Improving Advanced Illness Care:
The Evolution of State POLST Programs

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The views expressed herein are for information, debate, and discussion, and do not necessarily represent official policies of AARP.
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# TABLE OF CONTENTS

**ACKNOWLEDGMENTS** .................................................................................................................................................... ii

**EXECUTIVE SUMMARY** ............................................................................................................................................... v

**INTRODUCTION** ............................................................................................................................................................. 1

**BACKGROUND** ............................................................................................................................................................. 2

**EVIDENCE BASE** .......................................................................................................................................................... 6

**METHODOLOGY** ............................................................................................................................................................. 8
  Survey Limitations ........................................................................................................................................................ 9

**FINDINGS** ....................................................................................................................................................................... 10
  Legislative/Regulatory Comparison of POLST Programs .......................................................... 10
  Key Informants’ Survey Findings ................................................................................................. 12

**EXPERT REVIEW: LOOKING TOWARD THE FUTURE** ................................................................................................. 22
  There is a need for quality indicators for the patient-provider interaction in preparing POLST ........................................ 22
  States need a multiyear developmental perspective ........................................................................ 22
  Language is important ......................................................................................................................... 23
  Physicians and other health care providers are undereducated in end-of-life care knowledge and skills and resistant to education . . . but educable ................................................... 23
  Payment incentives should be improved ............................................................................................... 24
  Consider use of “report cards” to incentivize POLST ......................................................................... 24
  Opportunities exist for greater engagement with national provider and palliative care groups ......................................................................................................................... 25
  Electronic health records should include advance directives and POLST data and not just scanned copies of forms ........................................................................................................... 25

**CONCLUSION** ................................................................................................................................................................. 26

**APPENDIX A. POLST STATUTORY/REGULATORY COMPARISON (1/30/11)** .......................................................... 28

**APPENDIX B. POLST STATE THEMES/FEATURES** ......................................................................................................... 36
APPENDIX C. STATE PROFILES ................................................................. 44
  California .......................................................................................... 44
  Hawaii ............................................................................................... 44
  Idaho ..................................................................................................... 45
  Minnesota ........................................................................................... 45
  New York ............................................................................................ 45
  North Carolina .................................................................................... 46
  Oregon .................................................................................................. 47
  Tennessee ............................................................................................ 47
  Utah ...................................................................................................... 48
  Vermont ............................................................................................... 48
  Washington ........................................................................................ 49
  West Virginia ....................................................................................... 50

APPENDIX D. SAMPLE POLST FORM ......................................................... 51

APPENDIX E. ROUNDTABLE PARTICIPANTS ............................................... 54

List of Tables

Table 1. Differences between POLST and Advance Directives ......................... 4
EXECUTIVE SUMMARY

Physician Orders for Life-Sustaining Treatment (POLST) is a promising program to elicit and honor the treatment goals of people with advanced progressive illness or frailty. POLST began in Oregon in the early 1990s. By the beginning of 2010, at least 12 states had adopted the POLST paradigm, and proponents in most other states were developing programs. The current study explores the experience of 12 states with POLST programs to identify factors that helped or hindered adoption and meaningful implementation of the protocol.

WHAT IS POLST?

POLST is a tool for translating patients’ goals of care into medical orders in a highly visible, portable way. Following the protocol, health care professionals must discuss with seriously ill patients (or their surrogates) the available treatment options in light of their current condition—and help clarify the patients’ preferences. Then clinicians must document those preferences on a standardized medical order form and ensure that it travels with the individual if he or she changes settings of care. POLST differs from an advance directive (living will or health care power of attorney) in that it is an actionable medical order dealing with the here-and-now needs of patients—it can build on an advance directive but can be created for patients without advance directives.

POLST enables patients to choose from a full range of care options, from aggressive treatment to limited interventions to comfort care. Recent academic research documents POLST’s success in improving the documentation and honoring of patient preferences, whatever they may be. Management of pain and symptoms remains comparable to that of patients without POLST.

KEY FINDINGS

Detailed interviews with key informants in 12 states, a legislative and regulatory review, and an expert roundtable revealed the following:

- **Legislative and regulatory approaches** vary, although there are many common features.
  - States have used differing terminology for the POLST program, including POST (Physician Orders for Scope of Treatment), MOLST (Medical Orders for Life-Sustaining Treatment), MOST (Medical Orders for Scope of Treatment), and COLST (Clinician Orders for Life-Sustaining Treatment).
  - Two states (OR, MN) used clinical consensus rather than legislation to establish POLST, while 10 used legislation of varying nature and complexity.
  - POLST universally requires an authorized clinician’s signature—six states expand this authority beyond physicians to nurse practitioners and/or physician assistants.
  - None of the 12 states mandate completion of POLST forms, but two states (TN, UT) require health care facilities to offer POLST to certain patients and residents.
• **Key facilitators of POLST development** are effective organizing and incremental strategies.
  
  o Well-established statewide end-of-life coalitions or palliative care organizations helped jump-start POLST development.
  
  o A core of “physician champions” was a key component to achieving POLST awareness and acceptance in major health care institutions.
  
  o Many proponents used a deliberately incremental strategy, starting with a pilot program and then expanding statewide.
  
  o Advocates should expect a multiyear implementation process and define progressive yearly goals. Programs in operation for 10 or more years show high rates of POLST use in nursing homes, hospitals, and hospices.
  
  o Respondents and roundtable participants identified more than a dozen other facilitating variables.

• Proponents encountered close to 40 **issues and barriers** during initial enactment and subsequent implementation, including the following:
  
  o Whether patient consent must be documented on the form by signature
  
  o What elements and options the form should include
  
  o How to correct the misperception that POLST is a health care advance directive
  
  o The extent of surrogates’ authority to consent to POLST on behalf of a patient lacking decisional capacity
  
  o Resistance to changing existing institutional protocols
  
  o Integrating POLST into electronic health records (EHRs)

• **Training and education**, especially for physicians, posed the greatest implementation challenge.
  
  o Physicians and other clinicians need education in two priority areas: communication skills for facilitating conversations with patients and families, and knowledge of the impact of therapeutic impact of interventions such as cardiopulmonary resuscitation and tube feeding in older chronic care patients.
  
  o Funding for a multipronged, sustained training and education effort is critical.

• **Formal monitoring and evaluation** processes are lacking.
  
  o The majority of state POLST programs have none. Periodic review of POLST by stakeholders is critical.
  
  o Electronic POLST registries like Oregon’s provide promising opportunities to use data for assessment and quality improvement.
Federal regulations on EHRs have not yet addressed POLST; the ideal translation of POLST into EHRs would permit evaluation and monitoring of POLST usage.

- **POLST** rests on **meaningful discussion of options and preferences** between patients and clinicians.
  - Professional education is the primary strategy to ensure the quality of these conversations.
  - Quality measurement tools are lacking, but some existing checklists and feedback processes may form the basis for developing quality metrics.
  - Payment incentives for advance care planning with patients have been lacking.

- **Suggestions for people working to develop new programs** reflect the above findings but also include the following:
  - Be as inclusive as possible in developing POLST.
  - Don’t reinvent the wheel—consult the National POLST Paradigm Task Force and leaders in existing programs.
  - Know your state—all politics is local. Local politics may influence the terminology used, including the name of the program itself.
  - Allow flexibility to design and later revise the POLST form periodically.
  - Funding can be key to a successful long-term program.

The POLST paradigm has taken root in about a quarter of the states and is under development in the majority of others. The current study’s findings highlight numerous issues and program features that have challenged state stakeholders to date—and others that have enabled POLST programs to grow and become a major component of the standard of practice for seriously ill individuals.
INTRODUCTION

Physician Orders for Life-Sustaining Treatment (POLST) is a clinical paradigm designed to improve the quality of care for people who have advanced, progressive illness and/or frailty. Its central components include the clarification and communication of patient treatment goals and wishes, documentation in the form of medical orders on a distinctly recognizable form, and an obligation of health care professionals to honor these preferences across all care settings.

The POLST paradigm began in the early 1990s in Oregon. By early 2010, 12 states had approved, though not necessarily fully implemented, statewide programs, and several other states were at various stages of state or local development.

As versions of POLST have spread beyond Oregon, variants in nomenclature have also appeared, such as Medical Orders for Life-Sustaining Treatment (MOLST) in New York and Physician Orders for Scope of Treatment (POST) in West Virginia. Throughout this report, the term “POLST” will be used to represent all these variants.¹

Because of POLST’s potential to help elicit and honor the treatment goals of people with advanced progressive illness, this study set out to explore the experience of states that had adopted POLST statewide. The goal was to identify what factors helped or hindered the process of adoption and meaningful implementation. This assessment can enable other states to learn from the experience of POLST states, to avoid reinventing the wheel, and to facilitate the evolution of the POLST paradigm nationally.

¹ Throughout the report, the term “patient” is used for convenience but includes individuals in their own homes, residents in long-term care settings, consumers in home or community-based services, as well as patients in hospice care or hospitals.
BACKGROUND

The POLST paradigm fits within the much broader policy and practice landscape of advance care planning. Policy attempts to promote planning for health decisions began in the mid-1970s with the enactment of medical directives or “living will” laws, intended to provide a standardized means for terminally ill individuals to communicate their wishes about end-of-life care if they no longer were able to do so. A more flexible tool appeared soon thereafter, the durable power of attorney for health care, which enables an individual to give legal authority to another person—called a health care agent or proxy—to make health decisions in the event of incapacity.

Together these tools are generally known as health care advance directives. The laws originally creating these tools were based on what can be described as a legal transactional approach—that is, an emphasis on standardized legal forms or mandatory disclosures, prescriptive language, required formalities and restrictions on who may be witnesses or proxies, procedural requirements for certifying incapacity or medical condition, and limitations on decision-making, all intended to serve as protections against abuse and error. State-by-state legislative crafting produced tremendous variability in the laws and procedures across the states. As a strategy for advance care planning, this legalistic approach has been criticized for exacerbating the public’s confusion over and reluctance to use advance directives.

Over the past two decades, the legalistic approach has slowly and incrementally moved toward a communications approach. This approach shifts the emphasis from the completion of legal forms to an ongoing process of advance care planning. Advance care planning involves an iterative process of communication over time among the individual, the health care provider, the proxy, and others who may participate in the health care decision-making process to discern the individual’s priorities, values, and goals of care. Documentation in the form of advance directives remains important, but as a tool secondary to and supportive of the communication process.

Even with this shift in approach, other systemic barriers have remained. One key barrier is the frequent disconnect between patient preferences and the implementation of an actionable plan of care that reflects those preferences. These disconnects typically occur when the individual is in an advanced stage of illness when critical care decisions have to be made in crisis mode. Advance directives have not been effective in these situations for several reasons, including their frequent lack of availability when needed, their lack of

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3 Id., 221–224.
4 Id., 224.
clinical specificity with respect to the here-and-now medical decisions faced by seriously ill patients, and their lack of integration into medical orders.\(^6\)

In the early 1990s, leaders in the health care ethics community in Portland, Oregon, met to address this common challenge and, through the Center for Ethics in Health Care at Oregon Health & Science University, convened a state task force with representatives from various stakeholder health care organizations and agencies. This task force concluded that the best way to drive clinical action in hospitals and health care settings is through standardized medical orders. They developed a form, content, and process for implementation and evaluation of a clinical paradigm they named POLST. Review and improvement of the process has continued since then.

In simplest terms, POLST is a tool for translating patients’ goals of care into medical orders for a certain subset of patients—those with advanced, progressive illness and/or frailty.\(^7\) It represents a significant paradigm change in advance care planning policy by standardizing providers’ communications prescribing a plan of care in a highly visible, portable way, rather than focusing solely on standardizing patients’ communications.

In September 2004, the Center for Ethics in Health Care at Oregon Health & Science University convened a national task force of representatives from a handful of states that had established POLST programs. The primary goal of the task force is to facilitate the development, implementation, and evaluation of POLST paradigm programs in the United States. The task force created standards for “endorsed” POLST programs. As of the beginning of 2011, nine programs carried endorsed status, including one substate program in the La Crosse, Wisconsin, area. The task force, led by a board made up of representatives from each endorsed state, provides a clearinghouse of information and supportive materials at www.polst.org.

