

MOLST Demonstration Program: Recommendations for Statewide Expansion

Pilot Results 2011





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I. Executive Summary

Persons with life-limiting illness who are nearing the end of life need to know that they will be cared for with compassion and dignity, and that their preferences for medical treatment will be honored. Yet even when patients are well informed about care options, their goals of care are not always met. While some patients may undergo more intensive medical interventions than they want, others may receive less. This discrepancy between what patients want and what they receive often results from inadequate communication among the patient, the family and the health care provider. Recent initiatives such as the National Priorities Partnership, convened by the National Quality Forum, have acknowledged this issue by identifying effective communication about treatment options as an important element of compassionate care.

In Massachusetts there is no standardized way for patients to express life-sustaining treatment preferences in a way that can be readily understood and followed by members of the health care team in all settings of care. To address these concerns, the Massachusetts Legislature mandated the Medical Orders for Life-Sustaining Treatment (MOLST) Demonstration Program in 2008. To that end, a Steering Committee was charged with planning, designing and demonstrating how MOLST could be implemented in one region of the Commonwealth. Nine implementation sites across the continuum of care were recruited in the Worcester area.

MOLST is a process and a standardized form used to translate life-sustaining treatment preferences into valid medical orders that can be honored across all healthcare settings. MOLST is a tool clinicians may use to document patient preferences about life-sustaining treatment *after* thoroughly discussing with patients their medical condition, prognosis, the potential burdens and benefits of any recommended treatments, and the patient's values and goals of care. MOLST is intended for patients of any age who are nearing the end of life with a serious advancing medical condition, including (but not limited to) life-threatening disease or injury, chronic progressive disease and/or medical frailty. MOLST use is voluntary and the MOLST form may indicate that the patient accepts <u>or</u> refuses certain treatments. MOLST is not intended for routine use with patients who have early stage or stable medical conditions.

Based on the national paradigm POLST, or Physician's Orders for Life-Sustaining Treatment, the Massachusetts MOLST form was modified after interviews with scores of health care professionals and diverse consumer groups in the Commonwealth. Input from a broad array of participants, both professional and consumer, was also solicited and incorporated into the development of the MOLST process and other MOLST materials.

Clinicians began using the MOLST form in the demonstration sites on April 1, 2010. Use of the form and process was promoted by local site champions. Health care professionals at the sites and in the surrounding communities participated in MOLST training and informational sessions. The demonstration provided the opportunity to test the process of implementation, to identify facilitators and barriers in MOLST utilization, and to uncover other related issues.

Chief among the findings in the demonstration program was that MOLST was seen as an improvement over existing tools for documenting preferences for care near the end of life. Consumer groups identified MOLST as a tool that could greatly benefit patients and families. Clinicians welcomed the MOLST form as a document that is easy to use, well-organized, and adaptable for different settings. Strong support emerged from not only the demonstration sites but also from numerous other interested individuals and organizations.

As a result of the overwhelmingly positive findings from the MOLST Demonstration Program, the MOLST Steering Committee holds the vision that in Massachusetts:

- 1. Every suitable patient will be offered the opportunity to utilize a MOLST form in concert with that patient's clinician to communicate life sustaining treatment preferences across health care settings.
- 2. Every emergency medical technician will receive MOLST training and be authorized to honor valid MOLST forms.
- 3. Every major hospital system and health care plan will implement policies and procedures to facilitate the appropriate utilization of MOLST by clinicians and patients.
- 4. Every clinician will seek to improve communications skills with patients nearing the end of life; have access to MOLST education; and be encouraged by professional organizations and regulatory bodies (e.g. Boards of Registration, Massachusetts Medical Society) to utilize MOLST correctly.
- 5. MOLST forms as well as education and outreach materials will be uniform; linguistically appropriate; culturally relevant; easily available; accessible to persons with disabilities; and recognized by health professionals and consumers alike.

In order to achieve this vision, the Steering Committee believes that the following recommendations for statewide expansion of MOLST must be fulfilled:

- 1. Statewide MOLST expansion should be strategic and occur over time to assure program integrity and promote appropriate use of MOLST.
- 2. In keeping with the first recommendation, an organizational "MOLST home" and project coordinator should be designated with funding for three years to oversee MOLST expansion.
- 3. Ongoing statewide access to MOLST and end-of-life care training should be available and promoted for health care professionals.
- 4. An awareness campaign about end-of-life care in Massachusetts including MOLST should be conducted, as also recommended in the 2010 Report of the Massachusetts Expert Panel on End-of-Life Care.
- 5. To assure continuous quality improvement and maintain program consistency and integrity, ongoing tracking and evaluation activities should be incorporated at the institutional level by all organizations implementing MOLST.

In keeping with the spirit of collaboration, strategies for statewide implementation of MOLST should first include combining efforts with other initiatives with mutually enhancing aims, as well as beginning expansion with institutions that have shown interest in, and have capacity to, implement MOLST. The MOLST Steering Committee looks forward to working with the Executive Office of Health and Human Services to further develop plans for MOLST expansion.

II. The Need for MOLST in Massachusetts

Background

As life expectancy has increased in the United States, many Americans experience chronic illness, disability, and periods of decline and frailty in the last years of life. Ultimately, as the end of life approaches, seriously ill persons need to know that they will be cared for with compassion and dignity, according to their wishes. Yet too often these wishes are unknown, unspoken or unavailable to health care providers at the time treatment decisions need to be made. This can result in unmet needs, even discomfort for dying patients; disappointment and confusion for family members; and frustration and dissatisfaction for health care providers.

For individuals with serious advancing illnesses who are not likely to recover, conversations about life-sustaining treatment preferences among the patient, the family and the clinician are of particular importance. Such discussions are often difficult for everyone involved; however, they serve to help patients, their loved ones and health care providers better understand the patient's medical condition, treatment options and goals of care. Without explicit understanding of patient preferences, health professionals may feel compelled to provide unwanted medical treatments to extend life, and these interventions can sometimes increase patient suffering and diminish quality of life at the end of life.¹ Conversely, health providers or family members may assume the patient wants comfort measures alone, resulting in less intensive medical interventions than the patient would otherwise have chosen.

Patient-centered care addresses and fulfills the needs, desires, and goals of care as expressed by the patient in the context of meaningful discussion with a health care provider and with family members. In Massachusetts, however, even when patients with the gravest illness have had discussions with their clinicians and have made medical decisions related to life-sustaining treatments, there is no standardized way for them to express their preferences in such a way that they will be honored across the continuum of health care settings where end-of-life care is often provided (e.g. hospital, nursing home, outpatient, rehabilitation, etc.). All Massachusetts adults can, and should be encouraged to, sign a health care proxy form to appoint a health care agent² as a first step in the process of planning in advance for serious illness. However, the process of appointing a health care agent through a health care proxy does not necessarily take into account specific medical conditions or decision points, and is often executed without input from a clinician.³

¹ Mack JW, Weeks JC, Wright AA, Block SD and Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology*, 2010 Mar 1;28 (7):1203-8.

² The health care agent is the person authorized to make medical decisions on behalf of a patient who has lost capacity to make those decisions as determined and documented by the patient's clinician.

³ In 2005 a Massachusetts End of Life Commission (MEOLC)/AARP Massachusetts survey found that while 59% of respondents reported having signed a health care proxy form, only 17% had talked with their doctor about their end of life wishes. Dinger E. *Massachusetts AARP End of Life Survey* Washington DC, 2005)

To enable patients to communicate resuscitation preferences, the Comfort Care/Do Not Resuscitate (CC/DNR) Verification Protocol was established in Massachusetts in 1999. The CC/DNR form gives emergency medical responders an actionable verification of existing DNR orders for persons in out-of-hospital settings. However, this form is limited to EMT use in outpatient settings only, for resuscitation instructions only, and remains largely underutilized by many health professionals and patients to communicate patients' preferences for resuscitation even in these limited circumstances.

The absence of a standardized way to communicate patients' life-sustaining treatment preferences across care settings is further complicated by a widespread lack of knowledge, comfort and skill for end-of-life medical decision-making in Massachusetts – among patients and health providers alike. These manifest in the inconsistent use of end-of-life terms and mechanisms (e.g. proxy, agent, advance directive, living will⁴); confusion about who can serve as an authorized medical decision-maker in various situations or settings; insufficient information about patient preferences; and many missed opportunities for important discussions between clinicians, patients, and patient representatives about the patient's goals of care at the end of life.

However, despite these gaps and challenges, the Commonwealth has worked consistently over the past two decades to improve its end-of-life medical care. With the passage of the Health Care Proxy Law in 1990 and the landmark Health Care Reform Act in 2006⁵, which included the creation of the Massachusetts Health Care Quality and Cost Council ("MHCQCC"), Massachusetts has shown a commitment to improving care for patients at the end of life. Based on the report of the MHCQCC End-of-Life and Chronic Care Committee in 2008, the Massachusetts legislature has called for several related initiatives⁶:

- Creation of an expert panel on end-of-life care to recommend public policy and best practices for the delivery of such care to patients with serious chronic illness;
- Initiation of a public awareness campaign about the importance of end-of-life care planning; and
- Establishment of a pilot program to implement and test a physician order for lifesustaining treatment (POLST) paradigm program to assist individuals in communicating end-of-life care directives across care settings in at least one region of the Commonwealth.

⁴ Many patients, family members and health care agents don't know that there is no legal statute in Massachusetts to authorize the content of living wills. A comparison of end-of- life medical and legal instruments/terms is provided in Attachment H.

⁵ Chapter 58 of the Acts of 2006, Massachusetts General Laws

⁶ Chapter 305 of the Acts of 2008, Massachusetts General Laws

Massachusetts Medical Orders for Life-Sustaining Treatment: MOLST

The "Physician Order for Life-Sustaining Treatment (POLST) paradigm" was developed in 1991 in Oregon to address public concern that patients' end-of-life medical treatment wishes were not known or were not being honored. POLST programs feature "effective communication of patient wishes, documentation of medical orders on a brightly colored form and a promise by health professionals to honor these wishes."⁷ Like some other states, in Massachusetts we call our program "MOLST" - with an "M" for "medical" orders.⁸

MOLST is a process and a standardized form used to translate lifesustaining treatment preferences for patients across the life span into valid medical orders to be honored across all health care settings. Based on the principle of patient self-determination and an individual's right to accept or refuse medical care, *MOLST is an appropriate way to meet the clinical standard of care for communicating and honoring patients' life-sustaining treatment preferences across health care settings.*⁹

"To me, in this form here, you are empowering patients with these words. I think that this is great and I want it for me." - General community focus group participant

MOLST is intended as a tool clinicians may use to document preferences about life-sustaining treatment *after* discussing with patients their medical condition, prognosis, the potential burdens and benefits of any recommended treatments, and the patient's values and goals of care. MOLST is intended for patients of any age who are nearing the end of life with a serious advancing medical condition, including (but not limited to) life-threatening disease or injury, chronic progressive disease and/or medical frailty. MOLST use is voluntary and the MOLST form may indicate that the patient requests <u>or</u> refuses certain treatments. MOLST reflects a patient's current life-threatening medical condition and is not intended for routine use with patients who have early stage or stable medical conditions.

