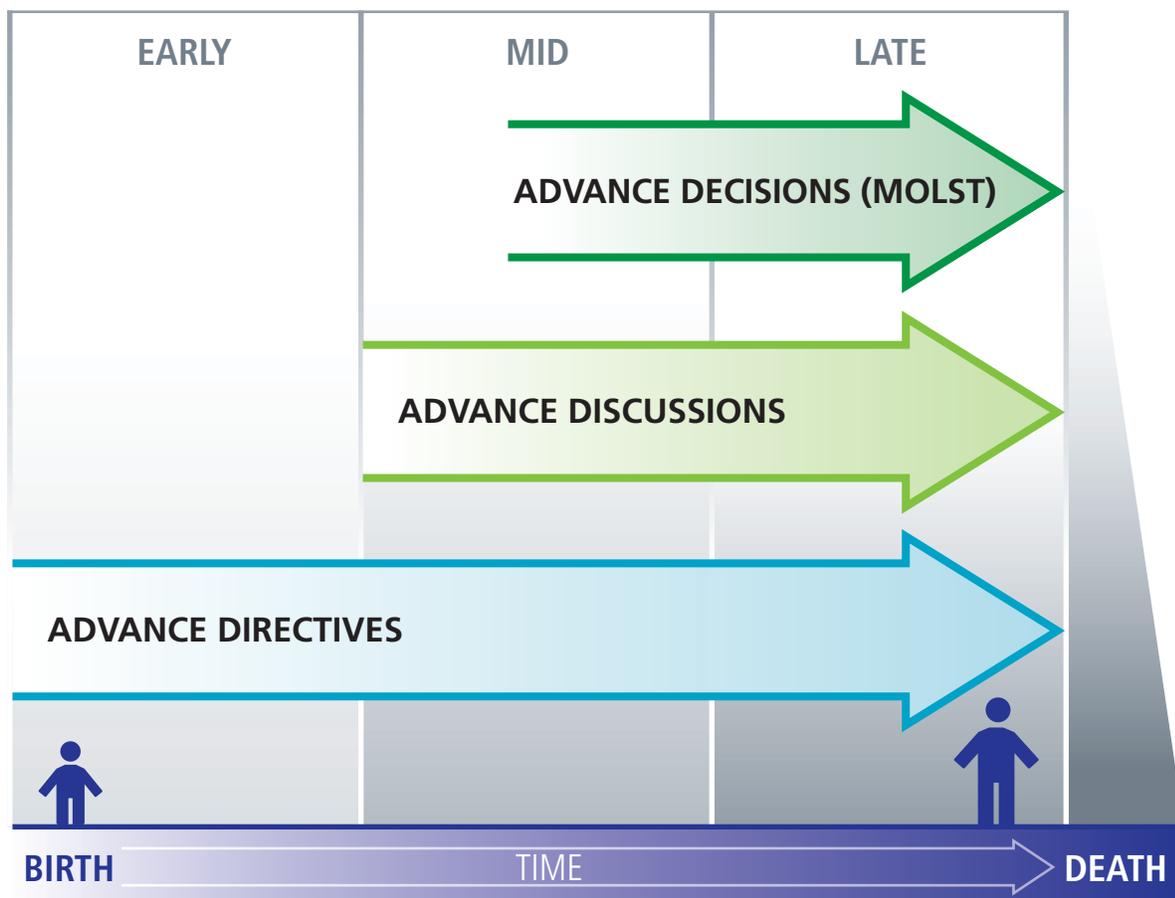
Summit Action Plan:  
**Recommendation 2 – (Update continued)**

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**III. Key Milestones**

- a. Develop guidelines to identify patients who need to have an advance care planning conversation or information; establish how to communicate.
- b. **Determine what tools hospitals are already using:**
  - i. Informational
  - ii. Basic

**Advance Care Planning Across the Life Span**



Update to:

## **Recommendation 3 – *Ensure a Knowledgeable, Competent and Compassionate Workforce, MA End of Life Expert Panel Report, 2010***

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### **I. Summary Statement**

**Recommendation 3 should be achieved through the following initial steps:**

- a. Convene a work group to complete an action plan for Recommendation 3.
- b. Gather information about what related training or education is currently being offered in schools, facilities, and communities.
- c. Identify baseline competencies for all disciplines.
- d. Develop “starter kit” (with video) as a training resource, and work with institutions to make it available.
- e. Build capacity for all disciplines to begin to discuss end of life, and accountability for all health professionals to participate in aspects of these conversations.
- f. Build capacity for clinicians to focus on prognostication.

### **II. Discussion**

- a. Work Group noted that workforce recommendations in the 2010 Report remain a priority.
- b. There may be different training needs for health care professionals who are community-based vs. those providing care in various clinical settings.
- c. There is good existing palliative care training that different institutions are currently using, although it’s not known who is using what, and there’s no consistency. We could establish a baseline training curriculum for core competencies but should not re-create the wheel. (Training already in use: End-of-Life Nursing Education Consortium or ELNEC, for nurses, and Education in Palliative and End of Life Care or EPEC, for physicians.)
- d. **The process from the discussion of EOL care to the documentation of the discussion and its outcome can be challenging, including signing the MOLST form:** How to get there? How to get the discussion going? How to have meaningful discussions and decision-making?
- e. **Barriers:** Time constraints; also, difficult to have this conversation due to anxiety. Need to establish first where the patient is. Medical culture is geared toward doing everything possible to make patients better. Prognostication is difficult. It’s helpful to hear feedback from patients, palliative care specialists and families.
- f. **Other points of discussion:**
  - i. Get feedback from families of patients who died about whether their preferences were met. Most people want to die at home but most die at the hospital. How do we change this, and ensure other preferences are honored?
  - ii. **Teach interviewer skills, one-liners to introduce the topic:** “Let’s talk/think about what’s most important to you;” use palliative care doctors for modeling, teaching and mentoring.
  - iii. **Define pathways and develop process steps independent of roles and settings:** How is discussion initiated? (Can be by multiple disciplines.) Who recognizes and communicates how serious the illness is? Who signs the MOLST form? What is the process for getting someone ready to communicate?

## Summit Action Plan: Recommendation 3 – (Update continued)

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- iv. Require MOLST training; educate providers that pain management is different at end of life; develop train the trainer models; use different approaches or providers in facilities, schools and communities.
- v. Consider Pri-Med as an educational tool, and look into the Accreditation Council for Graduate Medical Education milestones (curriculum being developed).
- vi. Leverage MA Board of Registration in Medicine Continuing Medical Education requirements for EOL and pain management; find out if palliative care has been included in Board of Nursing regulations.