The current POLST paradigm requires providers and patients or their surrogates to accomplish three core tasks:

- First, POLST requires a health care professional to initiate a discussion with the patient (or the patient’s authorized surrogate) about key advanced illness treatment options in light of the patient’s current condition. The objective is to discern and clarify the patient’s goals of care and preferences and the available care options. An existing advance directive can help inform the discussion, especially if the patient has lost decision-making capacity.

- Second, the patient’s preferences are incorporated into medical orders, which are recorded on a highly visible, standardized form that is kept at the front of the medical record or with the patient if the patient lives in the community. The form covers several key decisions common to seriously and chronically ill patients:

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\(^6\) U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, “Literature Review on Advance Directives” (June 2007), pp. 49–50

cardiopulmonary resuscitation; the level of medical intervention desired in the event of emergency (comfort only/do not hospitalize, limited, or full treatment); and the use of artificial nutrition and hydration. Some states address additional interventions such as antibiotics and ventilation. As technology and treatment options change, POLST forms will likely continue to evolve.

- Third, providers must ensure that the POLST form actually travels with the individual whenever he or she moves from one setting to another, thereby promoting the continuity of care and decision making. The order is recognized by all health professionals across all settings and is to be reevaluated whenever the patient’s medical condition or venue of care changes, or whenever the patient’s wishes change.

In the broad framework of advance care planning, a key concept to understand is that POLST is not an advance directive like a living will or health care power of attorney. Rather, it is an advance care planning tool that reflects the patient’s here-and-now goals for medical decisions that may confront him or her today and converts those goals into specific medical orders. Table 1 summarizes key differences between POLST and advance directives.

### Table 1

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>POLST Paradigm</th>
<th>Advance Directive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>Advanced progressive chronic conditions</td>
<td>All adults</td>
</tr>
<tr>
<td>Timeframe</td>
<td>Current care</td>
<td>Future care</td>
</tr>
<tr>
<td>Where completed</td>
<td>In medical setting</td>
<td>In any setting</td>
</tr>
<tr>
<td>Resulting product</td>
<td>Medical orders (POLST)</td>
<td>Advance directive</td>
</tr>
<tr>
<td>Surrogate role</td>
<td>Can do if patient lacks capacity</td>
<td>Cannot do</td>
</tr>
<tr>
<td>Portability</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
<tr>
<td>Periodic review</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
</tbody>
</table>

The primary target population for POLST is persons with advanced progressive illness and/or frailty. The pragmatic rule of thumb for initiating POLST is do so when the clinician would not be surprised if the patient were to die within the next year. Thus, in the time frame of advance care planning, POLST comes into the picture in the later stages of illness. In addition, the responsibility for initiating and implementing POLST is placed on the medical providers, not the patient. POLST can build on an advance directive but can also function in the absence of an advance directive. If the individual lacks decisional capacity, a surrogate can engage in the conversation and consent process that forms the basis of POLST.

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Another way to understand the POLST paradigm is as an extension of out-of-hospital do-not-resuscitate (DNR) orders, which are recognized by law or regulation in almost every state.\(^9\) Out-of-hospital DNR orders are written physician orders on standardized forms that require the consent of the patient or surrogate and result in a highly visible identifier (e.g., a bracelet or brightly colored order form) that stays with the patient and will be respected by emergency medical services (EMS) personnel. POLST is similar but more comprehensive—it is not limited to the single decision of resuscitation nor to EMS personnel. Moreover, POLST requires a dialogue with the patient or surrogates about the patient’s goals of care and does not presumptively call for withholding medical interventions. Instead, it permits a full range of plans, from comfort care to full treatment.
EVIDENCE BASE

From 1998 to 2009, several studies assessed POLST usage and/or confirmed that care preferences recorded on POLST forms were honored for a high percentage of patients studied, at least with regard to certain orders in nonhospital settings. Most of these studies were based on convenience samples of POLST users and did not include comparisons with “traditional” (non-POLST) practices.

- In a 1998 study, researchers reviewed charts of 180 residents at eight Oregon nursing facilities over a one-year period. Where the POLST forms of residents included “do not resuscitate” and “comfort measures only” orders, none of the residents received unwanted cardiopulmonary resuscitation (CPR), intensive care unit care, or ventilator support.

- A second, retrospective study (published in 2000) assessed records for the last two weeks of life for enrollees in a PACE (Program of All-Inclusive Care for the Elderly) site in Oregon where nursing home-eligible patients received services and supports in their homes and communities. Care matched POLST instructions to a high degree regarding CPR (91%), antibiotics (86%), intravenous fluids (84%), and feeding tubes (94%). Level-of-care instructions (from comfort care to full medical intervention) were followed less often (46%).

- By 2004, a telephone survey and form review in selected sites revealed that the POLST program was widely used in Oregon nursing facilities. A majority of individuals with DNR orders requested some other form of life-extending treatment, and advanced age was associated with individuals’ preference to limit treatment.

- Another 2004 survey of 572 EMTs in Oregon found that a large majority of EMTs felt that the POLST form provides clear instructions about patient preferences and is useful when deciding which treatments to provide.

- In 2009, researchers assessed the penetration of POLST in hospice programs in Oregon, Wisconsin, and West Virginia. A pilot study indicated that POLST was used widely in hospices in Oregon (100%) and West Virginia (85%) but only regionally in Wisconsin (6%). A majority of hospice staff believe POLST is useful at

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Improving Advanced Illness Care: The Evolution of State POLST Programs

preventing unwanted resuscitation and at initiating conversations about treatment preferences.

These studies have given POLST proponents an evidence base on which to move forward. A 2010 study comparing POLST with “traditional practices” provided the most dramatic evidence to date of POLST’s successes. The study compared POLST with “traditional advance care planning” and demonstrated the POLST paradigm’s efficacy at ensuring that patient preferences are documented and honored.15 Researchers conducted a stratified random sample medical record review of 1,711 nursing facility residents in Oregon, West Virginia, and Wisconsin. They found that—

- Residents with POLST forms had significantly more medical orders about a range of life-sustaining treatments than residents with traditional advance planning practices (i.e., CPR status orders, living wills, or no documentation reflecting preferences).
- POLST was more effective than traditional practices at limiting life-sustaining medical interventions residents did not want.
- Residents with POLST forms who desired full treatment received the same level of treatment as residents without POLST forms.
- There were no differences between the two groups on receipt of pain and symptom assessment and management.

Researchers concluded based on this first thorough comparative study that the use of POLST offers significant advantages over traditional methods to communicate treatment preferences in the nursing facility setting. The growing body of evidence supporting the efficacy of POLST in communicating and honoring patients’ goals of care provided the impetus for the current research to examine the expansion of the POLST paradigm nationally.

METHODOLOGY

This study used an exploratory case study design to understand and distill the experience of states that have adopted some version of POLST statewide. As of mid-2010, those states were—

- California
- Hawaii
- Idaho
- Minnesota
- New York
- North Carolina
- Oregon
- Tennessee
- Utah
- Vermont
- Washington
- West Virginia

An open-ended telephone survey of key informants directly involved in POLST development in these 12 states sought to identify: (1) the nature and extent of issues or barriers encountered by proponents in establishing and implementing POLST in the state; (2) the strengths or strategies that facilitated POLST adoption and implementation; and (3) the impact of identified concerns on the final design and operation of POLST.

Targeted open-ended questions also sought to discern the key features of state educational efforts in implementing POLST; monitoring and quality assurance efforts; and approaches states used to ensure that the conversations with patients or their surrogates on which POLST depends were meaningful and effective. Finally, respondents were asked what, if any, recommendations they would have for other states considering adoption of a POLST program.

Between three and seven in-depth telephone interviews were conducted with respondents in each state, starting with a known key informant and utilizing “snowball” sampling to identify other key participants in the formative and/or implementation stages of POLST in the state. The interviews followed a template of questions, all open-ended.

Forty-seven interviews were conducted in the 12 POLST states. An additional four interviews were conducted in Maryland for purposes of exploring a state that attempted but failed to adopt a POLST program, resulting in a total of 52 interviews.

Analysis of the interviews entailed an inductive process. The researchers distilled the detailed content of the interviews into summaries identifying themes, issues, and features described by respondents.

Concurrently, we conducted a legislative/regulatory review of each state to prepare a uniform description of the legal authority and key specifications of POLST in each of the states.

After completion of the surveys, content analysis, and initial findings, the Public Policy Institute convened a multidisciplinary, one-day roundtable of experts to review the results.

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16 POLST is well established in some regions within states, such as the La Crosse, Wisconsin, program that has been in operation since 1997. However, the study focuses only on statewide programs.

and weigh their implications for the future of POLST. Participants included POLST proponents, representatives of national stakeholder organizations, palliative care physicians, nurses, academics, and others with expertise in chronic disease and end-of-life care. The discussion of survey findings below as well as recommendations are based on the information provided by both survey respondents and roundtable participants.

**SURVEY LIMITATIONS**

Survey respondents consisted of a convenience sample of known and self-identified POLST experts and stakeholders, so the issues identified and opinions expressed cannot be validly extrapolated to a larger audience. In addition, the survey findings reflect the issues and factors that respondents identified in entirely open-ended questions. The interviewers did not posit a long list of possible issues to respondents to prompt their affirmation or negation of the issue. Therefore, the approach does not necessarily reveal all the issues respondents actually encountered or observed, but rather issues and dynamics that they perceived either as most important or simply most memorable in the process of establishing and implementing POLST.
FINDINGS

LEGISLATIVE/REGULATORY COMPARISON OF POLST PROGRAMS

Appendix A provides a complete compilation of selected legislative/regulatory features of the POLST programs of the 12 states reviewed in this report. This comparison is a snapshot in time (late 2010). State POLST programs tend to undergo an ever-evolving process, so even within months, features can change. The highlights of state law and regulatory differences are described here:

Terminology
Seven of the 12 states use the original Oregon POLST designation for their programs. Two states (ID, WV) use POST (Physician Orders for Scope of Treatment); and one state each uses MOLST (Medical Orders for Life-Sustaining Treatment) (NY), MOST (Medical Orders for Scope of Treatment) (NC), or COLST (Clinician Orders for Life-Sustaining Treatment) (VT).

Placement in State Code
Considerable variation exists in the legislative framing of POLST provisions. Significantly, not every state used legislation to launch POLST. Oregon developed POLST through clinical consensus, with subsequent regulatory recognition of POLST as a standard of care for EMS personnel. Likewise, Minnesota has used clinical consensus as the foundation for POLST. In other states, authorizing legislation tended to be idiosyncratic to each state; states focused on creating uniformity in procedure, patient protections, or provider immunity, or merely authorizing the health department to establish a POLST procedure. The placement of the POLST provision in states’ codes varied from incorporation into health decisions/advance directives acts (CA, ID, NY, UT, VT) to inclusion in do-not-resuscitate provisions (NY, TN), medical malpractice code sections (NC), or department of health authorizing provisions generally (HI, WA). The detail in POLST legislation ranged from fairly detailed specifications (CA, WV) to brief delegations of authority to the state health department to approve a process like POLST (NY, TN, VT, WA).

Regulations/Guidelines
In all the states, a POLST form has been approved by a regulatory body with jurisdiction over emergency medical services, health care facilities, and/or health professionals. However, most of the implementation guidelines and explanatory material supporting POLST have been developed and disseminated by nongovernmental organizations such as state end-of-life coalitions or professional associations. Only three states (TN, UT, VT) have promulgated procedures in formal regulations, although the EMS divisions in two other states (ID, NC) provide detailed guidelines not formally adopted as regulations.

POLST Signature Requirements
As a medical order, POLST universally requires an authorized clinician’s signature. Even if verbal orders are permitted, a confirming signature is needed. States differ with respect to which clinicians are authorized to write medical orders. In six states (CA, HI, ID, NY, TN, WV), only physicians may sign POLST. In the others, nurse practitioners or physician assistants may sign, although the physician assistant’s authority ordinarily must be within the scope of their supervisory agreement.
Notwithstanding the physician’s central role, virtually all states recognize that most of the counseling and discussion necessary to prepare POLST will likely be done by nurses, social workers, or other nonphysician health professionals. This is reflected by the inclusion of a space in most state POLST forms for identifying the health care professional assisting in preparation of the form.