The process begins with discussions about the goals of care between a clinician, patient and the patient's loved ones and healthcare decision-maker(s). These essential discussions to explore and clarify the patient's condition, prognosis, and the benefits and burdens of treatment, as well as the values of the patient, ensure that medical treatment decisions are clinically sound and based on the patient's understanding and preferences. Only then are treatment preferences documented as medical orders on the MOLST form.¹⁰

MOLST offers a significant new way for Massachusetts patients and families to make and express informed choices about lifesustaining treatments. Persons with serious advancing illness can now utilize MOLST with their clinicians to *relay specific instructions about refusing or accepting a range of lifesustaining treatments via medical orders to be honored by all* "Sometimes we view these things with skepticism ...aggressive treatment versus DNR...Who decides what gets offered to **us**?...For me, the MOLST form can indicate what **we want**...they can't assume that they would want the same things." - African American focus group participant

⁷ More POLST information may be found at <u>www.polst.org</u>.

⁸ In Massachusetts and in other states, POLST/MOLST forms may be signed by physicians, nurse practitioners or physician assistants.

⁹ Massachusetts Department of Public Health issued *Circular Letter: DHCQ 10-02-529*, endorsed by the Boards of Registration in Medicine, Nursing, and Physician Assistants and the Office of Emergency Medical Services

¹⁰ The Massachusetts MOLST form is provided in Attachment A.

health professionals in any care setting, including at home. The potential of MOLST in Massachusetts includes: increased shared end-of-life medical decision-making; increased adherence to patients' life-sustaining treatment preferences; and decreased provision of burdensome medical tests and treatments to patients who do not want them.

III. The MOLST Demonstration Experience

Charge and Leadership

In response to the Massachusetts legislation mandating the *establishment of a pilot program to implement and test a POLST paradigm program... in at least one region of the Commonwealth*¹¹, a state-level, multi-sector Steering Committee was convened in 2008. With oversight from the Massachusetts Executive Office of Health and Human Services Department of Public Health and the Executive Office of Elder Affairs, program management was provided by the Center for Health Policy and Research at Commonwealth Medicine, a division of University of Massachusetts Medical School. The Steering Committee's task was to plan, design and demonstrate how Medical Orders for Life-Sustaining Treatment could be implemented in Massachusetts, including education for health professionals; outreach to patients and caregivers; the development of measures to test the success of the program; and the development of recommendations for the establishment of a statewide program.

Selecting the Demonstration Locale

The Steering Committee selected the Greater Worcester area for the demonstration based on a number of factors including: size of the geographic area¹²; access to health care institutions with established referral patterns and shared patient flow; clinical leadership from University of Massachusetts Memorial Health Care; and prior experience with successful community collaboration to improve end-of-life patient care through the Better Ending Partnership, a Worcester-based end-of-life coalition which promoted advance care planning and the use of health care proxies in central Massachusetts during the previous decade .¹³ Nine organizations representing a variety of health care settings were then recruited as implementation sites: two acute care hospitals¹⁴, three nursing homes, two hospices, one managed care practice and local emergency medical services.

¹¹ Chapter 305 of the Acts of 2008, Section 43, Massachusetts General Laws

¹² With an estimated population of 182,882 (2009), Worcester is the third largest city in New England. Source: census.gov.

¹³ Better Ending Partnership was a community coalition of professional, civic, business, and religious leaders committed to improving end-of-life care in the central Massachusetts region from 2002 to 2009. A major initiative of the Partnership was the production and dissemination of the *Guide for a Better Ending, a* consumer educational brochure about advance care planning. See <u>www.betterending</u>.org.

¹⁴ One of the acute care hospitals joined the demonstration at a later date than the other sites and soon lost the primary site-level "MOLST champion" to a different health care institution. As a result, the hospital did not begin utilizing MOLST with patients during the demonstration period.

Community Engagement

Throughout all phases of the MOLST demonstration program, input from both the lay community and the health care community was encouraged, solicited and incorporated.

To gain perspectives on MOLST from the diverse consumer base in Worcester, 59 participants were recruited for five focus groups facilitated by the Central Massachusetts Area Health Education Center, Inc., a partner in previous Worcester-based Better Ending Partnership initiatives. The groups were comprised of English"We would have been afraid to talk about this before...but because of the education we have gotten in the past few years about the health care proxy, here at the senior center, we are ready now to talk about this...this very helpful." – Vietnamese focus group participant

speaking Caucasians, Spanish-speaking Latinos, English-speaking African-Americans, Vietnamese speakers, and individuals with various types of physical and mental disabilities residing in the Worcester area. Ten key stakeholder interviews were also conducted with select local community leaders and informants. Consumer perspectives were considered in developing the MOLST process, form and materials, in order to be as patient-centered as possible and to be responsive to the wide array of cultural perspectives about end-of-life and health care that were shared. Key consumer input included concern about the manner in which MOLST would be presented and the support that would be offered to patients; the need for (and doubt of receiving) ample clinician time to explain all aspects of MOLST; themes of mistrust and past difficult experiences with health care providers; the integral role of the family in MOLST discussions and decision-making; the importance of attending to relevant cultural and linguistic dynamics and needs during the patient-provider encounter (including interpretation and translation); the need for more explanation about end-of-life decision-making and tools (especially how MOLST differs from the health care proxy, DNR orders and living wills); and a general and unanimous dislike of the term "MOLST." Significantly, the participants recommended that the content of the MOLST form, along with descriptions of the potential treatments, be translated into Spanish and Vietnamese to assist speakers of those languages to better comprehend the nature of the medical interventions. Participants also made recommendations regarding how to make information accessible to persons with disabilities, particularly those with visual and auditory disabilities. All of the groups and interviewees repeatedly expressed recognition of the value and utility of MOLST.

Health professionals were also engaged from diverse health care settings and communities via

presentations at multiple health care and professional organization settings and through face-to-face key stakeholder interviews. Perspectives from potential clinician signers of the MOLST form as well as from nurses, social workers, clergy, emergency responders, medical interpreters, and other health professionals who could potentially engage with patients and families in the MOLST process were intentionally garnered to assure medical integrity and clinical relevancy. Key feedback included support for the intent and

"Please...make sure you involve the family!! If the doctor knows that they are going to talk about this, have the person bring a family member!" – Latino focus group participant potential of the MOLST program; the need for engaging in more of these important conversations with patients and their families; lack of clarity about the terms used and available resources for end-of-life care planning; and the desire for more related information and training.

Massachusetts MOLST Form

The creation of the initial demonstration MOLST form tailored for use in Massachusetts was an iterative process involving substantial and frequent modifications to the wording, concepts and format based on input from scores of health care professionals (including physicians, nurses, nurse practitioners, social workers and emergency medical personnel) as well as diverse consumer groups. Time was spent reviewing other states' POLST forms and then adapting them to reflect the social, medical, and legal environment in Massachusetts as well as the lessons learned when the Massachusetts Comfort Care/Do Not Resuscitate Verification Protocol (CC/DNR) form was introduced. The resulting MOLST form differs from other states' POLST forms in several respects, with medical orders for use in emergent situations on the first page and a series of patient preferences about other possible life-sustaining treatments on the second page. The form allows the patient and clinician to indicate that a particular issue was not discussed or that no decision was reached. The intent is to create a document that facilitates succinct communication of accurate information reflecting individualized treatment preferences across settings of care. Final changes were made based on feedback received during the demonstration program and, as finally proposed, the Massachusetts MOLST form meets with widespread approval from demonstration site participants and other health care professionals and consumers.

Demonstration Site Preparation

Between January and December of 2010, each demonstration site provided one or more key personnel to champion and coordinate site-level MOLST implementation. These individuals engaged in the substantial tasks of preparing institutional policies, protocols and infrastructure; identifying training strategies for staff and venues; creating tools and methods for tracking MOLST activity; and overall oversight and troubleshooting during MOLST implementation. These "champions" also engaged with one another across demonstration sites via regular meetings and consultations with clinical liaisons from the MOLST planning team, to discuss experiences, issues, successes and challenges arising during MOLST implementation at their respective sites. In February 2010, a MOLST launch event was held in Worcester with approximately 150 attendees from all sectors of the health care system as well as community participants. At the same time, the Massachusetts Department of Public Health issued *Circular Letter: DHCQ 10-02-529*, endorsed by the Boards of Registration in Medicine, Nursing, and Physician Assistants and the Office of Emergency Medical Services, to inform and prepare its regulated entities about the MOLST demonstration program.

Training and Outreach

Ensuring that health care professionals understand the purpose and the use of MOLST is essential to its implementation. Numerous questions arose in the course of MOLST training, not only about the use of the form but also about medical decisionmaking and communicating with patients about end-of-life issues. Successful implementation therefore requires not only disseminating information but also providing opportunities for trainees to ask question as well as a chance to participate in dialogue about their concerns. Accordingly, more than 1200 administrators, clinicians, and other health and social service professionals from the MOLST demonstration sites and

"It is very, very important for the doctor to be sensitive....ask the patient first if they are comfortable talking about this...respect their religious beliefs and their language...make sure they understand what you are saying...if they don't, use an interpreter. If they (patients) are not comfortable, maybe they will let you talk with their family...that can be their emotional support." – Vietnamese focus group

approximately 700 emergency medical technicians¹⁵ participated in face-to-face MOLST training, orientation or presentations. Outside of the demonstration sites, another 700 clinicians, health and social service professionals, first responders, policymakers, consumers, patient advocates and stakeholders also received face-to-face MOLST informational sessions. In addition, thousands of consumers, health professionals and other stakeholders received information about MOLST via print materials, video and/or the MOLST website at <u>www.molst-ma.org</u>.

MOLST Utilization with Patients

Clinicians began using the MOLST form with patients on April 1, 2010 at eight Greater Worcester area demonstration sites: three nursing homes, two hospices programs, one acute care hospital, one geriatric home-based physician program, and Region 2 emergency medical services.

After institutional MOLST policy and procedure development, the *nursing homes* introduced MOLST first to their nursing home patients who had already chosen to limit treatment (through DNR orders, for example) ¹⁶ or who were being transferred to hospitals or other care settings. Later MOLST was introduced to nursing home patients and their families during periodic care review meetings and to new admissions to the facility.

The *acute care hospital*, the largest and most complex of the demonstration sites, implemented MOLST slowly but steadily. After developing and approving an institutional policy and procedures to incorporate MOLST into current practices, use of the MOLST form advanced

¹⁵ Data provided by OEMS capture only EMTs who applied for OEMS MOLST training credits; the actual number trained (including local fire/police first responders) is higher. OEMS data were not tracked by region, though it is known that EMTs from most if not all regions of Massachusetts participated in MOLST training. In November 2010 there were approximately 24,000 EMTs in the Commonwealth, including basic, intermediate and paramedic levels. Therefore, a very large number of EMTs will still require MOLST training.

¹⁶ One nursing home administrator reported that 95% of their long term care patients already had DNR orders and so clinicians saw no urgency in also offering MOLST forms.

primarily in relation to the degree of awareness, interest and leadership of clinicians in various departments or inpatient floors, the strongest of which was in the hospital medicine service. Although it was not feasible for the hospital to track the number of MOLST discussions or forms signed throughout the demonstration program, a chart review of patients discharged from the hospital medicine service on three different days during the demonstration program showed an average of 20% of patients with inpatient limitation of treatment (LOT) orders had a signed MOLST form at discharge. Also noted during the demonstration time frame was an increase in the overall numbers of patients with LOT orders while hospitalized.¹⁷ By the end of the demonstration period, the hospital had plans for embedding MOLST into its quality improvement initiatives with the intention of continuing to offer to patients with serious advancing illness the opportunity to discuss life-sustaining treatments and documenting their preferences on a MOLST form.

The *emergency department* (ED), typically located within a hospital facility, is considered an outpatient clinical setting by regulation. Therefore, a separate policy and procedures were required to address the particular needs of that setting of care. The consensus among ED personnel was that the bedside nurse was the most likely person to take responsibility for the MOLST form, by entering that information into a medical record (whether paper or electronic), and by communicating to the rest of the clinical team the presence of a MOLST form.