### III. Key Milestones

- a. Assess/survey who is providing training in Massachusetts (schools and health care institutions).
- b. Determine what core competencies in palliative care every health care professional should have.
- c. Establish a baseline training curriculum for core competencies.

Update to:

## **Recommendation 4 – Create Financing Structures That Promote Patient-Centered Care, MA End of Life Expert Panel Report, 2010**

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### **I. Summary Statement**

**Recommendation 4 should be achieved through the following initial steps:**

- a. Revise/update advance care planning (ACP) billing codes for all disciplines across all settings.
- b. Revise/update palliative care billing codes for all disciplines across all settings.
- c. Reconvene work group.

### **II. Discussion**

**a. There was general agreement about:**

- i. The urgency of removing barriers in order to provide incentives and financing structures to promote patient-centered care.
- ii. ACP discussions should occur earlier in disease process to help document and communicate patient goals of care and personal quality of life and EOL care preferences.

**b. Distributed a brief outline of programs in place or in pilot to address Recommendation 4 which included the following:**

- i. Basic and MassHealth Plans now include hospice coverage, as recommended by the EOL Expert Panel, effective July 2013. (Except in skilled nursing facilities.)
- ii. CMS ongoing pilot (2012-2015) in place to evaluate cost/quality outcomes while addressing current shortcomings (Reduced hospice length of service), through provision of Medicare Hospice Benefit coverage concurrently with active cure-oriented therapies.

**c. Group members discussed existing billing code shortcomings for ACP/goals of care discussions, palliative care services billing codes and hospice reimbursement structure; agreed to focus efforts on addressing billing code deficiencies as the initial undertaking. **Financial incentives are needed for:****

- i. Procedure codes for goals of care values discussion (most important priority for Recommendation 4); these codes could be used by multiple providers: primary care provider, hospitalist, specialist, clinicians in all settings – skilled nursing facilities, long term care.
- ii. Reimbursement, whether money-wise or Relative Value Unit (RVU)-wise; sets up for quality measures to know how many conversations occur (i.e. when billing, look at documentation).

**d. Other discussion:**

- i. Re-analyze hospice/concurrent care reimbursement models.
- ii. Financial incentives for education in palliative care – clinicians, aides, etc. – skilled nursing facilities, long term acute care, etc. for people providing direct care.
- iii. Pay for performance measures that every patient in MA should have a health care agent name in the record – 100%.

## Summit Action Plan: Recommendation 4 – (Update continued)

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### III. Key Milestones

- a. **What:** Review existing palliative care codes in other states/Canada.
  - i. **How:** Online research
  - ii. **With what:** Research tools
  
- b. **What:** Develop a one-page statement for procedure billing codes; provide background for updated revisions and specific billing code changes to support and optimize patient-centered care in MA.
  - i. **How:** E-mail communication; research to support
  - ii. **With what:** Internet
  
- c. **What: Contact larger MA entities:** MA Medical Society; CMS/American College of Physician Executives; MA Association of Health Plans.
  - i. **How:** Prepare one-page document/statement for delivery to key stakeholders.

Update to:

## **Recommendation 5 – Create a Responsible Entity to Ensure Excellence and Accountability, MA End of Life Expert Panel Report, 2010**

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### **I. Summary Statement**

**Recommendation 5 should be achieved through the following initial steps:**

- a. Create an entity, possibly an independent 501(c) (3), with broad stakeholder support and representation for governance.
- b. Secure sustainability funding (including seed funding) from the Commonwealth, to create this membership organization.
- c. Provide governance by a community board with broad group of stakeholders, and staffed by content experts.
- d. Identify and promulgate metrics and best practices for palliative/end of life care.
- e. Report out progress on defined goals.

### **II. Discussion**

- a. Recommendation 5 Work Group agreed that there needs to be a “responsible entity” but not a legislative commission, (although it could continue some of the earlier work done by the MA Commission on End of Life Care).
- b. Scope needs to be broader, starting upstream and focusing much earlier with patients.
- c. Should keep focused on patient empowerment/choices – although the name Honoring Choices is taken, something similar that conveys this concern would be suitable.
- d. What kind of entity? Independent, not-for-profit (501(c)3); academic institution; Betsy Lehman Center and MA Coalition for Prevention of Medical Errors could serve as models.
- e. American Cancer Society – Quality of life: H. 2104, currently before the MA Legislature.

### **III. Key Milestones**

- a. Convene a Steering Committee to explore the feasibility of creating a responsible entity to implement and monitor Expert Panel recommendations.
- b. Secure seed funding, for initial phase of planning and development.
- c. Determine governance and staffing structure and other needed resources.

Update to:

## **Recommendation 6 – *Employ Quality Indicators and Performance Measurement, MA End of Life Expert Panel Report, 2010***

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### **I. Summary Statement**

**Recommendation 6 should be achieved through the following initial steps:**

- a. Determine which data are relevant, accessible, and provide good quality measures for palliative and end of life care in MA.
- b. Partner with national and state organizations and agencies to create a framework for measuring quality of end of life and palliative care in MA.
- c. Establish state benchmarks for measuring palliative and end of life care in various MA health care settings.

### **II. Discussion**

- a. Among the work group members was a wealth of clinical, academic, and administrative experience.
- b. The group agreed that we are just beginning in this area – even at the End of Life Summit meeting, there was almost no data. It is essential to have accurate quality data for palliative and EOL care, and we need to collect a variety of different types of quality measures and data.

### **III. Key Milestones**

**Define the data we want to collect. Steps include:**

- a. **What:** Partner with American Academy of Hospice and Palliative Medicine Quality and Practice Standards Taskforce; partner with National Hospice and Palliative Care Organization and American Society of Clinical Oncology campaign: “Measuring what Matters” (looking at existing National Quality Forum measures and hospices measures, trying to determine the 10 most valuable EOL measures, using researchers and clinicians) rather than re-invent the wheel. Consider state benchmark for hospice and palliative medicine groups.
  - i. **How:** There are monthly phone meetings; bring relevant data back.
  - ii. **With what:** Ethical; Compliance, Governance and Oversight Council; patient/family.
  - iii. **Comments:** Includes patient/family experience; global; physical aspects of care; structure/process; psychological; spiritual; utilization.
- b. **What:** Partner with Center for Health Information and Analysis to look at utilization data in last two years of life; get MA-specific data, maybe by county.
  - i. **How:** Talk with researchers involved.
  - ii. **Comments:** This will show variations across the state.