All the states except Minnesota, New York, and Oregon require the patient’s signature on the POLST form to confirm consent. Even these three states recommend signature by the patient and provide a signature line. New York additionally recommends but does not require two witnesses. Vermont does not require a patient signature for the DNR component if resuscitation is deemed futile and a second clinician so certifies. The Vermont form provides two patient signature lines—one for the order regarding resuscitation, and the other for all other orders. New York does the same.

All the states permit an authorized surrogate to sign POLST on behalf of a patient lacking decisional capacity, but the details of this authorization vary by state. Surrogate authority is usually spelled out in other state law provisions separate from POLST. All the surveyed states except Vermont permit POLST to be used with seriously ill minors contingent on parental consent and sometimes other medical requirements.

**Relationship to Conventional DNR Orders**
None of the survey states use POLST as the sole or exclusive format for issuing out-of-hospital DNR orders. Preexisting DNR forms and institutional protocols for DNR remain valid.

**Immunity for Providers**
All the survey states except Minnesota provide immunity from civil or criminal liability and from disciplinary actions for complying with POLST orders and procedures. Utah is somewhat atypical in providing immunity both for complying with a life with dignity order (its version of POLST and for “providing life sustaining treatment to a person when a life with dignity order directs that the life sustaining treatment be withheld or withdrawn.”18 In Minnesota, a state without POLST legislation, protection for providers exists to the extent that POLST becomes the recognized standard of care for clinicians and EMS personnel. This recognition can come about by acceptance in institutional policy or professional association policy or by the approval of POLST by regulatory bodies such as a state medical board.

**Legal Duty to Use POLST**
None of the survey states mandate completion of POLST forms for patients. That is because the validity of POLST depends on the voluntary informed consent of patients or their surrogates. Two states (TN, UT) require health care facilities to offer POLST to certain patients or residents. These two states also require that if a form exists, the facility has an obligation to make sure it accompanies the patient if transferred elsewhere. Nine states require providers to comply with POLST if one exists, although this duty has multiple exceptions and varies depending on the health professional involved.

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18 Utah Code Ann. §75-2a-106(6).
Evaluating POLST Programs: The Evolution of State POLST Programs

**Originals vs. Copies/Faxes**
A majority of the survey states specify a distinct, bright color for their POLST forms. Five states (ID, MN, TN, UT, VT) impose no color mandate for original forms. Copies or facsimiles are deemed valid in all but one of the survey states (NC). In West Virginia, copies are valid but must be photocopied onto pink paper.

**Conflicts between POLST and Advance Directives**
Where multiple legal forms address similar matters, there is always some risk of inconsistency that may raise concerns about the patient’s true intent. Survey informants did not flag inconsistencies between POLST forms and advance directives as an issue, but to the extent that there is a risk of conflict, the states differed in how to respond. The POLST form controls in three states (ID, NC, UT). The most recently completed controls in two states (CA, WA), and the advance directive controls in one state (TN). Two states (NY, WV) mandate that the substituted judgment/best interest standard be followed. Four states (HI, MN, OR, VT) do not address the conflict issue at all.

**Incomplete POLST Forms**
No state requires every section of the POLST form to be completed, since patients may not be ready to decide on all the options provided in POLST. However, in most of the surveyed states, sections left blank give rise to an explicit presumption of full treatment for that component. Only two states (NY, VT) impose no presumption. New York guidelines recommend but do not require crossing out the section with a notation, “Decision deferred.”

**Out-of-state POLST Reciprocity**
Five states (ID, NY, OR, UT, WV) explicitly recognize out-of-state versions of POLST, while only one state (NC) expressly limits validity to in-state forms. The other six states (CA, HI, MN, TN, VT, WA) do not address the issue at all.

**Key Informants’ Survey Findings**
The substantive findings of the 12-state survey are organized under six data categories:

1. Elements facilitating the development and implementation of POLST
2. Barriers and issues that arose in establishing and implementing POLST
3. Training and educational features of the POLST effort
4. Monitoring and evaluation features and issues
5. Ensuring the quality of POLST conversations
6. Advice for developing programs

Appendix B summarizes the survey findings at the most generalized, wide-angle level. Because of the qualitative nature of the data collection, frequencies of each issue or feature are not quantified numerically, but instead grouped into three levels:

1. Most commonly identified—operationally defined as identified in six or more states
2. Commonly identified—in three, four, or five states
3. Other noted themes or features—in one or two states
Facilitators of POLST
State informants most often identified three variables that facilitated successful establishment of a POLST program. First, the existence of an established state end-of-life or palliative care organization capable of effectively coordinating a statewide POLST coalition helped jump-start POLST development.

The following are examples of effective statewide organizations identified:

- The Coalition for Compassionate Care of California\(^{19}\)
- Kokua Mau of Hawaii\(^{20}\)
- The Idaho End-of-Life Coalition\(^{21}\) (formerly A Better Way Coalition)
- The Community-Wide End of Life/Palliative Care Initiative of New York\(^{22}\)
- The Tennessee End-of-Life Partnership\(^{23}\)
- The West Virginia Center for End-of-Life Care\(^{24}\)

Second, a core group of “physician champions,” often in connection with a medical society or other physician-led group, was seen as a key component to achieving POLST awareness and acceptance in major health care institutions. While nurses, social workers, and other health care workers were equally important to the success of POLST implementation, physicians were key to the initial institutional culture change that was necessary to establish the POLST paradigm.

Third was the use of a deliberately incremental strategy, typically starting with a pilot program and then expanding statewide, via legislation if needed, or by expanding clinical consensus. The particular steps involved were unique to each state, but two examples are provided in the box on page 14.

At the next level of frequency, “commonly identified” facilitating variables included the following:

- The availability of significant financial support, either through direct funding (grants, appropriations) or in-kind funding from a health system or association. For example, California respondents cited the California Health Care Foundation’s financial support of the statewide and regional POLST coalitions as the most critical factor in enabling POLST to take root and grow throughout the state.

\(^{19}\) http://www.coalitionccc.org.
\(^{21}\) http://www.idahoendoflifecoalition.org.
\(^{22}\) http://www.compassionandsupport.org.
\(^{24}\) http://www.hsc.wvu.edu/chel/wvi/.
Examples of Incremental POLST Strategies

**West Virginia**

Interest in POLST, called Physician Orders for Scope of Treatment (POST) in West Virginia, germinated around 2000 in a coalition of groups known as the West Virginia Initiative to Improve End-of-Life Care, based at West Virginia University. A trial program was started in the Morgantown and Parkersburg area on a voluntary basis with hospitals, nursing homes, and EMS. After the program showed promising results, the initiative implemented it statewide, with the impetus coming from the incorporation of the POST program into the West Virginia Health Care Decisions Act in 2002. That year, the West Virginia Center for End of Life Care (CEOLC) was established as a statewide organization housed at the university. With support from the West Virginia Legislature, the CEOLC is funded through the West Virginia Department for Health and Human Resources and has played a central role in bringing stakeholders together to support POST implementation statewide. In 2010, the CEOLC launched an initiative to establish an electronic registry for POST forms, DNR cards, and health care advance directives.

**New York**

The New York State MOLST program grew out of a regional collaborative initiative in the Rochester area with a mission to develop a set of broad end-of-life/palliative care projects. Called the Community-Wide End of Life/Palliative Care Initiative, it was launched in May 2001, and developing MOLST was among its priorities. It started with using MOLST in hospitals and nursing homes in a limited geographic area. Use of MOLST outside of institutions was not yet possible because of barriers in the state’s DNR law. Collaboration with groups across the state expanded, as did engagement with the Department of Health. In late 2005, the Department of Health approved use of MOLST statewide but only inside health care facilities. Then, a 2005 legislative amendment to the DNR law permitted a pilot program in two counties to use MOLST as a nonhospital DNR order. A year later, an amendment permitted the inclusion of do not intubate orders. The evidence-based success of the pilot helped bring about legislation in 2008 to make MOLST permanent and statewide as of July 8, 2008.

- A **supportive regulatory agency** that participated in and supported the goals of POLST development. Most often it was the state’s department of health that had regulatory oversight over emergency medical services as well as health care facilities. But in some cases it was the medical board or other agency that regulates or licenses health care professionals. Uniformly, states agreed that EMS representatives had to be part of the development and implementation process.

- The assistance of a well-situated **individual or entity with clout**. They included a particularly influential state legislator, an attorney general, or a religious spokesperson, civic leader, or group that assists by lending support or, in some instances, by agreeing **not** to speak in opposition to the establishment of POLST. While the establishment of a POLST program has been the fruit of a broad statewide coalition in most of these states, it has also come about through the high-level efforts of a relatively small group of well-situated individuals with clout (UT, WV) or a motivated medical society (MN, WA). And relatively small states have different opportunities for success than do larger states.
Respondents in smaller states commonly noted the **advantage of being a small state** in that most of the stakeholders already know one another and the number of participants who need to be brought into the decision-making process is more manageable.

The **framing of POLST within a broader end-of-life/palliative care mission** was commonly seen as a facilitator because it integrated POLST more effectively into the array of chronic care/end-of-life-care culture change goals and avoided portraying POLST as a stand-alone panacea for shortcomings in the system of care.

Nine other themes or features that facilitated POLST were identified in only one or two states each:

- The **emergence of an effective statewide coalition** around POLST that did not previously exist.
- The importance of nurturing a network of local coalitions in coordination with a statewide coalition. This was particularly emphasized in larger states.
- Having a legislative or regulatory opportunity that provides a vehicle for POLST development. For example, in Tennessee, a major legislative rewrite of the health decisions law offered an opportunity to initiate POLST. In the Tennessee law, the concept of a universal DNR order was the vehicle. In Washington, the broad statutory authorization of the Department of Health to develop guidelines for emergency medical personnel provided an opening.
- Having a clear consensus on what’s broken in the system as an effective motivator for establishing POLST. Respondents highlighted different motivators, including consensus on the shortcomings of health care advance directives, the limited availability of palliative care generally, recognition that too many patients were receiving end-of-life care inconsistent with their wishes, the emergence of multiple variations in POLST forms around the state, and problems with restrictive surrogacy rules.
- Having a highly inclusive coalition. For example, the support of a recognized “right-to-life” group was particularly emphasized as helpful in Hawaii, which had support from the Hawaii Family Forum. This element could be described as an example of an effective statewide coalition—a factor already noted above—but it highlights a recurring theme about effective coalitions: They must be fully inclusive, including those who may initially disagree with the objectives of the coalition, whether they be religious groups, disability advocates, or other minorities.
- Incorporating a strong, ongoing research component into the effort. This has been a feature of the Oregon program from its inception and has resulted in several published studies of POLST that have established an evidence base used to expand and improve the program not only in Oregon, but nationally. Oregon had the benefit of a health sciences university-based POLST coalition with the interest in and ability to pursue research.
- The existence of relatively few health systems was identified by Minnesota respondents. While not a small state geographically, Minnesota may share the
advantage identified by geographically small states in that there are fewer stakeholders who need to participate in the process.

- The leadership of a strong, charismatic physician champion who can devote time and institutional resources to the development of POLST was noted repeatedly in New York. Most states lack such an asset, but the example also highlights the fact that each of the POLST states has capitalized on different strengths in ways unique to its particular resources and realities.

Barriers and Salient Issues
Respondents were asked about barriers both to initial enactment of POLST and to its subsequent implementation, as well as about key issues that arose during both those stages. Respondents cumulatively identified 44 different barriers or salient issues that posed challenges to POLST, with six emerging as the most frequently cited.

First is the question of whether patient consent must be documented on the POLST form by signature. As described in the legislative comparison, most states opted for mandatory signature. Even in states where a signature is optional, their forms provide a signature space.

Second, form content decisions in general posed salient issues in the majority of states. The process of developing POLST requires every state to make myriad form content and language decisions, so this is not surprising. Generally, all controversies over specific content were resolved through deliberation by stakeholders.

Third, problems in distinguishing POLST from health care advance directives were quite common. Health care providers had a tendency to think of POLST as a short-form advance directive with more helpful instructions. POLST advocates generally used educational strategies to correct the misperception.