MOLST implementation in the *geriatric managed care home visiting program* proved to be a "good fit" for several clear reasons: patients were enrolled because of specific medical conditions that also made them suitable for MOLST; nearly all of the patients had capacity to engage in goals of care discussions and were able to sign the MOLST forms themselves; and monthly home visits conducted by nurse

"They should be offered support at the same time they are given this information." - General community focus group participant

practitioners allowed for discussions to occur over time with clinicians who had authority to sign MOLST forms with patients. Between April and November, 44% of enrolled patients were offered MOLST as an option, and half of them elected to sign MOLST forms.

Reports of *emergency medical technician (EMT) encounters* with patients who had signed MOLST forms in the field were relatively few due to the limited scope and time frame of the demonstration program. However, in the situations when MOLST forms were encountered, EMTs reported that the MOLST provided instructions that were helpful and were honored as appropriate. The Emergency Medical Control physicians, who are in radio contact with EMTs, reported that the usual procedure in their experience for honoring a CC/DNR form "in the field" is to communicate with Medical Control to get "permission" to honor the DNR order. The expectation from the Medical Control physicians was that the EMT would do the same when

¹⁷ This was probably due to a combination of improvements made in the hospital's electronic documentation tool for limitations of treatment (LOTs) and/or increased conversations about end-of-life care.

they encounter a MOLST "in the field." While this was not part of the official policy and procedure outlined, it seems to be the general practice within the region of the demonstration.

Hospice programs utilized the MOLST form less. Because most patients enrolled in hospice have already engaged in extensive discussions about goals of care and have already established life-sustaining treatment preferences, hospice personnel suggested that waiting to complete the MOLST form at this late stage was less likely to benefit most hospice patients.¹⁸ Still, hospice personnel indicated that MOLST could potentially help patients and their families engage in these important discussions and begin the decision-making process if it were introduced at earlier stages in their disease.

MOLST utilization in select demonstration sites	Number of patients	Number of patients offered MOLST (% of all patients)	Number of MOLST signed (% of all patients)	Patients offered MOLST who signed MOLST form (%)
Nursing Homes (n = 3)	351	65 (19%)	45 (13%) April – August	69%
Geriatric Home Visiting	260	115 (44%)	58 (22%) April –	50%
program			November	

It is important to recognize that because use of the MOLST form is voluntary, the measure of implementation success is not the quantity of signed MOLST forms, but the *number of suitable patients who were offered the opportunity to utilize MOLST to reflect the discussions that took place prior to signing MOLST forms.* At the same time, it is very difficult to determine the "denominator" – that is, the total number of patients who are suitable for MOLST. This denominator is not easily determined by a patient's age or diagnosis because every individual and situation is different. In fact, determining which patients may be suitable for or benefit from utilizing MOLST can be more of an art than a science.

It is also important to note that well over half of the patients who signed MOLST forms had DNR orders already, yet elected to sign a MOLST form, indicating a desire to express preferences about a wider range of life-sustaining treatments than previous documentation tools allowed.

The MOLST demonstration program was neither designed nor expected to evaluate patient outcomes, or the degree of adherence to patients' preferences. However, the question of whether patients with MOLST forms were more likely to have their life-sustaining treatment preferences known and honored at the end of life than patients without MOLST forms is one that should be explored. This type of evaluation will become possible as individual institutions begin to implement, embed and measure MOLST patient outcomes as part of their ongoing quality improvement initiatives.

¹⁸ Like the nursing homes, the hospice programs did offer and sign MOLST forms with a few patients who were transferred to hospitals or other settings.

Lessons Learned¹⁹

The MOLST demonstration provided the opportunity to: observe and test the *process* of MOLST implementation in various types of health care settings; track elements that inhibited or enhanced *utilization*; and note intervening or emerging *issues*. Some of the key findings in these areas were:

- MOLST can be implemented effectively in most institutions in a relatively short period of time with the appropriate commitment of time and other resources;
- Adequate time must be invested in the preparatory work of developing MOLST policies and procedures, and approval processes;
- Institutions need an on-site "MOLST champion" to succeed with MOLST implementation;
- Health professionals need training and access to ongoing coaching, support, and troubleshooting during MOLST implementation;
- Health professionals need training about how to discuss patient-centered medical decision-making, end-of-life care and goals of care with patients and their families;
- Patients, families and health professionals all need more education about end-of-life care terminology, related Massachusetts laws and medical decision-making processes;
- Limited clinician time for discussions with patients and families is a barrier in <u>every</u> setting;
- Patients want to use MOLST not only to document their preferences to *limit* life-sustaining medical treatment, but also to affirm their wish to *accept* life-sustaining treatment;
- Engagement and collaboration with individuals in the community is important because MOLST implementation must be individualized for every site and setting;
- Limited access to health care agents (for signatures) slows the process in nursing homes and at the time of discharge from acute care hospitals;

"We are not heard, we are not listened to...it's like we don't have the capacity to make our own decisions...MOLST could help us make our choices known and adhered to...that's why it's important to state that the MOLST will be honored, not may be honored." – Persons living with disabilities

 Persons living with disabilities focus group participant

- EMTs who received MOLST training found the transition to MOLST from the CC/DNR form easy and considered MOLST to be a better form;
- The emergency room is a challenging place to implement MOLST in the hospital because of competing demands for clinician attention, variable patient populations, and the intense, busy setting;
- Health professionals in all the demonstration site settings considered MOLST an improvement over existing documentation tools/systems;

¹⁹ More detailed lessons learned in the demonstration sites are provided in Attachment B.

• All the demonstration sites plan to continue using MOLST beyond the demonstration period.

"This is a beautiful way to be able to take care of your loved ones' last moments. I am at peace with my Mother's death...we were there with her the whole time...I feel pride that, as a family, we could take care of her every need...she had dignity and respect and comfort as she moved on to her next life." - Latino focus group participant

IV. Recommendations for MOLST Expansion

Although the MOLST Demonstration Program was complex and challenging on many fronts, the experience elicited overwhelming interest in and support for the MOLST process and form. Strong interest emerged not only from the demonstration sites, but also from numerous other public and private health care institutions, from professionals and consumers alike – all of this during a time of public conflict about end-of-life medical care related to national health care reform. The Steering Committee continues to field increasing requests for information and assistance from health care organizations throughout the Commonwealth that are eager to begin implementing MOLST with their patients.²⁰ It is clear that MOLST addresses an important unmet need in Massachusetts by providing a standardized process and tool for clinicians, patients and their families to discuss, understand, and arrive at challenging health care decisions and to communicate those decisions across health care settings.

Moreover, the demonstration experience suggests that MOLST fits well into Massachusetts' existing health care system reform goals. For example, there appears to be significant potential for MOLST to positively impact quality of care and to promote principles of patient-centered care. Based on findings from other POLST paradigm states and end-of-life care research, MOLST will likely promote patient choice and improve the quality of shared medical decision-making and thus provide for more patient-centered use of health care resources. In some cases this could help to ease transitions of care between institutions and reduce avoidable hospital re-admissions as well as avoid extended end-of-life hospital stays for patients who have expressly stated that they do not want them. Therefore,

²⁰ MOLST planning has begun at Harvard Vanguard, Partners HealthCare System and Children's Hospital of Boston, for example.

The MOLST Steering Committee recommends expanding MOLST implementation beyond the demonstration area beginning in 2011, with the ultimate goal of full statewide MOLST implementation by January 2014²¹, in keeping with the following vision and specific recommendations:

	VISION
assach	usetts,
>	Every suitable patient will be offered the opportunity to utilize a MOLST form in concert with that patient's clinician to communicate life-sustaining treatment preferences across health care settings;
۶	Every EMT will receive MOLST training and be authorized to honor valid MOLST forms;
\blacktriangleright	Every major hospital system and health care plan will implement policies and procedures to facilitate the appropriate utilization of MOLST by clinicians and patients;
>	Every clinician will seek to improve communications skills with patients nearing the end of life; have access to MOLST education; and be encouraged by professional organizations and regulatory bodies (e.g. Boards of Registration, Massachusetts Medical Society) to utilize MOLST correctly;
	MOLST forms as well as education and outreach materials will be uniform; linguistically appropriate; culturally relevant; easily available; accessible to persons with disabilities; and recognized by health professionals and consumers alike.

Recommendations

1) Statewide MOLST expansion should be strategic and occur over time to assure program integrity and promote the appropriate use of MOLST.

The use of MOLST as a tool to document decisions about life-sustaining medical treatments will provide the greatest benefit to patients, providers, and health care institutions when all have been properly trained and informed. To achieve the anticipated benefits of the program, a facilitated, step-wise rollout of the program is recommended. Full statewide implementation of MOLST in Massachusetts will require:

• *Cultural change* as health professionals and patients learn about and understand the intent and use of MOLST;

²¹ The recommendation to expand MOLST is supported by the Massachusetts Expert Panel on End-of-Life Care; the Massachusetts Health Care Quality and Cost Council; the Massachusetts Board of Registration in Medicine; the Massachusetts Care Transitions Forum; Greater Boston Legal Services; and Health Care for All. Did I hear Martina say there is a new name for the Expert Panel?

- *Community change* as communities plan MOLST implementation strategies with the best chance for success;
- Organizational change as hospitals, nursing homes, hospices, home health agencies, multi-specialty provider groups, insurers, physician practices and emergency responders expand their policies and procedures to utilize MOLST;
- Individual change as clinicians and patients learn about and adopt the MOLST process and form correctly as an appropriate way to meet the clinical standard of care for communicating patient preferences about end-of-life medical treatment across health care settings.

2) In keeping with the first recommendation above, an organizational "MOLST home" and project coordinator should be designated with funding for three years to oversee MOLST expansion.

The demonstration experience and continuing requests from health care organizations and individuals needing assistance with MOLST planning and use strongly support the need for a MOLST institutional home and dedicated staff. Full statewide expansion will require expertise to:

- Identify, coach and support institutional MOLST champions and teams;
- Coordinate expansion efforts between institutions, payers, patient groups, and providers;
- Assure a mechanism for reaching final decisions about changes to, and maintaining standardization of, the MOLST process and form;
- Track MOLST implementation progress; maintain and assure the relevancy and quality improvement of the MOLST website, training modules and educational outreach materials;
- Provide and facilitate technical assistance for communities and providers implementing MOLST;
- Engage individuals and organizations in communities in order to adapt implementation strategies to community needs;
- Communicate about MOLST with state government, health care systems and the public.

3) Ongoing statewide access to MOLST and patient-centered end-of-life care training should be available and promoted for health professionals.²²

Training of health professionals throughout the workforce is needed to maintain the patientcenteredness of the project and the appropriate emphasis on the MOLST communication process – especially the importance of goals of care discussions prior to completing MOLST forms and increased capacity of clinicians to engage in such conversations. The demonstration training materials and MOLST website, with additional adaptations, provide a solid foundation

²² A plan for statewide training is required for endorsement of statewide programs by the National POLST Paradigm Task Force.

and platform for training. Specific recommendations related to training health professionals include to:

- Establish webinars and/or statewide conference calls for MOLST training, troubleshooting and coaching;
- Create online training modules for professionals and track participants;
- Develop multimedia and video training about patient-centered end-of-life care conversations;
- Provide CMEs, CEUs, risk management credits, etc. for completion of MOLST training;
- Require MOLST training for Emergency Medical Technicians (EMTs);
- Collaborate with the Massachusetts Medical Society (MMS) for continued support of physician training for end-of-life care;
- Train a core of authorized MOLST training consultants, i.e. train-the-trainer sessions for EMS Regions I-V;
- Develop training for supporting professionals, such as medical interpreters, patient navigators, and geriatric care managers to assist patients and families in understanding MOLST.