## Summit Action Plan: Recommendation 6 – (Update continued)

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- c. **What:** Behavioral Risk Factor Surveillance System – Investigate if this can be adapted to capture data on informing and empowering residents of MA (evaluation of community engagement and knowledge).
  - i. **How:** Reach out to UMass faculty and MA DPH Associate Commissioner and report back.
  - ii. **Comments:** Behavioral Risk Factor Surveillance System – want this to capture patient experience.
  
- d. **What:** Develop electronic registry for advance care planning documents for MA residents, Oregon & New York style.
  - i. **Comments:** To be used for clinical care and data.

## Recommended Next Steps

Based on the input from the EOL Summit Work Group participants (see pages 6 - 16 for a summary of each Summit Work Group discussion and recommendations for action), we propose the following next steps.

It is worth noting that survey participants ranked the need for an End of Life Public Awareness Campaign (Recommendation 1) as the highest priority. (See Appendix C.) However, without a responsible entity to coordinate and move the EOL agenda in Massachusetts forward, as proposed in Recommendation 5, the work of other recommendations will be difficult to accomplish. For this reason, determining the feasibility of creating such an entity is accorded a high priority. Several of the work groups (Recommendations 1, 4, and 6 Work Groups) have already begun to work on their action plan.

| Steps                    | Rec 1:<br>Public<br>Awareness  | Rec 2:<br>Health Care<br>System   | Rec 3:<br>Workforce   | Rec 4:<br>Finance<br>Structures  | Rec 5:<br>Responsible<br>Entity  | Rec 6:<br>Quality &<br>Performance  |
|--------------------------|--|---|---|--|--|---|
| 1                        | <ul style="list-style-type: none"> <li>- Establish work group; develop work plan.</li> <li>- Identify institutional home for EOL Public Awareness Campaign.</li> <li>- Build coalition of stakeholders.</li> </ul> | <ul style="list-style-type: none"> <li>- Establish work group; develop work plan.</li> </ul>  | <ul style="list-style-type: none"> <li>- Establish work group; develop work plan.</li> <li>- Assess/survey who is providing training in MA schools and health care institutions.</li> </ul> | <ul style="list-style-type: none"> <li>- Establish work group; develop work plan.</li> <li>- Review existing palliative care codes in other states, Canada.</li> </ul> | <ul style="list-style-type: none"> <li>- Convene steering committee to determine feasibility.</li> </ul>               | <ul style="list-style-type: none"> <li>- Establish work group; develop work plan.</li> <li>- Partner with national organizations (AAHPM, NHPCO, etc.) to determine most valuable EOL measures.</li> </ul>   |
| <b>RE-CONVENE SUMMIT</b> |  |   |   |  |  |   |
| 2                        | <ul style="list-style-type: none"> <li>- Identify funding sources for PAC.</li> <li>- First stakeholder meeting.</li> <li>- Catalogue current EOL educational efforts in MA.</li> </ul>                            | <ul style="list-style-type: none"> <li>- Develop guidelines to identify patients who need to have ACP conversation or information.</li> </ul> | <ul style="list-style-type: none"> <li>- Determine core competencies in palliative care that all health care professionals should have.</li> </ul>  | <ul style="list-style-type: none"> <li>- Develop 1-page statement for procedure billing codes.</li> </ul>  | <ul style="list-style-type: none"> <li>- Determine governance, staffing, budget and other resources needed.</li> </ul> | <ul style="list-style-type: none"> <li>- <b>Investigate Behavioral Risk Factor Surveillance System in MA:</b> Possible to adapt survey to capture data for Recommendation 1.</li> </ul>   |
| 3                        | <ul style="list-style-type: none"> <li>- Second stakeholder meeting.</li> <li>- Develop plan for National Healthcare Decisions Day, April 16.</li> </ul>   | <ul style="list-style-type: none"> <li>- Determine tools already in use; form alliances with ACP programs.</li> </ul>                         | <ul style="list-style-type: none"> <li>- Establish baseline training curriculum for core competencies.</li> </ul>   | <ul style="list-style-type: none"> <li>- Contact larger MA &amp; OTHER entities (MMS, CMS / ACPE, MAHP); deliver 1-page statement to stakeholders.</li> </ul>          | <ul style="list-style-type: none"> <li>- <b>Secure seed funding,</b> planning and development.</li> </ul>              |   |
| <b>RE-CONVENE SUMMIT</b> |  |   |   |  |  |   |
| 4                        | <ul style="list-style-type: none"> <li>- Third stakeholder meeting.</li> </ul>   |   |   |  |  | <ul style="list-style-type: none"> <li>- <b>Develop plans for:</b> <ul style="list-style-type: none"> <li>- Partnering with CHIA to look at utilization data in last 2 years of life.</li> <li>- Feasibility of e-registry for ACP for MA residents.</li> </ul> </li> </ul> |

## Appendix A: MA End of Life Summit Participants

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## Appendix B:

### Description of Process to Update 2010 Expert Panel Report

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**In 2014, the MA Department of Public Health requested that Commonwealth Medicine review and update the recommendations for improving end of life care as set forth in the 2010 Expert Panel Report, and to re-establish MA end of life/palliative care priorities.**

**The following approach was developed:**

1. Conduct a brief survey among MA end of life (EOL) and palliative care (PC) experts regarding the six major recommendations in the 2010 Expert Panel Report.
2. Conduct key informant interviews with a smaller group of end of life and PC experts regarding the 2010 recommendations.
3. Use findings from the survey and interviews to inform a discussion for creating an action plan at the MA End of Life Summit to be held on April 9th.
4. Submit to MA DPH an updated report incorporating findings from these activities and a suggested action plan.

#### **End of Life Survey**

A brief online survey was sent in March 2014 over a two-week period to 91 MA end of life/palliative care experts and advocates, including members of the former expert panel as well as other current leaders across the state. Names of invitees were provided by the Expert Panel leadership, the MA Department of Public Health, and the Medical Orders for Life-Sustaining Treatment Steering Committee. Participants were told that the results would be reported in the aggregate. Of the 91 persons invited to respond, 47 (52%) completed the survey. All regions of MA were represented.

**Each recommendation from the Expert Panel Report was summarized in the survey, and a link was provided to the full report for reference as needed. The following instructions were given for each recommendation:**

- Please briefly describe any new initiatives or improvements in end of life care that you are aware of or are participating in.
- In your opinion what remains a priority for this recommendation in MA?

Respondents were also asked to rank recommendations 1 through 6 in order of priority for end of life work that remains to be done in MA, and were given an opportunity to comment on other EOL/PC priorities not included in the original report.