Fourth, the authority of surrogates to consent to POLST on behalf of a patient lacking decisional capacity posed challenges in at least half the states. A surrogate may be an individual appointed by the patient under some form of health care advance directive, a family member recognized as a default surrogate under state law, or a court-appointed guardian. Sometimes state law is unclear about the extent of surrogate authority in general, as in California. Elsewhere, the authority of surrogates for special populations such as persons with developmental disabilities posed an issue, as in New York. In response, New York developed special procedures for surrogate consent to POLST for special populations. In states where default surrogate decision-making for patients was well established by statute, this was less of an issue.

Fifth, respondents in at least half the states noted the difficulty in changing institutional protocols as a significant barrier. Hospitals frequently have a slow and laborious process for changing policies or protocols, and nursing homes that are part of national chains may be constrained by corporate policy over which they have minimal control. The availability of model policies from other states or institutions was helpful in overcoming institutional inertia.

Sixth, most states identified the challenge of integrating POLST into electronic health records (EHRs). A promising step in this direction has already been achieved in the form of an electronic POLST registry, operational in Oregon in 2010. West Virginia,
New York, and other states are in developmental stages. Some regional users of POLST already prominently incorporate POLST and advance directives into institutional electronic medical records, although the state of the art nationally has not advanced far. Respondents uniformly identified this as a critical future challenge of POLST implementation.

The second tier of barriers and salient issues—those commonly identified—include several issues:

- A common threshold concern is whether legislation is needed to establish a POLST program. As noted in the legislative review, neither Oregon, the first POLST state, nor Minnesota, one of the most recent programs, relied on legislation to initiate POLST. They instead approached it like any other clinical protocol, albeit more complicated because it extends across health care settings. The other 10 states in the study all used some form of legislation as a springboard for POLST. Different drivers tilted the strategy toward legislation, including the desire to ensure uniformity and recognition of POLST statewide and the need to remove specific state law barriers to POLST. For example, New York’s do-not-resuscitate law mandated a very specific DNR form and process that precluded use of POLST until it was modified. In other states, the perceived need for a political driver of change led to the decision to pursue legislation.

- In some states, clinicians had concerns about incurring civil or criminal liability or disciplinary action in connection with POLST. Because statutory immunity has become a common fixture in advance directive legislation, there tends to be an expectation that similar protection should apply to compliance with POLST, especially in states that are perceived as more litigious. Without legislation, clinicians can still have ample protection where POLST becomes recognized as the accepted standard of care. This is the same level of protection clinicians have for almost everything they do. But if professional groups place a high priority on immunity, legislation may be needed.

- Deciding which health care professionals can sign POLST posed an issue in several states. Generally, the issue concerned whether to extend this authority beyond physicians. The legislative comparison above summarizes the variations of outcomes.

- Some states struggled with nonhospital physician authority. In other words, can a hospital physician be bound by a POLST form signed by a physician who is not credentialed by the hospital? In California, the medical association originally expressed concern that such an obligation would violate federal Medicare rules and accreditation requirements of the Joint Commission on Healthcare Organizations. Further inquiry found that neither authority posed a barrier. In states where nonhospital physician authority has been an issue, resolution has generally involved a pragmatic balancing of continuity of care goals with hospitals’ quality of care goals. The result generally is an expectation that POLST will be reviewed upon admission and either reaffirmed, revised, or revoked as appropriate. But if there is no time to

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review the orders due to the patient’s condition, incapacity, and lack of an available authorized surrogate, then the orders can be followed, even if not signed by a physician with admitting privileges to the hospital. In Maryland, the one state in this survey that rejected POLST legislation, this was the barrier causing its demise. Maryland adopted a plan of care type form that looked similar to POLST but was not a doctor’s order and subsequently had little impact on practice patterns.

- Another physician issue involved the misperception of POLST as just another routine form that physicians can obtain and use with minimal training. Programs attempt to counter this perception with the constant messaging that POLST is a process and not a form. For example, New York has defined an eight-step POLST protocol, only one step of which is completing and signing the form. In addition, the training resources developed by POLST states focus largely on the skills training needed to discuss POLST and review options meaningfully with patients.

- A related barrier at the opposite extreme is the perception that POLST is overly cumbersome and time-consuming. Respondents report this as a common initial reaction by physicians to the introduction of POLST. However, once sufficiently trained in its use, most physicians reportedly come to find it an efficient and effective tool.

- Perceptions of POLST by nonphysician providers also posed barriers. This was particularly true of emergency medical personnel in some states. A common barrier to acceptance by EMS personnel is the view that POLST provides too many choices, making it more challenging for them to act on the scene. This is true particularly with respect to the options for persons who have a pulse and/or are breathing: comfort measures only (including a directive not to transfer to a hospital unless the patient’s comfort needs require hospitalization); limited additional interventions; or full treatment (options briefly defined on the forms). Again, the experience in successful POLST states has been that training modifies this perception.

- Common nursing home misperceptions about POLST tended to arise over questions of what is mandatory and what is not. In states that mandate nursing homes to offer POLST, facilities sometimes interpreted that as a requirement that every resident have a POLST form. However, no states mandate that any individual have a POLST form, because it requires the voluntary informed consent of the patient or surrogate. Nevertheless, what should be mandatory and what should not is a common point of contention in establishing POLST. Solutions vary. Some (UT) mandate that qualified nursing home residents be offered POLST; others mandate a duty to comply with POLST if one exists (NY); or require that if a POLST form exists, it must be conveyed to the receiving institution when an individual is transferred (TN).

- States commonly deliberated about the extent to which protections were needed to ensure appropriate decision-making by surrogates for patients lacking decisional

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capacity. Disability advocacy groups engaged in POLST development were most wary about safeguards for surrogate consent. Implementation responses varied from simply mandating the patient’s or surrogate’s signature on POLST as an assurance of consent, as required in most of the states, to creating differential procedures and checklists for completion of POLST on behalf of patients with developmental disabilities, minors, and patients in mental hygiene facilities (NY).

- **POLST accessibility and portability** issues commonly presented operational challenges. Decisions about access to POLST forms generally fell into two camps—states that make the form accessible for download on the Internet by anyone and states that limit distribution of the forms to clinicians and facilities. Once a POLST form is in place, the challenges of keeping it accessible in the medical record and ensuring that it travels with the patient during transfers pose primarily logistical obstacles. A variety of other issues affect accessibility and portability, such as whether the form must be a particular color and whether copies or facsimiles are valid. States were split on color requirements, but every state permitted the recognition of copies and facsimiles. And, as noted earlier, states are moving toward electronic versions of POLST within EHRs.

- Finally, **cross-cultural issues** were identified generally as a challenge to POLST implementation. The concerns are similar to those commonly associated with the use of health care advance directives, including not only language translation obstacles but also differing value systems and cultural norms around death, dying, and decision-making.

Twenty-six other specific barriers and salient issues were identified in one or two states each. These are listed in bulleted form in appendix B. Further narrative details about each state can be read in individual state profiles in appendix C.

**Training and Educational Features**
Survey respondents were asked to describe the state’s POLST training and educational efforts and to identify associated challenges. A significant majority most commonly identified a lack of funding or minimal funding to conduct training and education programs as the most significant challenge they faced, both in the initial establishment of POLST and in ongoing implementation. Most emphasized that training and education was the most critical implementation challenge of any POLST program, and that having a statewide plan with funding is critical. Successful implementation appeared to be strongly associated with regular ongoing trainings throughout the state and the existence of an extensive Web-based clearinghouse of resources, curricula, guides, multimedia presentations, and other aids. Of all the target groups for training and education, physicians were identified as the most challenging to engage.

**Monitoring and Evaluation**
Most of the POLST states lack any formal monitoring or evaluation process. The most common approach in states with more extensive experience in using POLST is the use of an expert working group or committee to periodically solicit and review feedback from stakeholders and recommend changes to the form or procedures as needed. A commonly identified challenge was the limited focus that the state department of health, or other agency with approval authority over POLST, gave to monitoring the proper use of POLST. Promising new opportunities identified for enhancing monitoring and evaluation
of POLST include the data potential of electronic POLST registries, as Oregon has implemented. For example, the Oregon registry has been able to identify unsigned or mis-signed POLST forms and to prompt corrections before a critical event occurred. Oregon researchers have been the most prolific in rigorous evaluation of POLST to date, possibly because the state POLST task force is the oldest in the country and has always been based in a university health sciences setting.

States now have a new option to collect data as part of the revised federal nursing home Minimum Data Set (MDS). A new subpart S of the MDS is available for states to add questions of their choice. Effective October 1, 2010, the MDS used in California asks whether the resident has a POLST, which choices are selected on the form, and with whom the form was discussed. This will provide valuable data on the extent and patterns of usage of POLST in nursing homes and may serve as a starting platform on which to construct outcome measures for POLST.

Quality of the Conversation
The key underlying premise behind the validity and efficacy of POLST is meaningful discussion between patients (or surrogates) and clinicians, resulting in informed decisions notated on the POLST form. Most respondents highlighted the importance of this issue and the fact that it poses an ongoing challenge. None of the respondents could identify existing measurement tools to assess the quality of those conversations.

Virtually all respondents viewed ongoing professional educational efforts as the primary strategy to ensure the quality of these discussions. Respondents generally pointed to a variety of in-person educational efforts and online resources (e.g., guidelines, checklists, publications, videos) developed to teach the POLST process and the communication skills necessary to engage patients meaningfully. One respondent mentioned a tool in development in California for obtaining patient/family feedback on the process. The effectiveness of the training and education efforts will only become verifiable if researchers develop effective outcome measurement tools adaptable for use in the field.

Advice for Developing Programs
Study investigators asked key stakeholders, “Do you have any suggestions for people working to implement POLST in their states now?” The points below represent a compilation of frequently mentioned suggestions and “lessons learned.”

• **Find the champions.** Passionate leaders—sometimes called physician champions—with the motivation and independence to devote substantial time to POLST development are needed. Start with a small working group of champions and then build a broad coalition.

• **Be as inclusive as possible.** Build partnerships; get everyone at the table. Necessary stakeholders include (in varying combinations in different states) nursing homes, hospitals, state regulatory agencies (health, EMS), physicians, religious groups, right-to-life groups, disability advocacy groups, minorities, and leaders of differing political persuasions.

• **Build coalitions on the local level, too.** This was particularly cited in larger states.

• **Start with pilots.** Then build out.
• *Keep POLST integrated into the larger spectrum of good end-of-life care.* POLST is about honoring patients’ wishes and ensuring that those wishes are known and followed across settings. But POLST is not a stand-alone intervention. It has to be understood as an integral part of the spectrum of good chronic and palliative care management.

• *Follow the lead of existing POLST states.* Network with POLST leaders in other states. Don’t reinvent the wheel. Learn the pitfalls. Use empirical data. Consult the National POLST Paradigm Task Force.

• *Know your state.* All politics is local. Will a legislative approach be a boon or a barrier? Where is the best “home” for the program? Who are the main actors?

• *Devise a legislative strategy if going that route.* There may be pitfalls in lumping POLST with other end-of-life issues and/or advance directives. Starting with a legislative resolution may help.

• *Allow flexibility to design and revise the form.* For example, don’t put a specific form in statute. Use an interdisciplinary group to design the form.

• *Plan an infrastructure for the long haul.* POLST will not implement itself, even after clear authorization for statewide use. Have a multiyear plan with three essential components: ongoing education, research, and quality improvement of practice.

• *Funding can be key.* Even a modest grant can make a big difference.

• *Think electronic.* The transition to EHRs has begun. Development of the standards and software capability to ensure that POLST, along with advance directives, are visible and accessible parts of EHRs needs to occur right now.
EXPERT REVIEW: LOOKING TOWARD THE FUTURE

In December 2010, an invited group of 27 health, chronic care, and POLST experts met in a roundtable format with AARP staff to review and discuss the preliminary findings of the survey project. A lively discussion of the findings and their implications ensued, with participants offering many recommendations for next steps. Much of the content affirmed the lessons learned above, but additional thoughts and perspectives deserve note.

THERE IS A NEED FOR QUALITY INDICATORS FOR THE PATIENT-PROVIDER INTERACTION IN PREPARING POLST.

