Pathways to POLST Registry Development: Lessons Learned

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On behalf of the National POLST Paradigm Task Force
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Letter from the Authors
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Dear reader,

We are pleased to provide this summary of current efforts to develop electronic registries and other technology solutions to increase access to POLST Paradigm documents in a crisis. Utilization of health information technology to enhance availability of medical records and other information has increased dramatically in recent years. This is also true for advance care planning documents, especially POLST forms. Many states have developed or are considering the development of POLST registries or other electronic solutions for document completion, storage, and access for health care professionals. This report serves as an attempt to summarize the varied pathways of POLST registry development in seven states with endorsed POLST Paradigm programs. Through interviews with registry stakeholders, developers, staff, and directors, this document presents valuable lessons learned and guidance for other groups considering registry implementation. Key factors such as collaboration, timing, content, structure, and technical function are considered.

This project was made possible by funding from The Retirement Research Foundation and the Archstone Foundation. In addition to our funders, we would like to thank all of the dedicated people who participated in these interviews and assisted in the preparation of their state summaries. We would also like to thank all of the members of the National POLST Executive Committee who reviewed and edited this summary: Margaret Murphy Carley, Pat Bomba, Judy Citko, Woody Moss and Bud Hammes. Above all, we extend special appreciation to Susan Tolle, whose unending energy and passion includes obtaining funding for the Oregon POLST Registry pilot project, soliciting funding for this project, legislative advocacy for the creation of the Oregon Registry, editing and oversight of this report and continuous education and leadership.

Sincerely,

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The Physician Orders for Life-Sustaining Treatment (POLST) Paradigm program offers patients with advanced progressive illness or frailty an important means of helping to ensure that their wishes for medical treatment will be known and honored in times of crisis. Because it is imperative that these treatment preferences are reliably accessible to health care professionals when needed, several states have developed an electronic registry—a secure repository for POLST forms that can be accessed by health professionals at any time.

This report examines the structure and content of POLST Paradigm registry systems in seven different states, surveying the variations in contextual issues, resources and approach that make each registry unique. Several key findings emerge:

- Defining the registry’s purpose prior to its development is essential. Among the critical questions to address are:
  - What is its proposed function?
  - Who will have access?
  - Where will it be housed?
  - What will it contain?
  - What is the mechanism to ensure timely submission and availability of registry content?

- A mature, widespread POLST program supports more rapid population of a POLST registry.

- Strong leadership from an effective statewide POLST Paradigm coalition (which may be part of a broader effort to improve end-of-life care) is essential to successful POLST program outreach and widespread use of a POLST registry.

- Integrating a registry into existing health care systems (e.g. within a statewide EMS system or Health Information Exchange) increases its use and economizes resources.

- Integrated health systems can serve some functions of a registry within (though not outside) the health system if the EMR is designed to rapidly and discretely locate POLST forms.

- How forms are submitted, and by whom, impacts the volume of submission.

- Launching a registry prematurely can divert resources (both financial and volunteer) from education and other programs necessary to firmly establishing a successful POLST program.

- Sustainable funding for registry operations is vital to long-term success.

These conclusions, which are explored in-depth in the following pages, provide a powerful road map, illuminating the factors that are most critical to establishing effective electronic registries capable of delivering POLST orders when a patient’s physical POLST form cannot be located in a time of crisis.
Patients with advanced progressive diseases are faced with the need to consider the benefits and burdens of important medical interventions. The 1990 federal Patient Self-Determination Act supports individuals' right to accept or refuse medical treatment and to complete advance directives (ADs)—legal documents that allow patients to specify treatment preferences for the future, and to appoint medical decision makers to speak on their behalf should they be unable to do so. Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Programs have been developed in a number of states to turn those treatment preferences into actionable medical orders that can be used across treatment settings.

One barrier to implementing both ADs and POLST orders is the challenge of accessing them in a timely manner in emergency medical situations when they are most needed. POLST orders in particular can be critical to making important determinations such as whether or not to: transfer a patient to a hospital; initiate intubation and mechanical ventilation; or attempt resuscitation after cardiac arrest. There may be only minutes in which to make these vital decisions.

One potential solution to the difficulty of finding paper ADs and POLST forms is the development of electronic registries of these documents and the wishes or medical orders they contain. In an era of ever-increasing technology and federal support specifically designed to expedite meaningful use of electronic health records, many states have, or are developing, electronic registries and/or other systems facilitating the completion of, and access to, ADs and POLST forms.

Because POLST forms are particularly time critical, contain important and actionable medical orders, and often influence treatment decisions, this report surveys registry activities in seven states with an endorsed POLST Paradigm program. Its purpose is to identify and share the factors that are most critical to creating an effective POLST registry.

In the early 1990s the POLST Program was developed to improve patient care and reduce medical errors by creating a system that turns patients' treatment preferences into portable medical orders. Designed to be used across settings—such as long-term care facilities, emergency medical services (EMS) and emergency departments—the system focuses on a growing segment of the United States population: patients with advanced, chronic progressive illness or frailty.