#### **Key Informant Interviews**

Seventeen additional EOL/PC experts and advocates were contacted during March and invited to participate in interviews conducted by two members of the earlier Expert Panel. Sixteen people responded and agreed to participate. One person later requested not to have his/her comments included in the final report. Participants were asked about any updates or new activities or programs in EOL/PC in MA they were aware of, and were asked to rate the relevancy and urgency of the 2010 recommendations today. The interviews lasted from approximately 30 minutes to 75 minutes, thus allowing more time for the respondent to elaborate on answers about current MA EOL/PC activities and priorities. All regions of MA were represented.

## Appendix B:

### Description of Process to Update 2010 Expert Panel Report (continued)

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#### **End of Life Discussion and Surveys: MA Coalition for the Prevention of Medical Errors**

In March 2014, a meeting of the MA Coalition for the Prevention of Medical Errors was dedicated to discussing the expert panel recommendations. A summary of the EOL survey was distributed among – attendees, who were asked to participate in a discussion based on one of the six Report recommendations. Several of the participants also completed the online survey.

#### **MA End of Life Summit**

After the survey and interviews were completed and tabulated, a summary of the identified activities and current priorities was provided to 47 participants (of 95 invited) who attended an EOL Summit that was held at Commonwealth Medicine in central Massachusetts on April 9, 2014. The attendees included many of those who had responded to the EOL survey or had been interviewed.

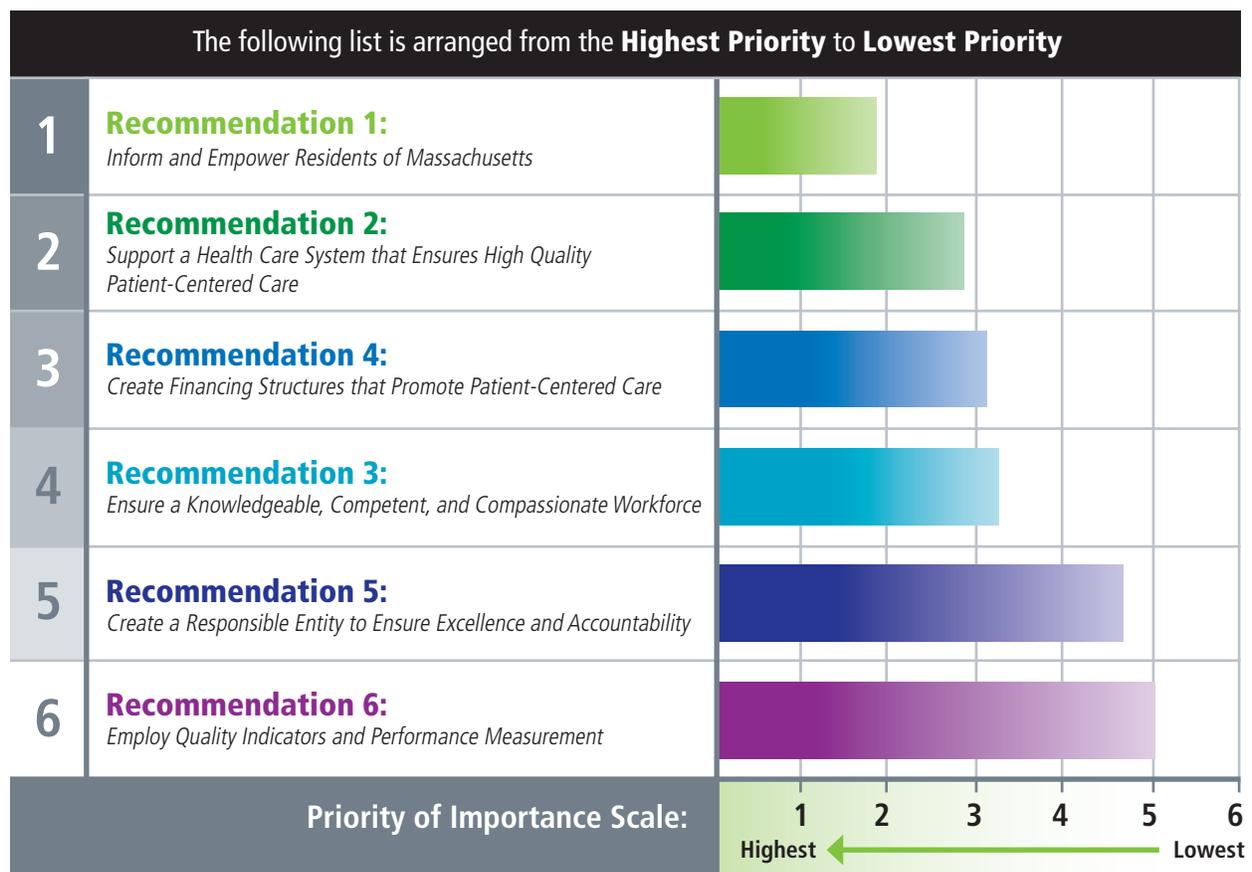
After a presentation which included the results of the survey and interviews, participants were asked to select one of the six work groups (based on the six major recommendations of the Expert Panel Report) in which to participate in a small group discussion. They were instructed to consider the identified priorities and updated activities in MA since 2010 for that recommendation, and to develop an action plan to address it.

Between 4 and 11 people in each work group participated for approximately an hour. They discussed the findings and prepared a summary statement that was presented to the entire group in the last segment of the summit meeting. (See page 21-25.)

## Appendix C: Results of Process to Update 2010 Expert Panel Report

### Survey Priority Ranking of Recommendations

Respondents were asked to rank Recommendations 1 through 6 in ORDER OF PRIORITY for end of life work that remains to be done in MA.



#### Survey Respondents: N=47

Half of the respondents were from health care institutions; the remainder were from state agencies, trade organizations, educational institutions, and other agencies. Slightly less than half were Palliative Care (PC)/ End of Life (EOL) specialists; slightly less than a quarter were members of the Expert Panel. All regions of MA were represented.

#### Key Informant Interview Participants: N=16

More than half were clinical personnel: physician, nurse, or social worker representing different care settings. Less than half were non-clinical personnel: attorney, health care administrator, family member /caregiver, public policy & state agency representative, and others. Approximately one third were members of Expert Panel. All regions of MA were represented.