The research literature on POLST provides an encouraging evidence base, indicating that it effectively documents critical treatment goals of seriously ill patients and enhances compliance with those goals of care across health care settings. However, this efficacy rests on the premise that these patients or their surrogates understand their current medical circumstances and options and that the orders agreed to on POLST accurately reflect their goals of care. The process to make that happen is a complex multifaceted intervention, requiring a high level of skill in educating patients and their surrogates, counseling them on their options, and working through the POLST form in an understandable way, both initially and whenever the orders require review. This process additionally occurs within a larger set of palliative and care management issues for these patients. For example, if POLST calls for comfort care only, what does that comfort care consist of and how good is it? These questions are not unique to POLST, but the options provided by POLST unavoidably depend upon the broader quality of care given in the health systems caring for the patient.

Validated, practical quality measures for the POLST patient-provider interaction do not exist yet. Informal periodic qualitative feedback solicited from providers has been valuable in mature POLST states, leading to revisions to the form or process. Oregon, which began using POLST in early 1990s, has revised its form and process seven times based upon this kind of qualitative review. New York developed detailed provider checklists for completing and documenting its version of POLST. These examples could provide the basis for POLST process measures. California has used nursing home chart spot audits in selected locales and is also working on a tool to elicit patient and family feedback on the POLST process. The latter may provide a step toward a patient-centered POLST quality measure.

STATES NEED A MULTIYEAR DEVELOPMENTAL PERSPECTIVE.

Expanding on the recommendation above to plan for the long run, participants framed POLST development ideally as a component of the broader challenge of end-of-life systems change and culture change. Effective POLST training and education should not be viewed in isolation. It requires long-term integration with medical and professional training and education on chronic care, long-term care, palliative care, and communication skills. Advocates should define realistic goals for a multiyear implementation process both for POLST and for the larger culture change goals.
The longitudinal nature of POLST implementation is best illustrated by programs that have a long track record. West Virginia has had POLST for almost 10 years (2002), and its most recent data show that 85 percent of hospices, 70 percent of nursing homes, and 50 percent of hospitals are actively using POST forms. 28 Oregon has the longest-running program, now at 20 years (1991), and reports that virtually all hospices, nursing homes, and hospitals actively use POSLT. 29 These rates of penetration take time to reach. They do not happen in the first couple years and require a continuing planning and implementation strategy.

**Language is important.**

Still fresh in the minds of participants was the public and political stir over the proposed but failed inclusion of Medicare reimbursement for advance care planning in the federal health care reform legislation of 2009. Connecting conversations about end-of-life decision-making to government reimbursement during the health care reform debate triggered baseless but vehement charges of government-sponsored euthanasia and “death panels.” Part of the reaction may be explained by a cultural aversion to talking about death. Language itself is value-laden and triggers the personal frames of reference and narratives through which individuals see the world. Thus, phrases such as “end-of-life counseling” can be threatening and inflammatory, while “advance care planning” is less so and at the same time more accurate, since advance care planning, if done well, is a lifelong process for adults.

For nomenclature of POLST, the use of “life-sustaining treatment” carries a value message that can likewise be misconstrued as threatening. It suggests a narrow range of choices (i.e., whether to “pull the plug on Granny”). While POLST concerns decisions for patients with advanced chronic illness, it goes beyond CPR, ventilators, and feeding tubes. It permits a broad range of choices, from aggressive curative treatments to comfort care only.

Because of the significance of the terms used—both in terms of accuracy and value messages—a few states have moved away from the original POLST terminology to more neutral descriptive terms, such as Physician Orders for Scope of Treatment (POST) in West Virginia, or Medical Orders for Scope of Treatment (MOST) in North Carolina. The choice of terminology will depend on an assessment of each state’s political and public culture. However, given the volatile experience with the subject in the context of national health care reform legislation, a few participants in the roundtable suggested that it may be time to consider a shift in terminology or branding of the paradigm nationally.

**Physicians and other health care providers are undereducated in end-of-life care knowledge and skills and resistant to education . . . but educable.**

Participants emphasized two areas sorely needing better physician education: communication skills for facilitating decision-making discussions with patients and

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28 Personal communication with Alvin Moss, MD, January 6, 2011.
29 Personal communication with Susan Tolle, MD, January 6, 2011.
families, and knowledge of the therapeutic impact of interventions such as CPR and tube feeding in elderly, chronic care patients. Physicians also tend to be the hardest group of health professionals to pull into in-depth training efforts, primarily because of never-ceasing time demands as well as the profession’s own end-of-life aversions. Nevertheless, communications skills relevant to POLST-related discussions are teachable, and teaching resources available 24/7 show promise. These include providing key questions, phrases, and scripts for providers, role-playing videos that model effective communication, and interactive software that engages users in role-playing.30

Even though POLST is most directly tied to the physician’s role, every POLST state recognizes that other health care providers—such as nurse practitioners, physician assistants, other nurses, and social workers—generally provide much if not most of the patient counseling and assistance in completing POLST forms. More often than not the physician role is to verify the choices made and the process used with the patient and then sign off on the orders. The La Crosse, Wisconsin, program, operating regionally for several years, has developed a trained “facilitator” model that requires completion of an approved training curriculum by nonphysicians who then serve as facilitators for all stages of advance care planning, including POLST.31

**PAYMENT INCENTIVES SHOULD BE IMPROVED.**

Most leaders in POLST implementation support the concept of Medicare and private insurance reimbursement for advance care planning counseling, including the time required to prepare POLST. Proposals to accomplish that purpose were pulled from health care reform legislation in 2010 because of the frenzy it triggered. Later, when included as an element to be offered under the new annual Medicare wellness exams regulation, the voluntary consultation was pulled just before the regulations went into effect in January 2011. Gaining recognition of the value of advance care planning in the Medicare reimbursement system will continue to be a challenge.

**CONSIDER USE OF “REPORT CARDS” TO INCENTIVIZE POLST.**

POLST states were all motivated by a desire to fix perceived problems with chronic and end-of-life care within the state. Enhancing the motivation can accelerate the adoption of POLST. Some participants recalled when a state-by-state national report card on dying in America was published by the Last Acts initiative in 2002.32 The generally poor state grades in that report spurred substantial efforts to improve care across the states. That report was one component of a major initiative on improving end-of-life care funded by the Robert Wood Johnson Foundation. Participants suggested that future foundation and coalition efforts at the national level should consider a reprise of that strategy.

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OPPORTUNITIES EXIST FOR GREATER ENGAGEMENT WITH NATIONAL PROVIDER AND PALLIATIVE CARE GROUPS.

Participants questioned whether POLST was sufficiently on the radar screens of the major national provider and palliative care organizations. While groups such as the National Hospice and Palliative Care Organization have been actively involved, some other professional and consumer groups could exercise considerable constructive influence if engaged in POLST development.

ELECTRONIC HEALTH RECORDS SHOULD INCLUDE ADVANCE DIRECTIVES AND POLST DATA AND NOT JUST SCANNED COPIES OF FORMS.

Participants expect significant steps toward more widespread adoption of EHRs over the next few years. At the federal level, the Department of Health and Human Services (DHHS) issued final regulations to implement the first stage of requirements under the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 and currently is developing second-stage requirements.33 Eligible clinicians and hospitals can qualify for Medicare and Medicaid incentive payments when they adopt certified EHR technology and use it to achieve specified advances in health care procedures and outcomes. One set of regulations defines “meaningful use” objectives that providers must meet to qualify for the bonus payments. For stage one (2011 and 2012), the regulations require eligible professionals to meet 15 core objectives for meaningful use as a starting point. In addition, they must choose five more objectives from a menu of 10 objectives that represent additional important activities.34 Documenting advance directive status is included in the latter optional menu for hospitals. POLST is not addressed at all. If the advance directive objective is selected, the rule does not specifically require the content of the advance directive to be noted. The regulations for stage two will add requirements, but it is not clear whether DHHS will go further in mandating documentation of advance directives for eligible clinicians, requiring that the advance directive be entered into the EHR, or requiring POLST be included in qualifying EHRs.

In the meantime, as health systems and providers move forward at differing paces in adopting EHRs, inclusion of POLST and advance directives will remain a priority for proponents of POLST. The ideal translation of POLST into EHRs will entail recording its content in data fields that will permit evaluation and monitoring of patterns of POLST usage. Merely scanning the document as a PDF into the record may meet the care goals of the individual patient, but it does not facilitate evaluation, monitoring, or research on the process.

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33 The HITECH Act was enacted as part of the American Recovery and Reinvestment Act of 2009, P. L. 111-5, signed February 17, 2009.

34 75 Federal Register 44569 (July 28, 2010); see http://www.cms.gov/EHRIncentivePrograms/30_Meaningful_Use.asp#BOOKMARK2.
CONCLUSION

As of the beginning of 2011, the POLST paradigm has taken root in about a quarter of the states and is under development in the majority of others. The findings of this survey and expert roundtable highlight numerous issues and program features that enable or challenge state stakeholders seeking to develop a POLST program. Among the many lessons learned, a few stand out, including the need for a broad, diverse range of participation, including physician leaders; the tremendous value of adequate financial resources; and the wisdom of using incremental strategies of development and implementation.

Collectively, the states adopting some version of POLST have struggled with and found solutions to several common issues relating to the structure, content, and operation of POLST. Core features of successful programs include robust, ongoing training and education of health professionals, especially in the communication skills and processes needed to implement POLST in a patient-centered, meaningful way, and ongoing monitoring and quality improvement of the POLST process. For states just beginning to consider the development of POLST, the documented experience of existing POLST states offers an instructive road map through a challenging medical, institutional, political, and cultural terrain.
APPENDIXES
### APPENDIX A. POLST STATUTORY/REGULATORY COMPARISON (1/30/11)

<table>
<thead>
<tr>
<th>1. Terminology</th>
<th>California</th>
<th>Hawaii</th>
<th>Idaho</th>
<th>Minnesota</th>
<th>New York</th>
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<td>Physician Orders for Life-Sustaining Treatment (POLST)</td>
<td>Physicians Orders for Life-Sustaining Treatment (POLST)</td>
<td>Physicians Orders for Scope of Treatment (POST)</td>
<td>Provider Orders for Life-Sustaining Treatment (POLST)</td>
<td>Medical Orders for Life-Sustaining Treatment (MOLST)</td>
<td>Medical Orders for Scope of Treatment (MOST)</td>
</tr>
</tbody>
</table>

## POLST Statutory/Regulatory Comparison (1/30/11) (continued)

<table>
<thead>
<tr>
<th>4. Entity responsible for development/approval of POLST</th>
<th>California</th>
<th>Hawaii</th>
<th>Idaho</th>
<th>Minnesota</th>
<th>New York</th>
<th>North Carolina</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Medical Services Authority §4780(a)(2)(B)</td>
<td>Department of Health, §327K-4</td>
<td>EMS Bureau, Idaho Department of Health and Welfare, § 39-4512A(6)</td>
<td>Minnesota Medical Association (voluntary consensus process)</td>
<td>MOLST created by the Community-wide EOL/Palliative Care Initiative, Rochester, NY. Development was led by Excellus BCBS, leader of the Initiative, in collaboration with DOH, and multiple collaborating partners. Statewide implementation now rests with the MOLST Statewide Implementation Team, through Compassion and Support.</td>
<td>Dept. of Health and Human Services, Division of Health Service Regulation. (Sell forms for 4 cents each)</td>
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</tbody>
</table>

| 5. Provider signature required | Physician §4780(c) | Physician §327K-1 and K-2 | Physician §39-4512B(1) | • Physician (MD/DO) • Nurse Practitioner • Physician Assistant (when delegated) | Physician only | • Physician (MD/DO) • Physician Assistant • Nurse Practitioner |

| 6. Patient signature required? | Yes §4780(c) | Yes §327K-1 and K-2 | Not required by statute, but required on approved form | No, but recommended | No, but consent is required. Verbal consent permitted. Two witnesses are always recommended. | Yes |

| 7. Surrogate signature permitted? (Agent/Default Surrogate/Guardian) | Yes §4780(b) & (c) | Yes §327K-1 and K-2 | Yes, §39-4504 | Yes | Yes, by health care agent, PHL surrogate, minor’s parent/guardian, or §1750-b surrogate. Verbal consent permitted. Two witnesses always recommended. | Yes |