4) An awareness campaign about end-of-life care in Massachusetts including MOLST should be conducted, as recommended in the 2010 Report of the Massachusetts Expert Panel on End of Life Care.

Such a campaign is vital to:

 Enhance public understanding and build a common vocabulary for these important end-of-life care conversations; "This MOLST...maybe this can help us be heard." – Persons living with disabilities focus group participant

- Educate the public about information and resources related to end-of-life care in Massachusetts;
- Inform patients and families about medical decision-making in Massachusetts especially about the vital role of the health care proxy and the MOLST process and form;
- Inform physician offices and groups about the MOLST process and form;
- Build a common understanding and trust between health professionals and the public about the intent and potential of MOLST to increase adherence to patients' end-of-life care treatment preferences.

5) To assure continuous quality improvement and maintain program consistency and integrity, ongoing tracking and evaluation activities should be incorporated at the institutional level by all organizations implementing MOLST.

Tracking and evaluation will be essential for determining the extent to which MOLST is being adopted and implemented in different parts of the Commonwealth to achieve full statewide expansion. These activities will:

- Promote the sharing of lessons learned from MOLST implementation in new communities;
- Provide important information about MOLST utilization, applicability and barriers for a diverse range of cultural, linguistic, and underserved populations in new communities;
- Assure appropriate use of the MOLST process and form.

V. Strategies for MOLST Expansion

Statewide implementation of MOLST should be accomplished by bringing a variety of key public and private agencies, organizations and institutions together to leverage the work already underway to improve the quality of medical care for patients in Massachusetts. Accordingly, we propose the following two phases and a suggested cast of "key players" for expanding MOLST statewide.

Phase One – Expansion through Strategic Collaboration and/or Capacity

Strategic Collaboration

Improving clinician, patient, and family communication in order to improve patient-centered care near the end of life, especially through goals of care discussions and shared medical decision-making, is a major aim of MOLST. Other important goals of MOLST are to increase documentation about patient preferences and to improve communication

among providers and between institutions during transitions of care, which can improve the quality of end-of-life care. There is great potential to achieve these goals through synergy with an impressive number of high-level, cross-continuum initiatives currently underway in Massachusetts. MOLST "champions" may be readily identified among participants in the initiatives listed in the table below. For example, the State Action on Avoidable Hospital Readmissions (STAAR) initiative aims to reduce all-cause 30-day re-hospitalizations and to increase patient and family satisfaction with transitions and coordination of care. Hospitals involved in the STAAR initiative will likely be eager to implement MOLST since it has the potential to reduce the occurrence of re-hospitalization for patients who prefer to remain in the home or a home-like setting at the end of life.

"Listen to what we want...be sensitive and patient...explain every detail...and provide support...don't just give us a pamphlet and send us home." - General community focus group participant As aptly stated by one member of the Massachusetts Health Care Quality and Cost Council and the MOLST Steering committee: *"None of these initiatives can go out in its own silo; MOLST is mutually beneficial and co-dependent on all these other things."*

CURRENT INITIATIVES	MUTUAL AIMS
Medical Orders for Life-	Improving clinician, patient, and family communication about end-of-life
Sustaining Treatment (MOLST)	medical care in order to improve patient-centered care
Massachusetts Expert Panel on	
End-of-Life Care	Increasing documentation and communication of patient preferences across
State Action on Avoidable	the care continuum, resulting in improved care transitions; fewer avoidable
Hospital Readmissions (STAAR)	hospital readmissions; and more meaningful use of resources
initiative	
Massachusetts Care Transition	Increasing education and awareness about medical decision-making and end-
Strategic Plan	of-life care issues and resources among health professionals and consumers,
INTERACT II (in 100 nursing	including disseminating best practices and lessons learned
facilities)	
Common Framework for	Engaging community members, health professionals, policy makers and other
Personal and Public	stakeholders in improving the quality of end-of-life care
Engagement in Health Care	
Massachusetts hospital quality	
improvement initiatives	

<u>Capacity</u>

"Capacity" refers to promoting MOLST expansion *first* in organizations or institutions that have demonstrated both interest in MOLST and also the capacity to implement MOLST effectively. This would also include expanding MOLST implementation to other health care organizations and institutions in the Worcester area. Beyond the Worcester area, several health care institutions with significant capacity to implement and expand MOLST within their various systems have already approached the Steering Committee with requests to begin MOLST implementation.

Phase Two – Expansion by Geographic Region

Once Phase One is well underway and MOLST has been rolled out in organizations with capacity through strategic collaboration, it will be possible to assess the extent to which MOLST has extended to other geographic areas in Massachusetts. If MOLST is not already being championed and implemented in most regions of the Commonwealth (e.g. North Shore/Salem, South Shore, Metro-West, Cape Cod, Boston, Western Massachusetts, Springfield), then it will be advisable to identify and support individuals and/or organizations who can champion, develop and implement MOLST in every region.

Key Players

The successful expansion of MOLST would benefit from the support and involvement of several public and private state-level entities with regulatory, sub-regulatory, membership, collegial and/or other relationships with the Massachusetts health care community. Although others are sure to emerge, key players (and their possible involvement) may minimally include:

ORGANIZATION	SUGGESTED ROLE
Massachusetts Department of Public	Continue supporting MOLST as an appropriate way to meet the clinical
Health (DPH)	standard of care for communicating patients' life-sustaining treatment
	preferences across care settings
	Release a circular bulletin in 2011 to licensed hospitals, long term care
	facilities, licensed ambulance services, and EMTs validating the
	utilization and honoring of MOLST
	Require MOLST training for EMTs
	Plan and facilitate a timeline and strategy to eventually phase out the
	CC/DNR verification protocol form as MOLST becomes the
	communication tool/document of choice
Massachusetts Executive Office of	Provide training on end-of-life issues, including MOLST, for
Elder Affairs (EOEA)	Massachusetts Family Caregiver Support Program specialists, home care
	program providers, Information and Referral staff, and Aging and
	Disability Resource Consortia (ADRC) member agency staff
DPH/EOEA Collaboration	Facilitate communication among key state agencies to determine
	initiatives related to family caregiver support and end-of-life discussions
	Identify ways to increase support for family caregivers caring for loved
	ones at home
	Continue to provide leadership throughout the expansion period of
	MOLST
	Promote consumer and provider education about MOLST via Aging
	Services Access Points (ASAPs), Senior Centers/Councils on Aging,
	primary care clinicians, community health centers, and other community
	health programs
Massachusetts Boards of Registration	Continue supporting MOLST as an appropriate way to meet the clinical
in Medicine, Nursing, and Physician	standard of care for communicating patients' life-sustaining treatment
Assistants	preferences across care settings
Massachusetts Hospital Association	Provide Massachusetts hospital leadership with information about the
Massa shugatta Madisal Casistur	intent and purpose of MOLST for patients
Massachusetts Medical Society;	Communicate about and promote the use of MOLST with Massachusetts
Massachusetts Nurses Association; Association of Physician Assistants	clinicians
Association of Physician Assistants	Continue to support end-of-life care professional education that incorporates CMEs, CEUs, risk management credits, etc.
Massachusetts Home Care Alliance;	Promote dissemination of MOLST training resources and information to
Mass Aging; League of Community	health professionals and consumers
Health Centers; Massachusetts Senior	Help build a common language and understanding about end-of-life care
Care Association; Hospice and Palliative	terms, issues and resources in Massachusetts
Care Federation of Massachusetts	
Massachusetts Association of Health	Support the use of MOLST by including end-of-life care measures and
Plans	documentation of MOLST conversations with appropriate patients as
	quality indicators
	Promote payment mechanisms for the time clinicians spend on MOLST
	conversations

Finally, full statewide expansion of MOLST should include a concerted effort to engage the support of key consumer groups and community organizations, such as Health Care for All, Partnership for Healthcare Excellence and Area Health Education Centers, as well as faith-based and fraternal organizations. These organizations can be encouraged to endorse MOLST as a way to improve the quality of care at the end of life and to promote awareness of MOLST and its potential among their members and constituents.

Conclusion

The Medical Orders for Life-Sustaining Treatment Demonstration Project has shown that MOLST is needed and desired in the Commonwealth by health care professionals and consumers alike. Full statewide MOLST implementation will require strategic oversight, financial resources, technical assistance and coaching from dedicated MOLST staff, as well as ample planning, championship and monitoring within institutions. Despite these challenges, we believe that the potential of MOLST is significant and inspiring. Statewide implementation of MOLST will improve quality of life for patients nearing the end of life and will advance the capacity of institutions in the Commonwealth to achieve health care reform, enable more patient-centered care, enhance quality of care, and use system resources more efficiently. The MOLST Steering Committee looks forward to working with the Executive Office of Health and Human Services to establish an ongoing "home" for the MOLST project and to further develop these plans and strategies for the full statewide expansion of MOLST.

VI. Attachments

- A. Massachusetts MOLST Form
- B. Greater Worcester area MOLST demonstration site details and data
- C. Massachusetts Department of Public Health Circular Letter: DHCQ 10-02-529
- D. Massachusetts MOLST Form: Demonstration Version
- E. Frequently Asked Questions about the Massachusetts MOLST form
- F. MOLST demonstration education and outreach activities
- G. MOLST demonstration materials developed and disseminated
- H. Glossary of terms used for end-of-life planning and care

Attachment A

MA MOLST Form - DRAFT

	SETTS MEDICAL ORDERS for NING TREATMENT na.org	Patient's Name Date of Birth Medical Record Number if ap	
 → This form sho patient's clinic → Sections A-C → If a section is 	Every patient should receive full attention to comfort. build be signed based on goals of care discussions betwee cian. care valid orders only if Sections D and E are complete. So not completed, there is no limitation on the treatment indi ffective immediately upon signature. Photocopy, fax or ele	ection F is valid only if Sections H a cated in that section.	and G are complete.
A	CARDIOPULMONARY RESUSCITATION: for a p	atient in cardiac or respiratory	r arrest
Select one circle ➔	O Do Not Resuscitate	O At	tempt Resuscitation
В	VENTILATION: for a patient in respiratory distr	ess (for non-invasive ventilation see S	ection F on page 2)
Select one circle ➔	O Do Not Intubate and Ventilate	O In	tubate and Ventilate
С	TRANSFER TO HOSPITAL		
Select one circle →	O Do Not Transfer to Hospital (<i>unless needed</i>)	for comfort) 0 Tr	ansfer to Hospital
PATIENT or patient's representative signature D Required - Select circle and fill in every line for valid orders	Select one circle below to indicate who is signin O Patient O Health Care Agent O Signature of patient confirms this form was signed of pa as expressed to the Section E signer. Signature by the p reflects his/her assessment of the patient's wishes and p of the patient's best interests. *A guardian can sign to about guardian's authority.	Guardian* O Parent/Guar tient's own free will and reflects his patient's representative (indicated a goals of care, or if those wishes are	/her wishes and goals of care bove) confirms that this form unknown, his/her assessment
orders	Signature of Patient (or Person Representing the Patient)	Date of Si	gnature
	Legible Printed Name of Signer	Telephone	e Number of Signer
CLINICIAN signature	Signature of physician, nurse practitioner or physician a discussion(s) with the signer in Section D.		
<i>Required</i> – Fill in every line for	Signature of Physician, Nurse Practitioner, or Physician A	Assistant Date of S	gnature
valid orders	Legible Printed Name of Signer	Telephon	e Number of Signer
Optional Expiration date and other patient care contacts	This form does not expire unless expressly stated. Health Care Agent Printed Name Primary Care Physician Printed Name	Telephone	r: Number Number
	SEND THIS FORM WITH THE PA HIPAA permits disclosure of MOLST to health car		