## Appendix C:

### Results of Process to Update 2010 Expert Panel Report (continued)

#### Recommendation 1 – Inform and Empower Residents of Massachusetts

(Priority #1 for survey; 2nd ranked highest priority from interviews.)

| Activities since 2010:<br>31 respondents  | Priorities in 2014:<br>33 respondents   | Comment Summary:   |
|---|---|--|
| <ul style="list-style-type: none"> <li>– <b>MOLST roll-out and training:</b><br/>Happening across the state; more work needs to be done. (~2/3 of respondents)</li> <li>– <b>Advance care planning (ACP) activities:</b> The Conversation Project, Honoring Choices, other ACP initiatives for patients and providers. (~1/2 of respondents)</li> </ul> | <ul style="list-style-type: none"> <li>– <b>Public awareness:</b> ACP, for the public (target adults 30-60 years) and across care settings. (~1/2 of respondents)</li> <li>– Importance of working with faith-based communities.</li> <li>– Need commitment to honor patient preferences.</li> <li>– Establish data bank registry for ACP tools.</li> <li>– Providers need to develop and practice communication skills.</li> </ul> | <ul style="list-style-type: none"> <li>– <b>We need a highly visible, ongoing educational campaign:</b> <ul style="list-style-type: none"> <li>• to engage the public in meaningful discussions re: options available for best care.</li> <li>• to provide ongoing clinical/frontline staff education re: importance of ACP/HCP (health care proxy) and how to have goals of care conversations.</li> </ul> </li> <li>– <b>We should use technology and social media to educate the public and health care professionals.</b></li> </ul> |

#### Recommendation 2 – Support a Health Care System that Ensures High Quality Patient-Centered Care

(Priority #2 for survey; 3rd ranked highest priority from interviews.)

| Activities since 2010:<br>24 respondents  | Priorities in 2014:<br>28 respondents  | Comment Summary:   |
|---|--|--|
| <ul style="list-style-type: none"> <li>– <b>Expanding palliative care (PC) programs across the continuum:</b> Hospital and outpatient, including clinics and home care. (~1/4 of respondents)</li> <li>– <b>Assisting with preparation of materials for DPH regulations,</b> Chapter 224, Section 103. (~1/4 of respondents)</li> <li>– <b>Funding increased for Pediatric PC Network.</b></li> <li>– <b>Using tools to facilitate goals</b> of care discussions, education, and identification of PC patients.</li> <li>– <b>Launching disease-specific initiatives.</b></li> <li>– <b>Developing PC-focused agenda</b> in research, programs and advocacy.</li> </ul> | <ul style="list-style-type: none"> <li>– <b>Broaden and expand PC,</b> including into the community. (~1/5 of respondents)</li> <li>– <b>Recommendation 2 remains a priority.</b> (~1/5 of respondents)</li> <li>– <b>Need financial and quality incentives.</b></li> <li>– <b>Educate providers</b> to know how to explain PC and hospice.</li> </ul> | <ul style="list-style-type: none"> <li>– <b>PC and hospice care have similar philosophies; which can confuse people.</b> Our descriptions don't differentiate between the timing for each approach to care. There are great timeline differences, and explaining the distinction to providers and to patients is very important.</li> <li>– <b>All patients and providers should receive accurate information about PC and hospice.</b></li> <li>– <b>Hospital leadership must make a commitment to PC,</b> providing financial resources and infrastructure.</li> <li>– <b>Every hospital should have PC,</b> and every clinician should have primary PC training.</li> </ul> |

## Appendix C:

### Results of Process to Update 2010 Expert Panel Report (continued)

#### **Recommendation 3** – *Ensure a Knowledgeable, Competent, and Compassionate Workforce* (Priority #4 for survey; 3rd ranked highest priority from interviews.)

| Activities since 2010:<br>22 respondents   | Priorities in 2014:<br>24 respondents   | Comment Summary:   |
|--|---|--|
| <ul style="list-style-type: none"> <li>– <b>Providing PC education for health care providers:</b> Clinicians, nurses, students, residents, fellows; partnering with medical school. (~1/4 of respondents)</li> <li>– <b>EMS training (MOLST).</b></li> <li>– <b>CME requirements for physicians.</b></li> <li>– <b>Preparing for Conversation Ready.</b></li> <li>– <b>Family/caregiver training and support</b> (home care and hospice).</li> </ul> | <ul style="list-style-type: none"> <li>– <b>Develop generalist PC curriculum:</b> Should be minimum goal for education. (~1/3 of respondents)</li> <li>– <b>Document that clinical staff have training.</b></li> <li>– <b>Support for family caregivers.</b></li> <li>– <b>Provide training</b> for how to have the conversation.</li> <li>– <b>Develop triggers for PC specialist consults.</b></li> </ul> | <ul style="list-style-type: none"> <li>– <b>We need a knowledgeable, educated workforce</b> to provide quality patient-centered care across the lifespan and across the health care continuum.</li> <li>– <b>Current EOL educational efforts are at the discretion of the individual institution.</b> State/medical schools must initiate more fellowships in PC to meet the rising professional training and population-based needs.</li> </ul> |

#### **Recommendation 4** – *Create Financing Structures that Promote Patient-Centered Care* (Priority #3 for survey; 3rd ranked highest priority from interviews.)

| Activities since 2010:<br>19 respondents  | Priorities in 2014:<br>20 respondents  | Comment Summary:   |
|---|--|--|
| <ul style="list-style-type: none"> <li>– <b>Not aware of any progress</b> toward payment for goals of care discussion. (~1/2 of respondents)</li> <li>– <b>Mass Health plans now cover hospice.</b></li> <li>– <b>Increased availability of open access hospice.</b></li> <li>– <b>Payment reform includes EOL discussion</b> for patient-centered medical home, but for highest level of certification only.</li> <li>– <b>Opportunities for aligning payment with ACO standards,</b> including end of life planning.</li> </ul> | <ul style="list-style-type: none"> <li>– <b>Payment reform</b> should address all issues specified in the recommendation, especially goals of care discussion. (~1/2 of respondents)</li> <li>– <b>Increase social and family support</b> for family caring at home. (~1/2 of respondents)</li> <li>– <b>Increase hospice coverage</b> of MA Health plans. (~1/2 of respondents)</li> <li>– <b>Overlap comfort and curative care.</b></li> </ul> | <ul style="list-style-type: none"> <li>– <b>Goals of care discussion should be a reimbursable procedure code.</b></li> <li>– <b>Improved palliative care won't happen until it's paid for.</b></li> <li>– <b>To provide quality care along the continuum and earlier in the disease trajectory,</b> finance reform is needed to cover/subsidize outpatient PC upstream.</li> </ul> |