<table>
<thead>
<tr>
<th>8. Applicable to minors</th>
<th>Yes, case law authority</th>
<th>Yes</th>
<th>Yes, §39-4504</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Form has box to identify h.c. professional assisting in preparation.</td>
<td>No Form has box to identify h.c. professional assisting in preparation.</td>
<td>POST is completed by provider on password protected interactive web page <a href="http://www.sos.idaho.gov/general/hcdr.htm">www.sos.idaho.gov/general/hcdr.htm</a></td>
<td>No Form has box to identify h.c. professional assisting in preparation.</td>
<td>Separate signatures required for CPR instruction and for other life-sustaining treatments. Capacity determination and review and renewal of MOSLT required. Requirements vary based on who makes decisions and where made.</td>
<td>(1) If patient representative approves orally, must then sign a copy of the form and return it for entry into med record. Original must note signature “on file.” (2) Form has box to identify h.c. professional assisting in preparation.</td>
<td></td>
</tr>
</tbody>
</table>

| 10. Exclusive DNR form? | No, §4780(a)(2) & (e) | No | No | No | No | No |

| 11. Immunity provided? | Yes, §4782 | Yes, §327K-3 | Yes, 39-4513 | No | Yes, PHL §2994-o, Family Health Care Decisions Act | Yes |

| 12. Duty to offer POLST? | No | No | No, but duty to ask if patient has a POST and to provide one if requested 39-4512C & 39-4512A(3) | No | No | No |

| 13. Duty to comply? | Yes, with limited exceptions §4781.2 | Yes, with limited exceptions §327K-2 | Yes, with limited exceptions 39-4512B & 39-4513(5) | No | Yes | No, but immunity provision does not apply if provider refuses with knowledge of the form’s existence |

| 14. Original vs. Copies/faxes? | Original pink. Copies are valid. | Original lime green preferred, but no color requirements. Copies are valid. | Yes, 39-4514(8)(b) | No color requirement for Original. Copies are valid. | Pink original is preferred. Copies are valid. | Pink original must be used. |

<p>| 15. Conflicts with AD addressed? | Most recent controls §4781.4 | Not addressed in statute | POST controls, 39-4512A(2) | No | Not specifically addressed but surrogates are obligated to follow patient’s known wishes; otherwise best interests. | Yes, Most form “may suspend any conflicting directions in patient’s AD.” |</p>
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<th></th>
<th>California</th>
<th>Hawaii</th>
<th>Idaho</th>
<th>Minnesota</th>
<th>New York</th>
<th>North Carolina</th>
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</thead>
<tbody>
<tr>
<td>16. Presumption if section of form left blank</td>
<td>Full treatment</td>
<td>Full treatment</td>
<td>Full treatment</td>
<td>Full treatment</td>
<td>No. Section may be crossed out with notation “Decision Deferred”</td>
<td>Full treatment</td>
</tr>
<tr>
<td>17. Out-of-state POLST recognized?</td>
<td>Not addressed</td>
<td>Not addressed</td>
<td>Yes, 39-4514(6)</td>
<td>Not addressed</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Additional Notes</td>
<td>POST identification jewelry authorized 39-4514</td>
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<td></td>
<td>MOLST completion is easiest with patient or h.c. agent; thus, effort is directed at obtaining h.c. proxies and fostering conversations early.</td>
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</tbody>
</table>
## POLST Statutory/Regulatory Comparison (1/30/11) (continued)

<table>
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<th>Washington</th>
<th>West Virginia</th>
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<tbody>
<tr>
<td><strong>1. Terminology</strong></td>
<td>Physician Orders for Life-Sustaining Treatment (POLST)</td>
<td>Physicians Orders for Scope of Treatment (POST)</td>
<td>Life with Dignity Order (LWDO) – generic term. POLST is the only DOH approved LWDO.</td>
<td>Clinical Orders for Life-Sustaining Treatment (COLST)</td>
<td>Physicians Orders for Life-Sustaining Treatment (POLST)</td>
<td>Physicians Orders for Scope of Treatment (POST)</td>
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<td><strong>3. Regulations/ Guidelines</strong></td>
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<td>(continued)</td>
<td>Same rule repeated for all other health care facilities, e.g. nursing homes, at 1200-08-06-.13 (30). Also see: <a href="http://health.state.tn.us/Boards/AdvanceDirectives/FAQs:http://health.state.tn.us/AdvanceDirectives/FAQ_POST.htm">http://health.state.tn.us/Boards/AdvanceDirectives/FAQs:http://health.state.tn.us/AdvanceDirectives/FAQ_POST.htm</a></td>
<td></td>
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</tbody>
</table>
| **5. Provider signature required** | • Physician  
    • Nurse Practitioner  
    • Physician Assistant Or. Admin. Rule 333-270-0030 | Physician, 68-11-224 | Yes  
    • Physician  
    • Advance Practice RN  
    • Physician Asst (w/in scope of supervisory agreement)  
    Also provides that other specified health professionals acting under the supervision of the above may “prepare” the LWDO. Form includes box for preparer signature, also. §75-2a-106(2) | Yes, physician or Osteopath, Advance Practice RN PA | Yes, physician or NP or PA | Yes, physician. §16-30-25 |
<p>| <strong>6. Patient signature required?</strong> | No, but recommended | Yes, 68-11-224 | Yes, §75-2a-106(3) | Yes, unless order based on futility in which case signature of a 2nd clinician required. | Yes | Yes, §16-30-25 |</p>
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<tbody>
<tr>
<td>7. <strong>Surrogate signature permitted?</strong> <em>(Agent/Default Surrogate/Guardian)</em></td>
<td>Yes, ORS 127.635 if specified conditions are met (default surrogate consent law)</td>
<td>Yes, but conditions must be met for withholding/withdrawal of nutrition &amp; hydration.</td>
<td>Yes, §75-2a-106(3)</td>
<td>Yes, §9708(a)(3)</td>
<td>Yes</td>
<td>Yes, §16-30-25</td>
</tr>
<tr>
<td>8. <strong>Applicable to minors</strong></td>
<td>Yes</td>
<td>Yes, 68-11-224</td>
<td>Yes, §75-2a-106(3)</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>9. <strong>Other execution requirements?</strong></td>
<td>No Form has box to identify h.c. professional assisting in preparation.</td>
<td>No</td>
<td>(1) If patient is a minor and POLST calls for forgoing LST, 2 physicians must certify that it is “in the best interest of the minor.” §75-2a-106(4) (2) Form has box to identify h.c. professional assisting in preparation.</td>
<td>Separate signatures required for CPR instruction and for other life-sustaining treatments. If in a health care facility, clinician must certify that the facility’s DNR policy has been followed. §9708(a)(4)</td>
<td>Form has box to identify h.c. professional assisting in preparation.</td>
<td>No</td>
</tr>
<tr>
<td>10. <strong>Exclusive DNR form?</strong></td>
<td>No DNR law</td>
<td>No</td>
<td>No R432-31-11</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>11. <strong>Immunity provided?</strong></td>
<td>Yes, Or. Rev. Stat. 127.555 (advance directive law) as interpreted by OAR 847-010-0110</td>
<td>Yes, 68-11-224</td>
<td>Yes, for complying and for providing LST in contravention of the LWDO §75-2a-106(6)</td>
<td>Yes, §9713</td>
<td>Yes, RCW §18.71.210</td>
<td>Yes,</td>
</tr>
<tr>
<td>12. <strong>Duty to offer POLST?</strong></td>
<td>No</td>
<td>Yes</td>
<td>Yes, must establish policies to determine who is appropriate for POSLT and offer. R432-31-4</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>13. <strong>Duty to comply?</strong></td>
<td>Yes, OAR 847-010-0110 Form must accompany patient on transfer or discharge.</td>
<td>No But facilities have duty to transfer copy of LDO with patient.</td>
<td>Yes</td>
<td>Yes, by EMS as the standard of care</td>
<td>Yes, §16-30-12 and 16-3010 and §16-30C-7</td>
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</table>
### POLST Statutory/Regulatory Comparison (1/30/11) (continued)

<table>
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</thead>
<tbody>
<tr>
<td>15. Conflicts with AD addressed?</td>
<td>No</td>
<td>Advance directive controls</td>
<td>LWDO controls §75-2a-106(7)</td>
<td>Not addressed</td>
<td>Forthcoming revision (Nov. 2010): most recent controls.</td>
<td>The person’s expressed directives control. 16-20-5(b)</td>
</tr>
<tr>
<td>16. Presumption if section of form left blank</td>
<td>Full treatment</td>
<td>Full treatment</td>
<td>Full treatment</td>
<td>No presumption</td>
<td>Full treatment</td>
<td>Full treatment.</td>
</tr>
<tr>
<td>17. Out-of-state POLST recognized?</td>
<td>Yes, OAR 847-010-0110</td>
<td>Not addressed</td>
<td>Yes, R432-31-11</td>
<td>Not addressed</td>
<td>Not addressed</td>
<td>Yes, DNR §16-30C-15 No, POST</td>
</tr>
</tbody>
</table>

**Additional Notes**
- Physician’s verbal orders are acceptable with follow-up signature by physician in accordance with facility/community policy
- LWDO bracelet or necklace is authorized to indicate possession of a LWDO
- DOH developing web page for electronic registry.
APPENDIX B. POLST STATE THEMES/FEATURES

Note: The row numbers are for convenience and do not indicate the rank order of response.

<table>
<thead>
<tr>
<th>#</th>
<th>CA</th>
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</thead>
<tbody>
<tr>
<td><strong>STRENGTHS</strong></td>
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<tr>
<td>1. Existing well-established statewide end-of-life (EOL)/palliative care organization led coalition</td>
<td>•</td>
<td>Coal. for Compassionate Care of CA</td>
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<td>●</td>
<td>Kokua Mau</td>
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<td>ID EOL Coal.</td>
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<td>Comm.-Wide EOL/Palliative Care Initiative</td>
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<td>2. Core group of physician champions or physician led organization</td>
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<td>MN Med. Assn.</td>
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<td>NC Med. Soc.</td>
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<td>3. Deliberately incremental – local pilots, then state legislation</td>
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<td>4. Significant financial support</td>
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<td>5. Well-situated individual(s) or entity(ies) with clout</td>
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<td>6. Supportive regulatory agency tied into the effort (such as EMS, DOH, licensing boards)</td>
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<td>7. Relatively small state</td>
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<td>8. Initiative had broader agenda than just POLST</td>
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<td>9. Emergence of an effective statewide coalition</td>
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<td>10. Local coalitions tied to statewide coalition</td>
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<td>11.</td>
<td>Legislative/regulatory opportunity provided an opening</td>
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<td>12.</td>
<td>Key motivators pushed POLST:</td>
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<tr>
<td></td>
<td>- Advance Directive shortcomings</td>
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<td>- Terrible state of palliative care</td>
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<td>- Pts receiving care inconsistent with their wishes</td>
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<td></td>
<td>- Health systems using different versions of POLST</td>
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<td></td>
<td>- Restrictive surrogacy interpretation</td>
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<td>13.</td>
<td>State Unit on Aging a strong advocate</td>
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<td>14.</td>
<td>Had support of Catholic right-to-life group</td>
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<td>15.</td>
<td>Strong ongoing research-oriented component</td>
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<td>16.</td>
<td>Relatively few health care providers</td>
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<td>17.</td>
<td>Charismatic physician champion</td>
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**POLST State Themes/Features (continued)**

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<th>STRENGTHS (continued)</th>
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- Most commonly identified
- Commonly identified
- Other noted themes/features
## POLST State Themes/Features (continued)

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<td><strong>BARRIERS/SALIENT ISSUES</strong></td>
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<tr>
<td>1. Patient consent by signature—Mandatory or Optional</td>
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<td>3. Confusion b/t ADs and POLST</td>
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<td>12. Perception that POLST is cumbersome/time consuming</td>
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<td>14. Mandatory vs non-mandatory (intra-facility v. inter-facility; using v. offering v. complying)</td>
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- Most commonly identified
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<td>29. Exceptions to patient signature (e.g., futility)</td>
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<td>31. Using POLST for minors</td>
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**POLST State Themes/Features (continued)**

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<td>8. New MDS subpart S on POLST</td>
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<td>10. Electronic registry provides new database for evaluative research</td>
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<td>11. Whether to include POLST in Advance Directive registry</td>
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**Legend:**
- **Most commonly identified**
- **Commonly identified**
- **Other noted themes/features**
## QUALITY OF THE CONVERSATION

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<td>3. Video vignette modeling of good communication</td>
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<td>4. EPEC curriculum often used</td>
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<td>5. Honoring (Respecting) Choices training available</td>
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<td>6. Statute recognizes other professionals as facilitators</td>
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<td>7. Developing tool for patient/family feedback on the process</td>
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APPENDIX C. STATE PROFILES

CALIFORNIA

The challenges presented by California’s great size and diversity were overcome by the strong organizational leadership of a statewide coalition and an initial seven pilot counties in 2007 to develop a uniform POLST form and process. This expanded to 10 more counties in 2008. A strong state POLST initiative would not have been possible without funding support from the California Health Care Foundation and others. The initial phase of the initiative culminated in state legislation, effective January 1, 2009, establishing POLST as a valid medical order statewide. The number of funded as well as unfunded local coalitions has grown significantly over time, and they continue to be the key infrastructure for POLST development just as much after legislation as before. “Physician champions” are seen as one of the key ingredients of the coalition effort because they carry the credibility and visibility to expand acceptance of POLST as an important clinical protocol. The statewide coalition keeps the physician champions networked by monthly calls.