Patient's Name	:F	Patient's DOB Med	ical Record # if applicable
F	Statement of Patie	ent Preferences for Other	Medically-Indicated Treatments
-	Intubation and Ventilation		
Select one circle 🔿	Refer to Section B on Page 1	 Use intubation and ventilation in Section B, but short term on 	
	Non-invasive Ventilation (e.	g. Continuous Positive Airway	Pressure - CPAP)
Select one circle 🔿	 No non-invasive ventilation 	 Use non-invasive ventilation (N Use NIV, but short term only 	IV) O Undecided O Did not discuss
	Dialysis	,	
Select one circle 🔿	 No dialysis 	 Use dialysis Use dialysis, but short term on 	O Undecided y O Did not discuss
	Artificial Nutrition		
Select one circle 🔿	 No artificial nutrition 	 Use artificial nutrition Use artificial nutrition, but shor 	Undecided Did not discuss
	Artificial Hydration		
Select one circle 🔿	 No artificial hydration 	 Use artificial hydration Use artificial hydration, but shore 	O Undecided
	Other treatment preferences spe	cific to the patient's medical condition	
	· · ·		
PATIENT or patient's representative signature G Required - Select	o Patient o Health C Signature of patient confirms this for to the Section H signer. Signature I the patient's wishes and goals of ca	irm was signed of patient's own free will any the patient's representative (indicated are, or if those wishes are unknown, his/h	Parent/Guardian* of minor and reflects his/her wishes and goals of care as expressed above) confirms that this form reflects his/her assessment of rer assessment of the patient's best interests. *A guardian questions about guardian's authority.
circle and fill in	Signature of Patient (or Person R	tepresenting the Patient)	Date of Signature
every line for valid orders	Legible Printed Name of Signer		Phone Number of Signer
CLINICIAN signature	his/her discussion(s) with the	signer in Section G.	confirms that this form accurately reflects
н	Signature of Physician, Nurse Pr	actitioner, or Physician Assistant	Date of Signature
Required – Fill in every line for valid orders	Legible Printed Name of Signer		Phone Number of Signer
 → Any change to the form. If n → Re-discuss th level of care, → The patient or 	listed in A, B and C and honor prefe o this form requires the form to be vo o new form is completed, no limitatio re patient's goals for care and treatm or if preferences change. Revise the	ided and a new form to be signed. To vo ns on treatment are documented and full ent preferences as clinically appropriate form when needed to accurately reflect is capacity), guardian*, or parent/guardia	unity for a clinician to review as described below. id the form, write VOID in large letters across both sides of treatment may be provided. to disease progression, at transfer to a new care setting or

MOLST Page 2 of 2

Attachment B

Key Findings from MOLST Demonstration Site Implementation

Nursing Home (NH), Home Health and Hospice Sites

Notre Dame Long Term Care Center (121 beds) Jewish Health Care (141 beds) Shrewsbury Nursing and Rehabilitation Center (103 beds) UMass Memorial Home Care and Hospice (home-based – no beds) VNA Care Hospice (primary demonstration role was collaboration with Fallon Clinic)

Notes: 20 total nursing homes in Worcester, 3 in the MOLST demonstration; beds in demonstration = 365 (15% of Worcester nursing home beds); 8 hospice programs in Worcester, 2 in demonstration

Key Findings:

- All the sites introduced MOLST starting with the "highest risk patients" and patients going out and returning from hospitals, then with patients during admission and at annual case reviews.
- Not many MOLST forms were signed with patients who already had CC/DNR form mostly for lack of clinician time (since orders were already in place) especially for the patients at "home" in the NH (i.e. not planning to return to their private homes or elsewhere).
- Both page one and page two of the MOLST form quickly became regarded as "official." Though page two did not get utilized as much as page one, it was probably mostly because of clinician's lack of time.
- Clinical staff perceived that MOLST "has more power" than the CC/DNR because it is an actual medical order.
- Policies stated that the MOLST form should be honored if a patient with a MOLST had a crisis before the clinician had a chance to "translate" the MOLST into NH orders.
- Clinical staff who had experience with the CC/DNR form were quick to understand the concept and utility of MOLST.
- A "majority" of patients in the NHs lacked capacity; therefore, the health care agent was usually the decision maker.
- A barrier for all NHs was delays in getting health care agent signatures.
- Getting patients' MOLST forms back from hospitals and other settings was also problematic in some cases.
- In the NHs nearly every patient given the option of using MOLST accepted. "By this time, at this stage the patients and their families are ready for it."
- The MOLST educational materials were thought to be very helpful. It will be important to have print materials continue to be available because many NH don't have internet access or resources to download info from website.
- Staff development coordinators, medical directors and directors of nursing in NHs should be the primary staff to receive MOLST information and outreach.

- Suggested minimal contents of NH tool kit: Sample MOLST policy for long term care centers; MOLST video; PowerPoint staff training module; MOLST coordinator to call when they have questions.
- Suggested minimal training elements for NH staff: "This is the MOLST form; this is what and who MOLST is for; this is how to do it; and to better explain the relationship between the front and the back of the form."

Acute Care Hospital Site²³

UMass Memorial Health Care (Hahnemann, Memorial and University Campuses) Notes: 781 beds; 1200+ active medical staff (www.umassmemorial.org)

"Snapshot" - MOLST utilization on four days in Hospital Medicine Service, Memorial Campus – UMass Memorial Medical Center:

2010	April	June	August**	November**
Total patients on Hospital Medicine service	45	42	45	54
Total with limitation of treatment (LOT) while inpatient	5 (11%)	3 (7%)	9 (20%)	10 (19%)
Total with MOLST at discharge	1 (20%)	0 (0%)	3 (33%)	3 (30%)
Pink original in inpatient record	0	0	2	2
Copy of MOLST in record	1	0	1	1

**Note: A change was effected in documentation of LOT in hospitalist's History & Physical, Daily Progress Notes, and Discharge Summary, to include standing required field for LOT with drop-down menu for: Full Code; DNR; DNI.

HIGHLIGHTS OF CHART REVIEW:

Pink original form was in the chart in a number of cases; unknown if patient took a copy with them to discharge destination or not. (Difficult part of paperwork process with no tracking of copies.)

Percentage of patients with LOT documented while in the hospital increased during the demonstration program. Not sure if that is due to improved documentation by hospitalists through a standardized drop-down menu on all of their electronic documentation tools, or instead due to increased conversations about EOL/LOT in general producing an improvement in number of conversations.

Key Findings:

- The acute care setting can be an appropriate place to discuss MOLST, especially with those patients who are already in a cycle of care transitions between nursing homes, rehabilitation, acute care, etc., and may not return to their primary care physicians.
- All clinicians in the acute care setting should regard goals of care discussions with patients near the end of life (which may result in signing the MOLST form) as a part of their role. This will require not only a cultural change in some medical practices, but also behavioral change among some individual clinicians.
- MOLST needs an administrative "home" and at least one clinical champion/coordinator within the institution. Personal attention and presence on the clinical floors (e.g. to carry out strategies as simple as placing blank MOLST forms in the charts of patients suitable for MOLST) was the best way to move MOLST from concept to implementation.
- Health providers need expert coaching when it comes to MOLST and other aspects of end-of-life care. Most clinicians have some degree of understanding of these complex topics, but even those with a high level of

²³ St. Vincent Hospital joined the program later than the other demonstration sites. Due to the departure of its lead "MOLST champion," the MOLST process and form did not go into use at St. Vincent Hospital during the demonstration.

expertise have something to learn from this new process, especially in regards to the process of medical decision-making, advance care planning, and the differences between advance directives and MOLST.

- Policy and procedure development and approval takes much more time than may be anticipated.
- To ensure that MOLST information and expertise are readily available throughout the institution, a train-thetrainers strategy would be most effective, rather than relying on one or two people to support the ongoing training and coaching needs of a large and varied staff.
- It is more effective to start small with the initial implementation of MOLST in a large, complex acute care site with "ones" (e.g. one department, one unit, one floor, one hospitalist).
- The most challenging place to implement MOLST is in the Emergency Department; too much "chaos;" too much going on.
- The Emergency Department clinicians anticipate that the MOLST form is at high risk of being lost during transitions between care settings, and encourages the use of electronic versions as much as possible.
- The Emergency Department physicians thought that the bedside nurse was the best person to be aware of the presence of a MOLST form and to take responsibility for communicating its existence to the Emergency Department team.
- Emergency Department clinicians anticipate using only the front of the form for most encounters in their clinical setting due to their time-limited role in patient care.
- Emergency Department clinicians report that they get a call from most EMTs "in the field" prior to honoring the current CC/DNR form encountered in the home setting and expect that a similar call will take place for encounters with the MOLST form.
- Emergency Department clinicians recommend making a copy of a MOLST form prior to sending it to the ED, in case the form is not returned to the referring facility or patient.
- Emergency Department clinicians indicate that there is currently no standardized process for asking about the existence of a CC/DNR form, MOLST form or other statements of patient preference in the emergency policies and procedures.

Primary Managed Care Geriatric Home Visiting Program

Fallon Clinic Geriatric Managed Care Home Run Program Notes: 150 patients at one time; fragile medical condition; most 65+

"Snapshot" of MOLST utilization in Fallon Home Run Program - An in-depth review by the Fallon Clinic Research Department in late November 2010 of the electronic medical records and paper charts of patients enrolled in the Home Run Program during the MOLST demonstration provided the following snapshot.

Overview	
Patient charts reviewed	260
Ages of the patients	61 -100 years old
Patients with CC/DNR verification forms	148/260
MOLST discussions	
Patient who discussed MOLST with clinician	115/260
Family members who discussed MOLST with clinician	37/260
Average discussions per patient before signing MOLST	4
MOLST form patient utilization	
Patients who signed a MOLST form	58/115
MOLST forms signed by the patient	47/58
MOLST forms signed by the health care agent	6/58
Unclear (to reviewer) if it was patient or agent that signed	5/58
Patients who signed MOLST who also had CC/DNR	53/58

MOLST forms with instructions in Section A	51/53	
MOLST forms with instructions in Section B	51/53	
MOLST forms with instructions in Section C	50/53	
MOLST forms with instructions in Section F	52/53	
Section F instructions about respiratory support	51/52	
 Section F instructions about dialysis 	52/52	
Section F instructions about artificial nutrition	52/52	
Section F instructions about artificial hydration 52/52		
Valid Section F (required information provided)	52/52	
MOLST forms with optional health care agent info in Section G	14/58 *	
MOLST forms were honored	8 known (these patients also had CC/DNR)	
MOLST forms voided	2	
MOLST forms with valid medical orders	32/58	
Note: Both Sections D and E must be correctly completed for	32 forms completed correctly in Section D	
valid orders in Sections A – C	(patient info); 43 forms completed correctly in	
	Section E (clinician info)	

* Note: 130 of the 260 charts reviewed contained health care agent information; the NPs opined that many patients incorrectly think that if they have filled out a power of attorney, that the power of attorney covers everything.