## Appendix C:

### Results of Process to Update 2010 Expert Panel Report (continued)

#### **Recommendation 5** – *Create a Responsibility Entity to Ensure Excellence and Accountability* (Priority #5 for survey; most often ranked highest priority from interviews.)

| Activities since 2010:<br>14 respondents  | Priorities in 2014:<br>19 respondents  | Comment Summary:   |
|---|--|--|
| <ul style="list-style-type: none"> <li>– Not aware of progress toward this recommendation. (~1/3 of respondents)</li> <li>– Mention of H. 2104 (MA Legislature):<br/>An Act to Improve Quality of Life by Expanding Access to Palliative Care.</li> <li>– Mention of DPH developing information packet for new regulations for Chapter 224, Section 103.</li> </ul> | <ul style="list-style-type: none"> <li>– Recommendation 5 is a priority. (~1/4 of respondents)</li> <li>– EOL Summit is important, but not sufficient.</li> <li>– Not sure whether state agency should be involved as responsible entity.</li> <li>– Integrate H. 2104 emphasis on quality of life – expand from focus on end of life.</li> <li>– Change “end of life” to “palliative and supportive care.”</li> </ul> | <ul style="list-style-type: none"> <li>– The importance of an independent funded entity with responsibility and authority to implement the Expert Panel Report Recommendations and ensure accountability cannot be overstated.</li> <li>– A responsible entity should be a collaborative enterprise and not reside within the government; we should ask insurers and other not-for-profits to contribute funds.</li> <li>– Revitalizing the MA End of Life Commission would be great.</li> </ul> |

#### **Recommendation 6** – *Employ Quality Indicators and Performance Measurement* (Priority #6 for survey; no highest priority ranking from interviews.)

| Activities since 2010:<br>12 respondents  | Priorities in 2014:<br>15 respondents  | Comment Summary:  |
|---|--|---|
| <ul style="list-style-type: none"> <li>– Not aware of progress toward this recommendation. (~1/2 of respondents)</li> <li>– Developing in-house quality metrics and dashboard.</li> <li>– Gap here, and there’s a need to work on community PC.</li> <li>– Center to Advance PC has state-by-state report card and PC registry to gather operational data.</li> </ul> | <ul style="list-style-type: none"> <li>– Annual progress report on PC and EOL care, using specified indicators; should measure whether patients preferences are honored. (~2/5 of respondents)</li> <li>– Establish measures to assess PC programs and training in ambulatory care. (~1/3 of respondents)</li> <li>– Report hospice and PC programs and PC training by name of hospital. (~1/4 of respondents)</li> <li>– Report PC programs and PC training programs in nursing homes and home care; and % of advance directives in nursing homes. (~1/4 of respondents)</li> </ul> | <ul style="list-style-type: none"> <li>– Quality measures are important. They provide focus and accountability.</li> <li>– Reporting PC and end of life quality indicators would put pressure on the system.</li> <li>– Institutions need to be held accountable; metrics should be imposed.</li> <li>– It’s important to look at and measure the patient and family experience.</li> </ul> |

## Appendix C:

### Results of Process to Update 2010 Expert Panel Report (continued)

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#### Key Informant Interviews: Other Identified Themes and Concerns

**Several additional themes for end of life care reform were noted during key informant interviews:**

- All of the recommendations are synergistic and are necessary for improvement in end of life care.
- We need to acknowledge the importance of collaborative efforts in goals of care conversations across settings of care.
- Large hospital systems (and fee for service) don't understand the palliative care business model.
- We need to focus on patient and family outcomes after death occurs, not just process measures.

**In 94% of the interview rankings, all of the six major recommendations were rated for 2014 as "very relevant" or "crucial," and "very important" or "urgent."**

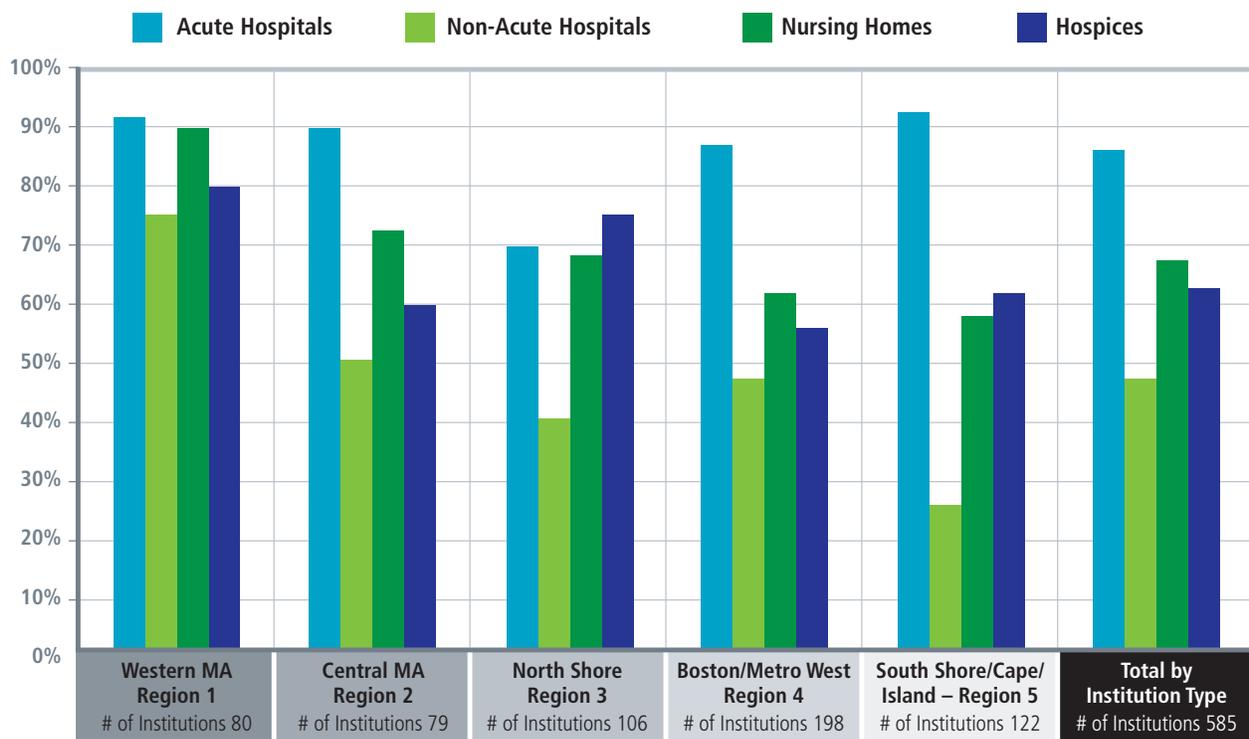
#### End of Life Discussion and Surveys: MA Coalition for the Prevention of Medical Errors

In March 2014, a meeting of the MA Coalition was dedicated to discussing the Report recommendations. In addition to themes identified in the survey and during the interviews, of particular note was input about the patient and family experience in end of life situations. **The following points were emphasized:**

- The urgency for health care provider education about the need for communication with patients and families.
- The need for connection to hospice care in long term care settings.
- The need to reach patients and families where they are, and to make sure that the team is attuned to their level of understanding.
- That communication and coordination of care need to go all the way across the continuum; there needs to be a concerted effort to ensure that this occurs.
- That feedback from families should be routinely elicited, and families should be encouraged to describe where the gaps are.
- Begin with the patient and family experience; build a team approach; turn feedback into easy steps; and create a set of "gold standards" to improve end of life care.