The coalition decided that state legislation was important for several reasons. California is so large and diverse that legislation was seen as the only way to ensure uniformity in the form and process. The legislation did not mandate POLST, but said that if a POLST exists, it must be followed. The mandate helped overcome hospital concerns in part and made all providers take notice and respond to POLST implementation more quickly. Finally, because health care providers perceive California as a very litigious state, providers wanted the guarantee of statutory immunity for complying with POLST.

HAWAII

Hawaii’s chief driver in establishing POLST was a statewide organization, Kōkua Mau, with more than 10 years of experience in promoting improved end-of-life care. Kōkua Mau was founded as a statewide end-of-life care coalition in 1999 under the Robert Wood Johnson Foundation’s (RWJF) Community-State Partnerships to Improve End-of-Life Care Program and as a direct result of the Governor’s Blue Ribbon Panel on Living and Dying with Dignity (1998). In 2007 it became a statewide hospice and palliative care organization.

The organization’s president attracted a core group of clinicians and a Department of Health representative who orchestrated a much larger coalition of stakeholders to bring to fruition a legislative proposal that recognized POLST but did not make it mandatory. The only opposition in the legislature came from an insular voice representing a conservative Christian perspective and claiming that the POLST permissive surrogate consent options would open the door to third parties euthanizing vulnerable individuals. Efforts to correct that misperception were successful in getting the bill through the legislature, but not entirely successful in allaying the governor’s concerns, which led to the bill becoming law without the governor’s signature.

35 These profiles describe the general approach to establishing and implementing POLST in each of the 12 states in the study. More detailed profiles will be posted on the AARP Public Policy Institute’s website.
The working group was also responsible for developing the standard POLST form, available at no cost on the Internet, and bearing the approval of the Health Department. But since use of the form is not mandatory, implementation has depended on the coalition’s continuing efforts to educate and train health care providers and the public. No formal monitoring or evaluation is in place, and the speed of penetration into the normal operations of facilities and providers appears slow. The preexisting out-of-hospital do not resuscitate (DNR) order is still effective and used in the state.

IDAHO

In 2003, A Better Way Coalition was formed statewide to address advance directives and advance care planning in response to poor “grades” on the RWJF-funded Last Acts Means to a Better End report. The coalition was the main initiator of POST. In 2006 it was able to get House Continuing Resolution 40 passed, directing the state Department of Health and Welfare, the Attorney General, the Secretary of State, and other parties to come together to draft new advance directive legislation including POST. A broad spectrum of groups, including those representing hospitals, long-term care facilities, the state medical association, hospice, elder law attorneys, and government entities met for most of a year to develop legislation. The legislation passed and became effective in July 2007. The Emergency Medical Services (EMS) Bureau of the Department of Health and Welfare provided guidelines including the POST form. The Secretary of State’s office maintains and operates the advance directive registry, which includes POST. A Better Way Coalition, now renamed the Idaho End-of-Life Coalition, continues to facilitate discussion of POST, to provide education through an annual conference, and to entertain possible programmatic changes. POST is unfunded other than through basic staffing at the EMS Bureau and the Secretary of State’s office.

MINNESOTA

Minnesota has relatively few health systems, of which Allina is the largest, and only four insurance companies, according to one respondent. Different health systems began using their own versions of POLST. For example, Allina started it as a pilot project in a rural region and gradually expanded. There were reportedly four versions in use in the state at one time. This decentralized interest spurred the Minnesota Medical Association to form an interdisciplinary work group in 2009, which came up with a single POLST form by consensus after four meetings. The EMS Regulatory Board, which had a representative on the task force, endorsed the form by motion and vote at its September 2009 meeting. No legislation nor health department regulation was sought because of the political volatility of end-of-life issues in the state and because of the medical community’s perspective that POLST is a medical order and a matter best dealt with by clinical consensus. Looking ahead, the task force intends to continue to play a role in developing and monitoring POLST, but that process has not been worked out in any detail.

NEW YORK

New York MOLST grew out of a regional collaborative initiative in the Rochester area with a mission to develop a set of broad end-of-life/palliative care projects that would result in quality improvements in the lives of those facing death. Called the Community-Wide End of Life/Palliative Care Initiative, it was launched in May 2001 and among other efforts, promoted Education for Physicians on End-of-Life Care. Interest in POLST grew out of that effort. The initiative’s approach was deliberately incremental and started
with using MOLST in hospitals and nursing homes in a limited geographic area. Use of MOLST outside of institutions was not yet possible because of the state’s DNR law. Collaboration with groups across the state expanded, as did engagement with the Department of Health (DOH). In late 2005, the DOH approved use of MOLST statewide but only inside health care facilities. Then, a brief legislative amendment to the DNR law was enacted in 2005 to permit a pilot program in two counties to use MOLST as a nonhospital DNR order. A year later, an amendment permitted do not intubate (DNI) orders to be included—necessary because DNI orders were not addressed in the state’s DNR law. The evidenced-based success of the pilot helped bring about legislation in 2008 to make MOLST permanent and statewide as of July 8, 2008.

The effectiveness of the coalition was substantially enhanced by a charismatic leader based in a major health plan with sufficient resources and commitment to lead and manage an effective broad-based coalition. Education, support, and advocacy have been the lifeblood of the coalition, which has been effective in mobilizing health care providers, legislators and regulators, and the community at large. Regional coalitions functioned in collaboration with the statewide initiative. MOLST was framed within the broader mission of improving all aspects of end-of-life care, not just MOLST. Training initiatives have been substantial, and the community web site, CompassionAndSupport.org (another project of the initiative) has abundant resources—from the MOLST form instructional material to a variety of targeted videos, PowerPoint presentations, professional guides and checklists, educational resources, and reference materials. Educational efforts have focused on training of advance care planning facilitators, system implementation, and community education.

The MOLST Statewide Implementation Team addresses ongoing and new implementation issues that have resulted from enactment of Family Health Care Decisions Act, effective June 1, 2010, the same day MOLST became an official state DOH form. This team provides information to statewide professional associations, regional coalitions, and the National Healthcare Decisions Day New York State Coalition. Dissemination of the MOLST is strengthened by development and implementation of the Community Conversations on Compassionate Care program (another project of the initiative), which helps individuals over 18 years of age complete a health care proxy by following Five Easy Steps.

NORTH CAROLINA

The program began in 2004 with a pilot project by a health system in Buncombe County utilizing the West Virginia POST form. The physicians who encountered the form liked it so much that they asked the North Carolina Medical Society (NCMS) to develop a form for the state. The NCMS agreed to do so and ultimately developed one with a multidisciplinary coalition of groups. Legislation was sought and approved in 2007, part of a larger set of amendments to the state’s advance directive laws. While it was successfully enacted in one legislative session, there was a great deal of opposition from conservative “right to life” groups. However, the Catholic Church stayed neutral in the end. It took intensive work to counter misperceptions, and negotiations resulted in changes to the form. Physician legislators were an asset. The form was modified several times during the legislative negotiations.

Once enacted, there was a great deal of resistance from many quarters, such as the hospital association, because they simply had not paid much attention to it. Education has
been the biggest challenge, especially education of physicians. Area Health Education Centers, the Medical Society, and the Community Partnership for End of Life Care have put much effort into education, but there is a long way to go. Use of MOST is quite variable and still generally low but improving. Monitoring and evaluation are largely seen as a local issue. The state Department of Health and Human Services approved the form and distributes it, but is not active otherwise.

OREGON

Oregon was the first state to develop a POLST program. In 1990, the Center for Ethics in Health Care at the Oregon Health Sciences University convened a task force after clinical ethics leaders as well as emergency medical services personnel recognized that preferences for life-sustaining treatment of patients with advanced chronic progressive illness were frequently not found, not transferable, or not honored. The task force included representatives from stakeholder health care organizations. Pursuing its goal of developing a new method to translate patient preferences into actionable medical orders that follow patients across settings of care, the task force created the Medical Treatment Coversheet (renamed POLST in 1993). The task force decided to develop and implement the form through a grassroots approach to improving the standard of medical care and through administrative rule changes as needed. There were no barriers to implementing POLST in existing state legislation, and stakeholders viewed the grassroots rollout of the protocol as the most expedient approach for Oregon.

Over the next 20 years, the program moved from development and piloting of the protocol to release, refinement, expansion to selected populations, and greater effectiveness through an electronic registry (with legislative authorization and support). Oregon has been a leader and a source of technical expertise for the rest of the country as POLST implementation has expanded.

TENNESSEE

The Tennessee End-of-Life Partnership (TELP) was created in the late 1990s with the goal of improving end-of-life care in Tennessee. These “founding fathers” were largely nurses frustrated with care in the state and wanting to reach out to providers to improve care. When the RWJF-funded Means to a Better End report gave Tennessee a bad grade, that provided more impetus to deal with advance directives, advance care planning, and issues of overtreatment and futile care. TELP brought in speakers from other states with POLST (Pat Dunn from Oregon, Woody moss from West Virginia, Bud Hammes from La Crosse, Wisconsin), and that influenced the partnership to initiate POLST and ultimately to take a legislative approach.

In 2004, after meetings of a task force including TELP, clinicians, and lawyers, the state passed its Health Care Decisions Act (2004 Tennessee Laws Pub. Ch. 862, a revision of prior health care decisionmaking law) and included a provision on “universal do not resuscitate orders” (Tennessee Code Annotated 68-11-224). As defined in the statute, a universal DNR order is signed by the patient’s physician and states that cardiopulmonary resuscitation (CPR) should not be attempted if the patient suffers cardiac or respiratory arrest. The statute gave the Board for Licensing Health Facilities authority to promulgate rules and create forms regarding procedures for withholding resuscitative services. Those rules and the POST form were promulgated in 2005 when an active TELP member was the Assistant Commissioner of the Department of Health. An Attorney General opinion
(Opinion No. 05-093, June 13, 2005) agreed that the board had authority to go beyond CPR to address other life-sustaining treatments in Sections B, C, and D of its proposed form.

TELP has continued to work to spread the use of POST in Tennessee, to provide educational sessions, and to engage in advocacy on POST-related issues, in part through its regional groups. However, funding is scarce and there is no true home or program, “just a great form,” according to one proponent. Also, with turnover at the state Department of Health and Board for Licensing Health Facilities, the challenges have become greater than at the time of original implementation.

UTAH

Utah’s experience with POLST goes back to roughly the year 2000 and a committee convened by the Department of Health to develop regulations regarding advance directives, including a POLST-like document. This was triggered in part because of the interest of a nurse who was chair of the DOH’s Health Facilities Committee at the time. The committee has responsibility for drafting facility regulations. Regulations adopted in 2002 by the Department of Health recognized POLST for the first time, but in the absence of a legislative mandate, use of POLST was confined largely to individual institutions. And because the rule was promulgated pursuant to the advance directive statute, there was confusion about the difference between POLST and advance directives.