Key Findings:

- Several unique characteristics of the Home Run program lent to its value and contribution as a MOLST demonstration site: it was the only "primary managed care" demonstration site; its Home Run program features monthly home visits conducted (in collaboration with VNA Care Hospice another MOLST demonstration site) by nurse practitioners capable of discussing goals of care with patients and authorized to sign MOLST forms with them²⁴; nearly all of the patients enrolled in Home Run could be suitable for MOLST; and Fallon's electronic medical record/data base allowed for the tracking of MOLST experiences per individual patients.
- The Home Run program established the following protocol for utilizing MOLST with patients: 1)discuss existing limitations of treatment and/or related patient preferences and goals of care; 2)introduce basic concept of MOLST and provide MOLST educational materials; 3) inform patient/family about what to do next if they are interested in MOLST (who to call with questions, process of necessary discussion with the nurse practitioner or other physician); 4) ensure patient/family understanding that the MOLST form is <u>not</u> to be first filled out *without the clinician* and then given to the nurse/doctor for signature; 5) inform patient's primary provider when MOLST information is given to prepare primary providers for next steps; 6) discuss and sign MOLST orders with patients as appropriate; 7) copy MOLST forms for entry in patients' medical record.
- Most patients offered MOLST used it, even though they had CC/DNR already; furthermore they utilized all sections of the form to express more preferences than accommodated by the CC/DNR.
- The majority of MOLST forms were used to refuse treatment. MOLST forms were not routinely offered for use by patients who wanted full treatment.
- An average of four visits preceded the patient signing the MOLST form. "Some (patients) are ready right away" but often the nurse practitioners (NPs) chose to leave the MOLST materials for the patients to consider with their families, then continued the MOLST discussions and started filling out the form at the second visit.
- The average total amount of time taken to sign the MOLST from start to finish was one hour.

²⁴ Most home visiting programs employ nursing aids, LPNs, RNs or social workers for visits to patients' homes.

- According to the NPs, the most common obstacle preventing patients who wanted a MOLST from actually signing one was their adult children, who don't want their parents signing anything and/or don't want to let go.
- Another barrier (to all advance care planning) is that patients "are afraid that if they sign a MOLST they won't get cared for properly."
- A lot of time was spent explaining the medical treatments with patients and families who often do not understand them, especially CPR. NPs said they seem to think the hospital is some magical place and that after they receive these treatments they will come back in the same (or healthier) state as before.
- Using the MOLST form led to more thorough conversations between the NPs and patients and families (especially about life-sustaining treatments beyond resuscitation).
- NPs said, "MOLST is a great thing. It should be all over the state. A public education campaign about all of these (EOL) issues is very important, especially targeting the adult children/caregivers of elderly."

Emergency Medical Services

UMass Memorial Health Care EMS, Central Massachusetts EMS, some local first responders Notes: Region Two EMTs were required to honor MOLST forms; EMTs statewide were authorized but not required to honor MOLST.

Key Findings:

- EMTs immediately understand the MOLST form (in the context of their experience with Comfort Care form).
- Most EMTs that received training considered the MOLST form an improvement from the Comfort Care form.
- EMTs like the simplicity of page one of the MOLST form, tailored for ease of pre-hospital use.
- If they participated in training, EMTs understood that MOLST does not change their current protocols.
- They expressed concern that physicians would not fill in the form correctly for it to be valid.
- They expressed concern about the portability of the form.
- They thought a registry would be helpful.
- EMTs requested that patients, families and health providers all receive better information about EMTs' role, because "as with Comfort Care the biggest issue will be educating the public and the medical community (healthcare providers at hospitals, nursing homes and assisted living facilities) so everyone understands the proper use of MOLST in conjunction with the pre-hospital community."
- They expressed nearly unanimous concern that Massachusetts EMTs are currently or might soon be required to honor the MOLST form without receiving any information or training about MOLST. *"There should be a defined implementation date with ample time to train all the necessary agencies that may be involved in patient care. (Director of a hospital-based life support service)*
- EMTs asked that MOLST training be required for re-certification if MOLST goes statewide, because "the MOLST form looks interesting but full of potential for misinterpretation and confusion especially to newer pre-hospital providers."



Attachment C

Massachusetts Department of Public Health Circular Letter: DHCQ 10-02-529

DEVAL L. PATRICK GOVERNOR TIMOTHY P. MURRAY LIEUTENANT GOVERNOR JUDYANN BIGBY, MD SECRETARY JOHN AUERBACH COMMISSIONER

> The Commonwealth of Massachusetts Executive Office of Health and Human Services Department of Public Health 250 Washington Street, Boston, MA 02108-4619

Circular Letter: DHCQ 10-02-529

- TO: Acute Care Hospitals Chief Executive Officers Emergency Department Directors and Chief Nursing Officers Long Term Care Facility Administrators, Medical Directors and Directors of Nursing Licensed Ambulance Services EMS Accredited Training Institutions EMS Regions I-V EMCAB
- EMCAB **FROM:** John Auerbach, Commissioner, Department of Public Health Alice Bonner, Director, Bureau of Health Care Safety and Quality Stancel Riley, Executive Director, Board of Registration in Medicine Jean Pontikas, Director, Division of Health Profession Licensure Rula Harb, Executive Director, Board of Registration in Nursing
 - Rula Harb, Executive Director, Board of Registration in Nursing Sally Graham, Executive Director, Board of Registration of Physician Assistants Abdullah Rehayem, Director, Office of Emergency Medical Services
- DATE: February 4, 2010

Introduction:

This is to notify you of a demonstration program to implement a MOLST (Medical Orders for Life-Sustaining Treatment) process and form in select Worcester area health care settings, starting in early spring, 2010.

In its April 2008 Annual Report, the Massachusetts Heath Care Quality and Cost Council ("MHCQCC") recommended that Massachusetts establish a pilot program to improve communication across health care settings regarding patient preferences about end of life treatments. In its report, the MHCQCC found widespread evidence that many

patients nearing the end of life lacked awareness of treatment options and had not discussed their preferences for treatment and care with their clinicians. Further, the MHCQCC noted that even when such discussions did occur and the clinician documented patient treatment choices in the patient's medical chart, the medical system lacked a mechanism to ensure that such documentation would be communicated and honored by clinicians across health care settings. Following this recommendation, in August, 2008, the Legislature enacted Chapter 305, Section 43 of the Acts of 2008, which, in part, requires that the Executive Office of Health and Human Services ("EOHHS") establish a pilot program to test the implementation of a POLST Paradigm program "to assist individuals in communicating end-of-life care directives across care settings in a least 1 region of the commonwealth."

Although the demonstration program will be implemented in select health care facilities located in the Worcester area, the Department of Public Health ("DPH") is circulating this announcement state-wide to provide clinicians with background information about the MOLST process, form, and the Massachusetts Medical Orders for Life-Sustaining Treatment demonstration program ("MA MOLST program").

MA MOLST Demonstration Program:

The MA MOLST Program is being coordinated and managed by the UMass Medical School-Commonwealth Medicine Center for Health Policy and Research, with oversight from a 30-member broad-based Steering Committee, chaired by representatives from DPH and the Office of Elder Affairs. The goals of the MA MOLST Program are: 1) to facilitate discussions between clinicians and their patients nearing the end of life about treatment options and preferences for care; and 2) to provide clinicians and their patients with a mechanism for translating these preferences into portable signed medical orders (through the use of a MOLST form) which travel with the patient and can be honored across health care settings.

Modeled on a nation-wide initiative known as the POLST (Physician Orders for Life-Sustaining Treatment) Paradigm Program¹ the MA MOLST Program is similar to programs currently in effect in all or parts of twenty (20) states within this country. Such programs are grounded on well-established legal and ethical principles involving patient self-determination and a patient's right to accept or refuse medically-indicated treatments, including lifesustaining treatments. MOLST is intended for voluntary use by patients nearing the end of life due to serious advancing medical conditions, including but not limited to life-threatening diseases, chronic progressive diseases, life-threatening injuries or medical frailty. Clinicians can collaborate with the patient, health care agent or guardian to complete a concise document--the MOLST form--that reflects the patient's preferences for medically-indicated treatments. When completed and signed by the patient and attending physician, nurse practitioner or physician assistant, the patient's MOLST form constitutes an actionable medical order that can be recognized and honored across treatment settings.

¹See <u>www.polst.org</u> for more information.

Attached is a sample form entitled Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST) that will be used in the MA MOLST demonstration program. The front side of the form is designed to be easily accessible to all health professionals and particularly useful to EMS personnel in emergency settings. The form is similar to the form currently honored by EMS personnel under the Comfort Care/Do Not Resuscitate ("CC/DNR") Verification protocol established by DPH's Office of Emergency Medical Services ("OEMS"). *Please note that because the MOLST processes and form are not being implemented state-wide at this time, the CC/DNR Verification protocol will remain valid in the MOLST demonstration area and throughout the Commonwealth.*

The MOLST form contains instructions relating to three treatment options: A) cardiopulmonary resuscitation in the case of cardiac or respiratory arrest (either "do not resuscitate" or "attempt resuscitation"); B) intubation and ventilation ("do not intubate and/or ventilate" or "intubate and/or ventilate" and C) transfer to hospital ("do not transfer to hospital, unless needed for comfort" and "transfer to hospital") and requires the signatures of both the clinician and the patient or health care agent/guardian. The back side of the MOLST form contains the patient's preferences about other medically-indicated treatments that may be offered in a clinical setting, including respiratory support, dialysis, artificial nutrition, artificial hydration and any other preferences the patient chooses to document.

The DPH, the Boards of Registration in Nursing and Physician Assistants and the MA Board of Registration in Medicine support the use of the MOLST process and form as an appropriate way to meet the standard of care for communicating patient preferences regarding life-sustaining treatment options. Further, given the intent of the MOLST demonstration project, DPH, the Boards of Registration in Nursing and Physician Assistants and the MA Board of Registration in Medicine encourage all health professionals to honor valid MOLST forms as bona fide medical orders.

Implementation Plan:

The MA MOLST demonstration program will be implemented in the following health care settings: UMass Memorial Medical Center, St. Vincent Hospital; Shrewsbury Nursing and Rehabilitation Center; Notre Dame Long Term Care Center and Hospice; Jewish Healthcare Center and Hospice; UMass Memorial Home Health & Hospice; VNA Care Hospice; Fallon Clinic, and EMS services in Worcester County. It is expected that the actual MOLST process and form will go into use within the implementation sites by late March, 2010.

In order to fully prepare for this activation, the MA MOLST Program, together with DPH staff and other EOHHS representatives are proceeding with the following steps:

• Training MOLST signatories (physicians, nurse practitioners and physician assistants) and other health professionals (nurses, EMTs, social workers, and other staff) in the demonstration sites about the MOLST process and form;

- Conducting outreach and education to other health providers and stakeholders in the greater Worcester area that may encounter patients with MOLST forms;
- Conducting outreach and education to inform potential consumers (patients, their families and caregivers) in the demonstration sites and Worcester area about the MOLST program;
- Convening a MOLST launch event for Worcester-area health professionals, consumers, and other interested stakeholders, on February 10 in Worcester;
- Posting MOLST information, resources and materials to a MOLST website (at: <u>www.molst-ma.org</u>) to be accessible by March 2010;
- Finalizing the design of the evaluation and quality improvement measures to be utilized to test the efficacy of the demonstration program and to make recommendations for a state-wide expansion of the MOLST process and form;
- Submitting a report to the Legislature regarding the findings of this demonstration program and recommendations for state-wide implementation of MOLST by December 2010.

Conclusion:

In closing, we want to acknowledge the tremendous amount of work that has already been accomplished to develop a MA MOLST demonstration program that is tailored to patient needs and the Massachusetts health care system. We would like to thank all those who have participated in this effort. We also would like to extend our appreciation to the demonstration sites that have agreed to implement the MOLST process and form with their patients. We thank you for your participation and for all of your work to further this important patient-centered care initiative.