## Appendix D: MOLST Statewide Expansion

**MA Institutions Participation in MOLST TA Session, Downloaded MOLST Form and/or Requested MOLST DVD (Mar 15, 2012 - Dec 31, 2013)**



|                     | Western MA Region 1   | Central MA Region 2   | North Shore Region 3   | Boston/Metro West Region 4 | South Shore/Cape/Island Region 5 | Total by Institution Type |
|---------------------|-----------------------|-----------------------|------------------------|----------------------------|----------------------------------|---------------------------|
| Acute Hospitals     | 11 of 12              | 9 of 10               | 9 of 13                | 26 of 30                   | 12 of 13                         | 67 of 78 (86%)            |
| Non-Acute Hospitals | 3 of 4                | 2 of 4                | 2 of 5                 | 7 of 15                    | 1 of 4                           | 15 of 32 (47%)            |
| Nursing Homes       | 53 of 59              | 43 of 60              | 57 of 84               | 83 of 135                  | 53 of 92                         | 289 of 430 (67%)          |
| Hospices            | 4 of 5                | 3 of 5                | 3 of 4                 | 10 of 18                   | 8 of 13                          | 28 of 45 (62%)            |
| <b>TOTAL</b>        | <b>71 of 80 (89%)</b> | <b>57 of 79 (72%)</b> | <b>71 of 106 (67%)</b> | <b>126 of 198 (64%)</b>    | <b>74 of 122 (61%)</b>           | <b>399 of 585 (68%)</b>   |

## Appendix E:

### MOLST Evaluation Report Executive Summary

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Medical Orders for Life Sustaining Treatment (MOLST) is both a process and a standardized form used to translate life-sustaining treatment preferences into valid medical orders that can be honored and accessed across health care settings in Massachusetts. Massachusetts aims to expand the use of MOLST among all providers, an effort lead by the Massachusetts Department of Public Health (DPH), the Executive Office of Elder Affairs (EOEA), and the University of Massachusetts Medical School (UMMS). In July 2012, the Center for Health Policy and Research (CHPR) at UMMS was asked by the MOLST project team to evaluate the early statewide MOLST expansion effort; specifically to determine the degree to which institutions are adopting MOLST, assess how providers use MOLST technical assistance resources, and identify common practices among MOLST early adopters. To address these aims, the evaluation surveyed provider institutions across the state and conducted interviews with key informants at select “early adopter” sites.

Evaluation findings indicated that provider institutions are taking steps to adopt MOLST. Three-quarters of the institutions surveyed had designated a MOLST clinical champion and a similar percent had begun to use the MOLST form (or anticipated doing so soon). Surveyed institutions had also developed MOLST policies and procedures and trained staff, although these two activities were less widespread than use of the MOLST form and clinical champion designation. Survey findings further suggest that the MOLST technical assistance (TA) resources have been helpful in both advancing knowledge about MOLST and guiding institutions about how to implement MOLST.

A closer examination of eight early adopter sites suggest that organizational adoption of MOLST is facilitated by the presence of strong leadership and culture around EOL care, the willingness and ability to invest resources in MOLST adoption activities, and the use of external resources to support adoption efforts. Key informants also identified on-going challenges, including how to secure and maintain stakeholder buy-in and how to manage patient transfers among provider sites that do not honor MOLST.

Given the positive response to MOLST technical resources reported among survey and interview respondents, we recommend that existing web-based TA resources be maintained, especially related to developing MOLST policies and procedures, staff training, stakeholder buy-in, and guidance around patient transfers. These efforts could help ensure that institutional policies, procedures and staff training related to MOLST are keeping pace with use of the MOLST form and to support institutions in their efforts to sustain MOLST adoption. This report is issued as the DPH prepares to promulgate regulations which require Massachusetts licensed hospitals, long term care facilities, clinics and assisted living residences to provide information about advance care planning, palliative care and end of life options to patients diagnosed with a terminal illness or those who may benefit from these services.

See full report at:

[http://molst-ma.org/sites/molst-ma.org/files/MOLST%20Evaluation%20Report\\_FINAL%2004-23-14.pdf](http://molst-ma.org/sites/molst-ma.org/files/MOLST%20Evaluation%20Report_FINAL%2004-23-14.pdf)

## Appendix F: MOLST Committee Membership

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## Appendix F

### MOLST Committee Membership (continued)

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## Appendix G: End of Life/Palliative Care Policy-Related Activities in Massachusetts and Other States

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### Palliative Care Legislation:

**In 2013, a total of five states – Maryland, Connecticut, Rhode Island, New Hampshire, and Massachusetts –** introduced palliative care legislation. The legislation in Maryland was an evolution of a previous bill meant to expand access to palliative care, while the bills in the other four states were new initiatives.

Driving these bills has been the growing awareness that palliative care can benefit all people with serious illness, not just those who may be at the end of life, and that this care is a crucial aspect of healthcare quality. Not only has palliative care been shown to improve quality of life for patients and families facing serious illness, in one study it has even been shown to prolong life when delivered early after diagnosis.

### Passed

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#### **Connecticut:** *An Act Concerning an Advisory Council on Palliative Care*

**Signed into law:** May 28, 2013

#### **Key provisions:**

- Establishes a 13-member palliative care advisory council charged with analyzing the current state of palliative care in Connecticut and advising the Department of Public Health on matters relating to the improvement of palliative care and the quality of life for persons with serious or chronic illnesses. All council appointments must be made by December 31, 2013, and the council must provide a report to the Commissioner of Public Health and to the Joint Standing Committee of the General Assembly on Public Health by January 2015.