The Commission on Aging was an important driver for amendments to the state advance directive law in 2007. General familiarity with the concept of POLST because of its place in state regulations for the previous five years may have made the legislation more palatable. The legislative initiative was driven primarily by the Commission on Aging, but with effective collaboration from the DOH and a contact within the Bureau of EMS. Also vital to the legislative effort was connecting to a key community leader not in the legislature but with the influence to stop any legislation not looked upon favorably. While the key leader did not endorse the legislation, no barriers were put in the way. These efforts resulted in explicit statutory recognition of POLST, referred to as a Life with Dignity Order in the law, effective January 2008. Among other things, the new law extended the use of POLST to minors. The Department of Health released implementing regulations in 2010, effective October 1. Current efforts are aimed at educating all stakeholders, although a coordinated and funded state strategy is lacking. Plans to develop an online registry for advance directives and POLST forms are also under way with funding—a Beacon grant of $200K to the Commission on Aging.

VERMONT

The impetus for POLST (called Clinician Orders for Life-Sustaining Treatment, or COLST) came from Attorney General William Sorrell in 2003–04, who created an Attorney General’s Initiative on End of Life Care, which identified as its priorities pain and symptom management and health care decisionmaking. The report of the initiative, dated January 31, 2005, included several recommendations, among them a recommendation “that the Department of Health promulgate standardized forms for clinicians orders for life sustaining treatment and DNR identification and revocation.” As a result, legislative amendments to the advance directive law in 2005 included a rulemaking requirement for “clinician orders for life-sustaining treatment” (18 V.S.A. § 9719). It also required that if a COLST existed, it must be transmitted with the patient in
any transfer to another setting (18 V.S.A. 9709(b)(5)). But COLST was not defined in the law. An amendment in 2009 provided a definition of COLST at 18 V.S.A.§9701(6). The Department of Health worked with the Vermont Medical Society and others to design a form, and in 2006 promulgated regulations setting forth a COLST form and instructions.

The promulgation of the form was not backed by an aggressive regulatory campaign to implement it. Education and implementation has been variable but generally weak, although there are indications that interest is growing. The Vermont Ethics Network has been the key statewide driver of education, but its size and resources are very limited.

WASHINGTON

Since 1992, the state’s Department of Health authorizing statute has included language requiring the department to adopt “guidelines and protocols for how emergency medical personnel shall respond when summoned to the site of an injury or illness for the treatment of a person who has signed a written directive or durable power of attorney requesting that he or she not receive futile emergency medical treatment.” The broad authorization gave the Department of Health great flexibility. The state adopted a prehospital DNR form in 1993. But the State Department of Social & Health Services (DSHS), which regulates nursing homes and residential care, had made a very narrow interpretation of state’s informed consent statute (Wash. Rev. Code Ann. §7.70.065) that held that once a person became incapacitated, a surrogate could not consent to a DNR order except in very specific circumstances. When this issue came to light at a forum of the Regional Ethics Network of Eastern Washington in 2000, DSHS agreed to a work group look at the issue. Also in 2000, the above statutory language was amended to include a mandate for the Department of Health to provide guidelines which “shall include the development of a simple form that shall be used statewide.” Borrowing from Oregon’s experience, the work group and DSHS agreed that POLST would provide a good way to reinterpret the statute, especially because it could be made to require both the physician’s signature and the patient’s or surrogate’s signature.

A pilot project using POLST was begun in nursing homes in two counties (Whitman and Spokane) in 2002 with funding from the Medical Society. DSHS participated in the training for it. After about six months, DSHS was satisfied that POLST was effective in honoring patients’ wishes and ensuring informed consent. It gave unofficial approval of POLST and wrote letter to providers approving a POLST-like form. Policies for nursing homes, hospitals, and physicians were developed and approved by DSHS, and letters to administrators from DSHS gave approval to the form. Eventually, the Department of Health, which had jurisdiction over the DNR form, made an administrative decision to replace it with POLST.

Washington State Medical Society agreed to be the home of POLST through the End of Life Consensus Coalition, which it sponsors. It developed a POLST Task Force with broad representation, including DSHS. Thus, the whole effort moved ahead with a relatively small group of activists, benefiting from the fact that DOH had enough flexibility to develop POLST under the existing statutory language, and DSHS found POLST a reasonable way to deal with surrogate decisionmaking issues.
WEST VIRGINIA

Initially, interest developed in the Center for End of Life Care (CEOLC), which was an RWJF-funded Community-State Partnership Program until funding ended in 2001. Its Advance Care Planning Committee looked at POLST and thought it was a good idea. A trial program was done in the Morgantown and Parkersburg area on a voluntary basis with hospitals, nursing homes, and EMS. After it showed promising results, it went statewide.

Physician Orders for Scope of Treatment (POST) was incorporated into the state’s health decisions law in 2002. Dr. Moss personally recruited the support of the Statewide Director of EMS, the Hospice Council, the nursing home and hospital associations, and other stakeholder leaders. Health leaders had advised that legislation was necessary to make it work because of the nature of the state’s legal climate. CEOLC did much work on the form before it went to the legislature. CEOLC also worked with minority, right to life, and disabilities communities to resolve potential issues before they became barriers.

CEOLC is recognized as the place to go for issues about POST, advance care planning, and DNR cards, so it is in constant touch with stakeholders around the state. West Virginia is a relatively small state, and CEOLC is able to bring together the perspectives of all stakeholders.

Funding is a key part of the state’s success in implementing POST. The state legislature gave CEOLC $250K a year, and the POST program management is paid for from those funds. This happened the same year the legislation was passed. CEOLC has also gotten some private funds over the years to promote the POST program—it currently has grant from the Benedum Foundation for statewide education for rollout of an electronic registry.
APPENDIX D. SAMPLE POLST FORM

2011 California POLST Form

Effective April 1, 2011

In order to maintain continuity throughout California, please follow these instructions:

*** Copy or print POLST form on 65# Cover Ultra Pink card stock. ***

Mohawk BriteHue Ultra Pink card stock is available online and at some retailers. See below for suggested online vendors.

Ultra Pink paper is used to distinguish the form from other forms in the patient’s record; however, the form will be honored on any color paper. Faxed copies and photocopies are also valid POLST forms.

Suggested online vendors for Ultra Pink card stock:

Med-Pass - www.med-pass.com
(also carries pre-printed POLST forms on Ultra Pink card stock)

Boyd’s Imaging Products - www.iboyds.com

Mohawk Paper Store - www.mohawkpaperstore.com
Appendix 2. POLST State Themes/Features

Directions for Health Care Provider

Completing POLST
- Completing a POLST form is voluntary. California law requires that a POLST form be followed by health care providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician who will issue appropriate orders.
- POLST does not replace the Advance Directive. When available, review the Advance Directive and POLST form to ensure consistency, and update forms appropriately to resolve any conflicts.
- POLST must be completed by a health care provider based on patient preferences and medical indications.
- A legally recognized decisionmaker may include a court-appointed conservator or guardian, agent designated in an Advance Directive, orally designated surrogate, spouse, registered domestic partner, parent of a minor, closest available relative, or person whom the patient’s physician believes best knows what is in the patient’s best interest and will make decisions in accordance with the patient’s expressed wishes and values to the extent known.
- POLST must be signed by a physician and the patient or decisionmaker to be valid. Verbal orders are acceptable with follow-up signature by physician in accordance with facility/community policy.
- Certain medical conditions or treatments may prohibit a person from residing in a residential care facility for the elderly.
- If a translated form is used with patient or decisionmaker, attach it to the signed English POLST form.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid. A copy should be retained in patient’s medical record, on Ultra Pink paper when possible.

Using POLST
- Any incomplete section of POLST implies full treatment for that section.
- Section A:
  - If found pulseless and not breathing, no defibrillator (including automated external defibrillators) or chest compressions should be used on a person who has chosen “Do Not Attempt Resuscitation.”
- Section B:
  - When comfort cannot be achieved in the current setting, the person, including someone with “Comfort Measures Only,” should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
  - Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations.
  - IV antibiotics and hydration generally are not “Comfort Measures.”
  - Treatment of dehydration prolongs life. If person desires IV fluids, indicate “Limited Interventions” or “Full Treatment.”
  - Depending on local EMS protocol, “Additional Orders” written in Section B may not be implemented by EMS personnel.

Reviewing POLST
- It is recommended that POLST be reviewed periodically. Review is recommended when:
  - The person is transferred from one care setting or care level to another, or
  - There is a substantial change in the person’s health status, or
  - The person’s treatment preferences change.

Modifying and Voiding POLST
- A patient with capacity can, at any time, request alternative treatment.
- A patient with capacity can, at any time, revoke a POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing “VOID” in large letters, and signing and dating this line.
- A legally recognized decisionmaker may request to modify the orders, in collaboration with the physician, based on the known desires of the individual or, if unknown, the individual’s best interests.

This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force.

For more information or a copy of the form, visit www.caPOLST.org.
## APPENDIX E. ROUNDTABLE PARTICIPANTS

### AARP Roundtable Attendees, December 6, 2010

<table>
<thead>
<tr>
<th>TITLE</th>
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| Patricia Bomba | Vice President and Medical Director Geriatrics  
Excellus BlueCross BlueShield |
| Kathy Brandt | Senior Vice President  
Office of Education and Engagement  
National Hospice and Palliative Care Organization |
| Margaret Carley | Chair, Oregon POLST Task Force  
Executive Director, National POLST Paradigm |
| John Carney | Vice President, Center for Practical Bioethics |
| Judy Citko | Executive Director, Coalition for Compassionate Care |
| Jonathan Evans | Treasurer, American Medical Directors Association |
| Maureen Fitzgerald | Director, Disability Rights  
Disability Policy Collaboration  
A Partnership of The Arc and United Cerebral Palsy |
| Ellen Fox | Chief Ethics in Health Care Officer  
U.S. Veterans Health Administration |
| Patricia Grady | Director, National Institute for Nursing Research  
National Institutes of Health |
| Mary Jane Koren | Vice President, Picker/Commonwealth Fund  
Long-Term Care Quality Improvement Program  
The Commonwealth Fund |
| Nancy Kupka | Project Director, Department of Health Services Research  
Division of Healthcare Quality Evaluation  
The Joint Commission |
| Becky Kurtz | Director  
Office of Long-Term Care Ombudsman Programs  
U.S. Department of Health and Human Services Administration on Aging |
| Alvin Moss | Professor of Medicine, Section of Nephrology  
Director, Center for Health Ethics and Law  
West Virginia University |

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36 The organizational affiliations represent the individual’s affiliation on December 6, 2010, when the Roundtable took place.
## AARP Roundtable Attendees, December 6, 2010 (continued)

<table>
<thead>
<tr>
<th>Title</th>
<th>Organizational Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evvie Munley</td>
<td>Senior Health Policy Analyst</td>
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<tr>
<td></td>
<td>Amer. Assoc. of Homes &amp; Services for the Aging</td>
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<tr>
<td>Kate O’Malley</td>
<td>Senior Program Officer</td>
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<td></td>
<td>California Healthcare Foundation</td>
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<tr>
<td>Beverly Paukstis</td>
<td>Executive Director of Hospice</td>
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<td></td>
<td>The Washington Home and Community Hospices of DC, VA, MD</td>
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<tr>
<td>Judith R. Peres</td>
<td>Clinical Social Worker</td>
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<td></td>
<td>Supporting Successful Transitions</td>
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<tr>
<td>Stephanie Pincus</td>
<td>Scholar-in-Residence</td>
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<td></td>
<td>Institute of Medicine</td>
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<tr>
<td>Terri Schmidt</td>
<td>Associate Director</td>
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<td></td>
<td>Center for Ethics in Healthcare</td>
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<td></td>
<td>Oregon Health Sciences University</td>
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<tr>
<td>Joe Sroka</td>
<td>Financial and Human Resources Director</td>
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<td></td>
<td>Florida Hospices and Palliative Care</td>
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<tr>
<td>Joan Teno</td>
<td>Professor of Community Health</td>
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<td></td>
<td>Public Health-Health Services Policy and Practice</td>
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<td></td>
<td>Brown University</td>
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<tr>
<td>Susan Tolle</td>
<td>Director</td>
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<td>Center for Ethics in Health Care</td>
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<tr>
<td>James Tulsky</td>
<td>Professor of Medicine and Nursing</td>
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<td>Director, Center for Palliative Care</td>
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<tr>
<td></td>
<td>Duke University Medical Center</td>
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<tr>
<td>Nancy R. Zweibel</td>
<td>Senior Program Officer</td>
</tr>
<tr>
<td></td>
<td>The Retirement Research Foundation</td>
</tr>
</tbody>
</table>

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