ATTACHMENTS:

MA MOLST FORM-SAMPLE

MA MOLST STEERING COMMIITTEE MEMBERSHIP

Attachment D

MA MOLST Form – Demonstration Version

Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST) www.molst-ma.org

Patient's Name

Addre Date of Birth Print name and phone # of Patient's Primary Care Provider, if available:

Gender

- Sections D and E must be fully completed for a valid form; photocopy, fax or electronic copies of signed MOLST forms are valid.
- If a section is not completed, there is no limitation on the treatment indicated in that section.
- > This form is effective immediately upon completion. Send this form with the patient at transfer or discharge.

	Every Patient Should Receive Full Attention To Comfort			
A	Cardiopulmonary Resuscitation: for a patient in cardiac or respiratory arrest			
Select one box	Do Not Resuscitate			
В	Intubation and Ventilation: for a patient in respiratory distress			
Select one box	Do Not Intubate and/or Ventilate			
С	Transfer To Hespital			
Select one box	Do Not Transfer to Hospital (unless needed for comfort)	pital		
D Signature of the patient or health care agent, guardian* or parent/ guardian* of a minor patient	 Signed in section D by: (Check one box to indicate who is signing) the patient, or the patient, or the patient, confirms that he/she signed of own free will and this form reflects his/her treatment preferences as expressed to Section E signer. If signed by the health care agent, guardian* or parent/guardian* of a minor patient, confirms that the form reflects the signer's assessment of the patient's wishes, or, if those wishes are unknown, the signer's assessment of the patient's wishes, or, if those wishes are unknown, the signer's assessment of the patient's best interests. 			
	Signature of patient, health care agent, guardian* or parent/guardian* of mine	or Date of Signature		
"A guardian can sign to the extent permitted				
by Massachusetts law. Consult legal counsel with questions about a guardian's authority.	Print name and contact number(s) for person signing Section D			
E Signature of Physician, NP or PA	Signature of Physician, Nurse Practitioner (NP) or Physician Assistant (PA) Signature confirms this form accurately reflects discussion(s) with Section D signer	Date of Signature		
	Print name and contact number(s) for person signing Section E			
Record of Periodic Review: Upon review, if no change to this form is needed, the Physician, NP or PA should sign and print name and contact number(s) below: Date reviewed with Section D signer				
1.				
2.				
3.				
4.				

HIPAA per	mits disclosure of MO	LST to health care providers as nec	essary for treatment		
F	Patient's Preferences for Other Medically-Indicated Treatments Section F is valid only when signed and dated at the bottom of Section F.				
Only select 🗲	Respiratory Support ○ No non-invasive ventilation	O Use non-invasive ventilation	O Undecided		
	Dialysis Support	 Use non-invasive ventilation, but short term only 	 Did not discuss 		
Only select 🗲	○ No dialysis	○ Use dialysis ○ Use dialysis, but short term only	 Undecided Did not discuss 		
Only as last	Artificial Nutrition				
Only select relation one circle	 No artificial nutrition 	 Use artificial nutrition Use artificial nutrition, but short term only 	 Undecided Did not discuss 		
Only aslast	Artificial Hydration				
Only select one circle	 No artificial hydration 	 Use artificial hydration Use artificial hydration, but short term only 	 Undecided Did not discuss 		
	Other treatment preferences	5			
A guardian can sign to the extent permitted by Massachusetts law:	Signature of patient or healt minor patient Print name of person signing	th care agent, guardian or parent/guardian* of g Section F	f Date of Signature		
Consult legal counsel with questions about a guardian's authority.	 If signed by the patient, confirms that the patient signed of own free will and that Section F reflects his/her treatment preferences on the date signed. If signed by the health care agent, guardian' or parent/guardian' of a minor patient, confirms that Section F reflects the signer's assessment of the patient's preferences, or, if those preferences are unknown, the signer's assessment of the patient's best interests. 				
G	Print name and contact num	iber(s) of patient's health care agent, if agent h	as not signed this form.		
Health Care Agent	Name	Contact number			
Directions for Health Care Professionals Honoring the MOLST Form Follow orders listed in A, B and C until there is an opportunity for a Physician, NP or PA to reassess the dirical situation. The patient or health care agent (if the patient lacks capacity), guardian" or parent/guardian" of a minor patient can request and receive previously refused treatment at any time. Changing the MOLST Form The patient's preferences should be re-discussed periodically and the MOLST form updated whenever: the patient is transferred from one care setting or level of care to another, or there is a significant change in the patient's health status, or if the patient's treatment preferences change. If the review indicates: - <i>No change</i> to the MOLST, the Physician, NP or PA should sign and date the review panel at the bottom of page one to indicate that the form is current as of the date reviewed. - <i>Change</i> to the MOLST, the Physician, NP or PA must void this form by writing the word VOID in large letters across both pages of the form. After voiding the form, a new form should be completed. <i>If no new form is completed, no limitations on treatment are documented and full treatment and resuscitation may be provided.</i> Complete a MOLST Form Complete a MOLST form after conversation(s) based on the patient's current medical condition and preferences for medically-indicated treatments at the time of signing. For a valid MOLST form, both Section D (patient into) and Section E (clinician info) must by <i>fully</i> completed					
Updated: 01/20/2010		form with the patient at transfer or discharge. < or electronic copies of signed MOLST forms are valid.	Page 2 of 2		

Attachment E

Frequently Asked Questions about the Massachusetts MOLST Form

The proposed MA MOLST form was developed based on research concerning the POLST/MOLST experience in other states, dozens of key informant interviews before the demonstration was launched, and comments solicited during the course of the demonstration.²⁵ The following table sets forth some of the comments/concerns that were expressed as well as the responses reflected on the recommended MA MOLST form.

IMPORTANT NOTE: MOLST does not eliminate the need to appoint a health care agent.

All Massachusetts residents over age 18 should sign a health care proxy form to appoint a health care agent, and have conversations with their health care agent about their preferences should they lose the capacity to make and communicate their own health care decisions.

	Question	Response		
Wha	What is a MOLST form and who should consider using one?			
1	What is a MOLST form?	A MOLST form is one possible outcome of planning for care at the end of life. MOLST serves as a portable form that documents the discussions about life- sustaining treatments so that clinicians can build on earlier conversations.		
2	Should everyone have a MOLST form?	No. MOLST is most suitable for patients with a serious advancing medical condition, including, but not limited to: life threatening disease, chronic progressive disease, acute injury, or medical frailty.		
Pur	Purpose and Use of MOLST			
4	Does MOLST require individuals (or their agents) to decline treatment?	No. MOLST can be used either to limit or to allow specific types of medically-indicated treatments.		
5	Can these difficult medical issues be discussed and decided in one conversation?	Multiple conversations over time are the norm. The form allows for indicating that the patient is currently undecided about a certain intervention or that the intervention was not discussed.		
6	Will the MOLST form be used as a script for patient conversations?	It should not. Clinicians need to communicate with patients <i>first</i> about their medical condition, prognosis, the potential burdens and benefits of any recommended treatments, as well as the patient's values and goals of care <i>before</i> introducing a MOLST form.		
7	Why are the choices on the MOLST form limited?	A MOLST form must be usable by emergency		

²⁵ Interviews were conducted with Massachusetts clinicians with training and experience in geriatrics, palliative care, critical care, emergency medicine, pulmonary medicine, hospice care, home health care, as well as social workers, hospital and nursing home administrators, first responders, lawyers, and staff at the Massachusetts Department of Public Health (DPH), the DPH Office of Emergency Medical Services (DPH OEMS), the DPH Office of Long-Term Care, and the Boards of Registration. Consumer focus groups were held and follow-up comments were received from people who had experience using the form.

8	Why isn't the phrase "Comfort Measures" used?	or ambiguous instructions. MOLST is best understood as an enhanced CC/DNR Verification Protocol form since it includes more treatment options, may be used to request or refuse treatment, and is honored by all health professionals. Comfort Measures means different things to different
		clinicians at different institutions. The instructions state "Every patient should receive full attention to comfort."
Sect	ions A, B and C (emergency medical orders) first page	
9	Many other states use forms that give patients a choice between three different levels of treatment: "Full Treatment", "Limited Intervention," or "Comfort Measures Only." Why aren't those choices included on the MOLST form?	MOLST encourages the development of an individualized, patient-centered plan of care rather than defining limited categories of care to meet every patient's needs.
10	Do the orders conflict if someone opts for CPR under Section A but doesn't want Intubation and Artificial Ventilation under Section B?	Sections A and B represent responses in different clinical situations. Section A is the response to cardiac or respiratory <i>arrest</i> while B is the response to respiratory <i>distress</i> . Anyone who requests CPR in Section A will get all the treatments that are part of that procedure, including intubation. Clinicians should provide education to patients about each intervention during discussions about MOLST.
Sect	ion F (patient preferences) second page	
11	Why were these specific choices included?	The form must be simple enough to be usable without trying to address every possible choice. MOLST includes common life-sustaining interventions needed as many chronic illnesses progress, but individual preferences can be added in the section called 'Other Treatment Preferences' within Section F.
12	Why aren't "antibiotics" included as a treatment preference?	Experience in other states indicates that including antibiotics has not been helpful. Use of antibiotics is one of a number of treatment options that may be used for curative or palliative purposes and whether its use will be appropriate is difficult to predict in advance. Though it is not specifically listed, it can be included in "other treatment preferences" under Section F, if appropriate.
13	Why doesn't the form indicate forms of artificial nutrition?	It is the clinician's role to fully explain any appropriate types of medically-indicated treatment to the patient when needed; MOLST is intended to express whether or not the patient wants that type of support, if needed. Specific forms of artificial nutrition can be included in "other treatment preferences" under Section F, if appropriate.
14	How is "short-term" defined? It seems vague.	"Short-term" isn't defined. The time frame should be determined by the clinician and patient based on each situation and patient. MOLST gives the patient a chance to indicate whether or not they agree to the treatment on a long-term/indefinite basis or for a "time-limited trial" with specific treatment goals.
Sign	ature Provisions – Sections D and E and Sections G and	
15	How are "guardian" and "health care agent"	The definitions used for the Comfort Care/Do Not

	defined?	Resuscitate Verification Protocol apply. The guardian must be court appointed and the health care agent must be designated on a valid health care proxy.
16	Why are both the clinician and the patient or patient representative required to sign the first page? In other words, why include Section D and Section E?	The clinician's signature is required to create a medical order. The patient or patient representative signature indicates that the MOLST is consistent with the patient's goals of care as discussed with the clinician signer. Sections A, B and C are valid orders ONLY if both Sections D and E are completed.
17	Why are both the clinician and the patient or patient representative required to sign the second page? In other words, why include Section G and Section H?	The clinician signature assures that the preferences expressed were discussed with the clinician, adds weight or significance to the preferences, and could help deter unauthorized people from signing. The patient or patient representative signature indicates that the Section F preferences are consistent with the patient's goals of care as discussed with the clinician who signed Section H. Section F is valid ONLY if both Sections G and H are completed.
18	What if sections D and E are signed but sections G	Then Sections A, B and C would be valid orders but
	and H are not signed?	Section F preferences would not be valid.
	tional General Issues	
19	What if a section of the MOLST form is not	If a section has not been completed there is no
20	completed? If the MOLST is intended to be reviewed periodically,	limitation on the treatment indicated in that section. The need to review and modify the form periodically
	why not specify a time-frame for review or require an expiration date?	will depend on each patient's circumstances. Consistent with the CC/DNR Verification Protocol form, MOLST includes an <i>optional</i> expiration date at the bottom of page one allowing for a periodic review requirement to be developed by individual institutions/agencies, if appropriate.
21	Will there be a problem differentiating an outdated MOLST form once revisions have been made from the new MOLST form created? In other words, how will we know if a MOLST form is the most current version?	Use of original MOLST forms is encouraged; however, experience with the CC/DNR Verification Protocol form indicated that it was unduly limiting to require use of original forms only. As a result, photocopy, fax or electronic copies of MOLST are acceptable. Care needs to be taken to account for old copies of the form to be sure they are voided. This issue is covered in instructions for clinicians and patients/families.
22	What happens to the current CC/DNR Verification Protocol form and how does the MOLST form compare to the CC/DNR Verification protocol form?	The CC/DNR Verification Protocol form remains valid in Massachusetts. EMS personnel are authorized to honor either a MOLST form or a CC/DNR Verification form. It is possible that MOLST could eventually replace the CC/DNR Verification form after a successful statewide MOLST rollout.
23	Where should individuals display their MOLST forms to assure that emergency responders will find them in a timely way?	Emergency responders are trained to ask if there is a MOLST form and then, in homes, to check the refrigerator door and bedside areas. Original MOLST forms are bright pink. Non-pink copies are also valid but may be harder to locate and recognize. Patients are encouraged to carry their MOLST form (or a copy) when they travel outside of their homes.