#### **Maryland:** *Hospitals – Establishment of Palliative Care Pilot Programs*

**Signed into law:** May 2, 2013 (text of HB 581 available [here](#))

#### **Key provisions:**

- Establishes 5 palliative care pilot programs in hospitals in Maryland. These programs must collect data on “costs and savings to hospitals and providers, access to care, and patient choice.” The precise data to be collected will be determined by the Maryland Health Care Commission, stakeholders, and the pilot programs. The pilot programs must report this data and best practices to the Health Care Commission and the Senate Finance Committee by December 1, 2015, with the objective of establishing standards for palliative care programs in hospitals. Once these standards have been developed, the possibility of mandating that palliative care be available in hospitals statewide may be more feasible. The pilot sites will be chosen by the Maryland Healthcare Commission “in a manner that ensures geographic balance in the state.”

## Appendix G: End of Life/Palliative Care Policy-Related Activities in Massachusetts and Other States (continued)

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### Passed (continued)

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#### **New Hampshire:** *An Act Establishing a Commission to Study Palliative Care and Associated Quality of Life Initiatives*

**Status:** Passed both houses. Awaiting signature by Governor.

**Key provisions:**

- Establishes a 16-member commission, composed of providers, legislators, facilities, and the public. This Commission would be charged with (a) assessing the general knowledge of the citizens of New Hampshire regarding palliative care and hospice services, (b) evaluating the access, effectiveness, utilization, and timeliness of palliative and hospice care, (c) considering requiring continuing education credits for re-licensure of health care providers involved with palliative, hospice, and pain management services, and (d) reviewing options for increasing the knowledge and use by the public of advanced directives. The commission would be required to report its findings and any recommendations for proposed legislation by June 1, 2014 (an interim report would be due by November 1, 2013).

#### **Rhode Island:** *State Palliative Care and Quality of Life Act*

**Status:** Passed both houses. Awaiting signature by Governor.

**Key provisions:**

- Establishes a 9-member state palliative care and quality of life interdisciplinary advisory council. Members will include providers and caregiver advocates. The council will consult with and advise the Department of Health regarding palliative care initiatives in the state.
- Establishes a consumer and professional information and education program. The DOH must publish information on its website about palliative care, including continuing education opportunities for providers and best practices for palliative care, and provide links to resources.
- Requires all licensed healthcare facilities to consult with the organizations' physicians on how to provide information about appropriate palliative care services to the facilities' residents or patients.

## Appendix G: End of Life/Palliative Care Policy-Related Activities in Massachusetts and Other States (continued)

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### In Committee

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**Massachusetts:** *An Act to Improve Quality of Life by Expanding Access to Palliative Care*

**Status:** Referred to the committee on Public Health.

**Key provisions:**

- Establishes a State Palliative Care and Quality of Life Interdisciplinary Advisory Council charged with consulting and advising the Department of Public Health on palliative care initiatives in the state.
- Requires the Department of Public Health to publish information and resources related to palliative care for providers, facilities, and the public, including continuing education opportunities for health care providers; information about palliative care delivery in all settings; best practices for palliative care delivery; and referral information for consumers.
- Provides that after January 1, 2015, no original license shall be granted to establish or maintain a health care facility, health maintenance organization or acute-care hospital, unless the facility has established a system for identifying patients or residents who could benefit from palliative care, providing those patients information about palliative care, and facilitating access to appropriate palliative care. In carrying out this section, the Department of Public Health would take into account factors that may impact the development of such a system and its ability to facilitate access to palliative care, including the size of the organization; access and proximity to palliative care services, including the availability of hospice and palliative care board-certified practitioners and related workforce staff; and geographic factors.

## Appendix G: End of Life/Palliative Care Policy-Related Activities in Massachusetts and Other States (continued)

### Policy Priorities

#### Opportunities and Challenges for Palliative Care Professionals in the Age of Health Reform

Devon S. Fletcher, MD, Joan T. Panke, MA, RN, ACHPN. *Journal of Hospice and Palliative Nursing*. 2012; 14(7):452-459.

| Table A. Selected Policy Priorities for Hospice and Palliative Care |   |
|---|---|
| <b>Access</b>   | <ul style="list-style-type: none"> <li>• Adherence to national consensus guidelines, standards, and preferred practices to ensure provision of high-quality hospice and palliative care and to reduce variation.</li> <li>• Increased outpatient and home care services and ongoing administrator, provider, and public education to improve perception of palliative and hospice care's scope and positive outcomes.</li> <li>• Primary palliative care training for all specialties will increase provider skills and focus specialty-level palliative care services for the most complex needs.</li> <li>• Triggers to allow for early identification of high-risk patients in need of palliative services across settings (Hospital, emergency department, nursing facilities, rehabilitation and specialty hospitals, outpatient settings).</li> <li>• Regulatory and accreditation requirements to reduce variation in services.</li> </ul> |
| <b>Workforce</b>  | <ul style="list-style-type: none"> <li>• Increase specialist-level workforce across disciplines; providers trained, credentialed, and certified in hospice and palliative care (across disciplines).</li> <li>• Expansion of the number of training sites for providers (nurses, physicians, social workers, chaplains, and others) to receive standardized training.</li> <li>• Loan forgiveness programs to offset costs of subspecialty training.</li> </ul>   |
| <b>Research</b>   | <ul style="list-style-type: none"> <li>• Funding for hospice and palliative care research may be the highest priority.</li> <li>• Testing new delivery models and demonstrating hospice and palliative care outcomes.</li> <li>• Evaluating and reporting on quality outcomes based on new measurement standards.</li> <li>• Exploring and testing opportunities for improved communication and response to needs including social media and other technology-based communication methods.</li> <li>• Specific research priorities as outlined in hospice and palliative care membership organizations.</li> </ul>  |

## Appendix G:

### End of Life / Palliative Care Policy-Related Activities in Massachusetts and Other States (continued)

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#### Policy Priorities (continued)

*Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis.* IOM Report Brief September 2013.

Link: <http://www.iom.edu/Reports/2013/Delivering-High-Quality-Cancer-Care-Charting-a-New-Course-for-a-System-in-Crisis.aspx>

#### GOAL 2

In the setting of advanced cancer, the cancer care team should provide patients with **end of life care consistent with their needs, values, and preferences.**

##### Recommendation 2

- Professional educational programs should **train clinicians in end of life communication.**
- The cancer care team should **revisit** and **implement** their patients' **advance care plans.**
- **Cancer care teams should provide patients with advanced cancer:**
  1. **Palliative care**
  2. **Psychosocial support**
  3. **Timely referral to hospice for end-of-life care**
- CMS and other payers should design, implement, and evaluate **innovative payment models.**