Attachment F

MOLST Education and Outreach Activities through June 2010²⁶

		ACUTE CA	ARE SITES		
Dates	Duration	Locations	Participants by Profession	Numbers reached	
September	Range: 10 -	MarshallMANANAC Crist Marsart (2)	Chiefs, ethics, physicians, NPs, PAs,	Range: 8 - 60;	
2009 - June 2010	90 minutes	Mostly UMMMC, Saint Vincent (2), Barre Family Medical Ctr., Fairlawn	nurses, residents, social workers, care coordinators, clergy, patient care services,	Average 23	
Julie 2010	Average 37 minutes	(1); Great Brook Valley (1)	lawyers, medical interpreters, pharmacists	Total 562	
		EMTs and FIRS	RESPONDERS	<u> </u>	
Date	Duration	Locations	Participants by Profession	Numbers reached	
February -	60 min	OEMS regions throughout MA;	EMTs, fire fighters, police, administrators	EMTs certified	
November 2010		fire/police in Shrewsbury, Northborough, Sterling, others		(per OEMS):	
2010		Northborough, Sterning, others		Total 700+	
NURSING HOMES, HOME HEALTH, HOSPICE and Fallon Clinic					
Date	Duration	Location	Participants by Profession	Numbers reached	
February -	Range: 15 -	Shrewsbury Nursing & Rehab, VNA	Administrators, physicians, nurses, social	Range: 5 - 50	
June 2010	90 minutes	Care Hospice; Jewish Health Care, Notre Dame Long Term Care	workers, resident council members, physical therapists and assistants,	Average 21	
	Average 32	Center, UMass Memorial Home	occupational therapists and assistants,	Total 535	
	minutes	Care & Hospice; Fallon Clinic	chaplains, volunteers,		
COMMUNITY GROUPS and ORGANIZATIONS					
Date	Duration	Location	Participants by Profession	Numbers reached	
June 2009	Range: 20 -	Various, mostly Central	Health professionals, policy-makers,	Range: 2 - 150	
- June	90 minutes	Massachusetts and Boston	health care administrators, health plan	Average 21	
2010	Average 52		administrators, state expert panel, state officials, lawyers, judges, consumer	Total 479	
	Average JZ		orneiais, iawyers, juuges, consumer	10tal 473	

²⁶ With the exception of EMT training, these data were tracked until June 2010. Training and outreach continued untracked throughout December 2010, so numbers of participants reached in all groups and settings are higher than those indicated here.

Attachment G

MOLST Demonstration Materials Developed and Disseminated

Concurrent with MOLST form development, the Steering Committee and work groups were engaged in drafting and testing essential MOLST educational materials for patients and their caregivers, clinicians and other health professionals. This process, involving significant engagement of and input from both health professionals and community members resulted in a wide range of resources for multiple audiences as shown below.

Resource/Material	Approximate number of hard copies disseminated	Patients, Families, Caregivers	Clinicians and other health professionals	General public, professionals and groups
MOLST sample form (translated into	2300	Х	Х	Х
Spanish, Portuguese, and Vietnamese)	2200	V		
Patient and family MOLST brochure Understanding the MOLST form 2-page guide (translated into Spanish and Vietnamese)	2200 2000	<u> </u>		
13-minute original informational MOLST video – hard copies and viewable on MOLST website	110 discs	Х	X	X
Frequently Asked Questions of patients and families (translated into Spanish and Vietnamese)	1850	Х		
Clinical guidance booklet for using MOLST	350		Х	
MOLST training module for clinicians/signers	TBD		Х	
MOLST training module for health professionals	TBD		Х	
MOLST training module for EMTs/First Responders	TBD		Х	
Frequently Asked Questions – Clinicians	1050		Х	
Frequently Asked Questions – health professionals	1350		Х	
Frequently Asked Questions– EMTs/First Responders	900		Х	
Frequently Asked Questions – Assisted Living Residences	150		Х	
Frequently Asked Questions – Lawyers	60			Х
Differences - MOLST and Health Care Proxy Form	250	Х	Х	Х
Glossary of end-of-life terms	1750	Х	Х	Х
MOLST website with all materials and other resources Mar 1 – Dec 31, 2010 <u>www.molst-ma.org</u>	# visits: 2921	Х	Х	X

Attachment H

Glossary of Terms Related To End-of-Life Planning and Care

<u>Advance care planning (ACP</u>) is an ongoing process of discussing and clarifying the current state of a person's goals, values and preferences for future medical care. The discussion often, but not always, leads to the signing of documents known as advance directives. A health care proxy is the only advance directive authorized by Massachusetts statute.

<u>Advance directive (AD)</u> is a general term referring to a written document for future medical care in the event that a person loses capacity to make health care decisions (i.e. becomes "incapacitated."). It sometimes results from the process known as advance care planning. A health care proxy or a living will is considered to be an advance directive.

<u>Artificial hydration and nutrition (AHN)</u> is a medical treatment that supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and/or fluids through a tube placed directly into the digestive tract (enteral); or through a tube directly into a vein (parenteral).

<u>Cardio-pulmonary resuscitation (CPR)</u> is a set of medical procedures that attempt to restart the heartbeat and breathing of a person who has no heartbeat and has stopped breathing. Such procedures may include pressing on the chest to mimic the heart's functions and cause blood to circulate; insertion of an airway into the mouth and throat, or insertion of a tube into the windpipe; artificial ventilation such as mouth-to-mouth or other mechanically assisted breathing; the use of drugs to stimulate the heart; and/or electric shock (defibrillation) to stimulate the heart. CPR can be life-saving in certain cases for otherwise healthy people but is much less effective when a person has a serious chronic illness.

<u>Comfort Care/Do Not Resuscitate Verification protocol (CC/DNR)</u> is followed by emergency medical service (EMS) personnel when encountering an authorized CC/DNR Verification Form outside of a hospital setting. The CC/DNR protocol directs that a patient in respiratory or cardiac distress be made as comfortable as possible, but that no resuscitative measures be attempted.

Decision-making capacity refers to the ability to make and communicate meaningful decisions based upon an understanding of the relevant information about options and consideration of the risks, benefits, and consequences of the decision. The ability to understand other unrelated concepts is not relevant. Capacity can vary according to the task: it may be possible for an individual to appoint a health care agent, for example, yet not make a decision about a medical procedure. Capacity should be assessed routinely and is not the same as competence, which is a legal determination made in court. In Massachusetts a physician must make the determination of a patient's lack of capacity in writing before a health care proxy can be put into effect.

Dialysis is the process of filtering the blood through a machine via two small tubes inserted into the body in order to remove waste products from the body in the way that the kidneys normally do. Dialysis can be done temporarily in order to allow the kidneys time to heal or it can be done on a longer-term basis in order to prolong life.

Do Not Hospitalize orders (DNH) are medical orders signed by a physician that instruct health care providers not to transfer a patient from a setting such as a nursing facility (or one's home) to the hospital unless needed for comfort.

Do Not Intubate orders (DNI) are medical orders signed by a physician that instruct health care providers not to attempt intubation or artificial ventilation in the event of respiratory distress.

Do Not Resuscitate orders (DNR) are medical orders signed by a physician that instruct health care providers not to attempt cardio-pulmonary resuscitation (CPR) in the event of cardiac and respiratory arrest.

Durable Power of Attorney for Health Care is a term used in some states for a health care proxy. (See definition below.)

Guardian is a court-appointed individual granted authority to make certain decisions regarding the rights of a person with a clinically diagnosed condition that results in an inability to meet essential requirements for physical health, safety or self-care. In Massachusetts not every guardian has authority to make health care decisions. If a health care proxy is in effect, a healthcare decision of the agent takes precedence over that of the guardian (absent an order of the court to the contrary). Further, guardians who do have authority to make health care decisions may be subject to limitations on their authority to make decisions regarding life-sustaining treatments.

Health care agent is a trusted person, officially appointed, who speaks on behalf of a person 18 years of age or older who is unable to make or communicate health care decisions. In Massachusetts this person is appointed in advance via a health care proxy. The agent is called upon only if the doctor determines in writing that a patient lacks capacity to make health care decisions. Unless otherwise limited by the person, the agent has all the rights that the patient has with regard to medical decision-making, including the rights to refuse treatment, to agree to treatment, or to have treatment withdrawn. Decisions should first be made based on the patient's stated wishes, if known; or if unknown, an interpretation of what the patient would have wanted; or finally, an assessment of the patient's best interest.

Health care proxy (HCP) is a document in which a person appoints a health care agent to make future medical decisions in the event that the person becomes incapacitated. This may be an outcome of the advance care planning process and is expressly authorized in Massachusetts by statute (MGL 201D).

Hospice is a philosophy of holistic end of life care and a program model for delivering comprehensive palliative care to persons who are in the final stages of terminal illness and their loved ones in the home or a home-like setting. Hospice provides palliative care in the last months of life. It involves a team-oriented approach that is tailored to the specific physical, psycho-social and spiritual needs of the person and includes support to the family during the dying process. Hospice also provides bereavement support after death occurs.

Life-sustaining treatment refers to medical procedures such as cardio-pulmonary resuscitation, artificial hydration and nutrition, and other medical treatments intended to prolong life by supporting an essential function of the body in order to keep a person alive when the body is not able to function on its own.

Living will (LW) is a document in which a person specifies future medical treatments in the event of incapacity, usually at end of life or if one becomes permanently unconscious, in a persistent vegetative state or "beyond reasonable hope of recovery." Since there is no statute in Massachusetts that expressly authorizes living wills they are not considered to have legal authority. They may, however, be used as evidence of a person's wishes.

<u>Medical (or Physician's) Orders for Life-Sustaining Treatment (MOLST /POLST)</u> is a document intended for seriously ill patients that stipulates wishes for life-sustaining treatment based on the patient's current condition. A MOLST form becomes effective immediately upon signing and is not dependent upon a person's loss of capacity. It does not take the place of a health care proxy. Consideration of MOLST may be an outcome of the advance care planning process.

<u>Palliative care</u> is a comprehensive approach to treating serious illness that focuses on the physical, psycho-social and spiritual needs of the patient. The goal of palliative care is to prevent and relieve suffering and to support the best quality of life for patients and their families through such interventions as managing pain and other uncomfortable symptoms, assisting with difficult decision-making, and providing support, regardless of whether or not a patient chooses to continue curative, aggressive medical treatment.