The National POLST Paradigm Task Force (NPPTF) was convened in September 2004 to establish quality standards for POLST forms and programs and to assist the growing number of states wanting to develop such programs. (Criteria created by the Task Force for developing, endorsed and mature programs can be found at www.polst.org). The NPPTF includes one representative chosen by each state with an endorsed POLST program. An Executive Committee includes individuals elected annually by the Board of Directors, as well as two non-voting members providing legal and EMS consultation respectively. (For more information on POLST Task Force and POLST Paradigm Program Requirements, see http://www.ohsu.edu/polst/developing/core-requirements.htm.)

As of August 2012, 15 states had endorsed POLST Paradigm programs (sometimes under other names such as POST, MOLST, LaPOST and MOST), and 28 additional states were developing POLST programs. (Figure 1)

The foundation of the POLST Program is thoughtful advance care planning conversations between health care professionals, patients and those close to them, to determine what treatments patients do, and do not
orders for their clients, and has had an electronic version of the form available to their on call health care professionals since the late 1990s, retrospectively evaluated deaths during a one-year period, reviewing for presence and effectiveness of POLST forms. They found matched POLST instructions in 84% of cases for IV fluids, 94% for feeding tubes and “do not attempt resuscitation” was consistent with CPR use for 49 out of 50 participants (91%).

• A 2004 study of 572 emergency medical technicians’ (EMTs) experiences with the POLST program found that, when present, POLST orders changed treatment in 45% of cases and 93% of responders agreed that the POLST form is useful in determining treatment when the patient is in cardiopulmonary arrest.

• A recent study of the use of POLST in three states surveyed 71 hospice programs that use POLST and did a chart review in 15 programs. Treatment limitations were respected in 98% of cases and no one received unwanted CPR.

• The largest study to date was a retrospective observational study of a stratified, random sample of 1700 residents in 90 nursing facilities in Oregon, Wisconsin, and West Virginia, comparing patients with and without POLST forms. Residents with POLST forms were more likely to have treatment preferences other than DNR orders documented as medical orders than those who did not. Residents with POLST forms indicating orders for comfort measures only were less likely to receive medical interventions (e.g., hospitalization) than residents with POLST full treatment orders, residents with traditional DNR orders, or residents with traditional full code orders.

However, despite evidence of the effectiveness of POLST orders, the use of ADs and POLST forms in emergency situations is not without barriers. ADs are legal documents that are meant to apply at some point in the future. While they effectively appoint surrogate decision makers in emergency situations, it is often hard to tell whether the patient intended to have them take effect at the time of the emergency call. Many healthy people have an AD but want all available EMS treatments until their prognosis for recovery is clarified.

In addition, EMTs and paramedics function under medical orders. A 1998 study from states where legislation allowed EMTs to act on ADs reported that only 28% of respondents had acted on an AD without medical control. EMTs attributed their lack of action on ADs to the fear of legal consequences, the moral issue of withholding care, uncertainty in patients’ wishes from the AD, and the lack of actionable medical orders. POLST orders, on the other hand, are medical orders, signed by a health care professional, that are meant to apply in the present. Most EMTs would honor a state-approved DNAR form, such as POLST, but not patients’ ADs or living wills. Emergency physicians, who are not constrained by working under standing orders and may have had more time to assess the patient’s current condition, are more likely to follow an AD if available and wishes can be verified.

Another key barrier to the effectiveness of both ADs and POLST is inaccessibility of the documents intended to guide care. Research focusing on acute hospitalizations indicates that an inaccessible AD leads to unwanted treatment, and one study found that only 26% of geriatric patients admitted with AD documentation had those wishes recognized during their admission. A 2004 survey of Oregon EMTs indicated that the POLST form can be difficult to locate in an emergency—with 25% of respondents indicating that the last time they expected to find a POLST form, they were unable to do so in a timely way. A 2001 study found that ADs were not present in most skilled nursing facilities when residents were transferred to EDs for evaluation. A 2008 study of nursing home patients over 65 years old transferred to the ED found that many patients arrived in the ED without their ADs and, when the AD was sent, it did not always agree with other information in the record, thereby limiting its use.

Simply having an AD or POLST form does not indicate how much treatment a patient wants to receive. In a 2012 study by Fromme and colleagues, nearly 25% of patients with a POLST form wanted CPR. Further, most patients who choose “Do Not Resuscitate” on their POLST form choose more than the least amount of treatment in another section of the form. In 2009 Susan Hickman and colleagues found that 20% of hospice patients did not want “comfort measures only” and specifically wanted to return to the hospital for basic medical treatment.

This research reminds health care professionals that POLST and ADs are useful in recording any and all treatment wishes, whether they request full medical treatment or limitations on care.

Given these challenges, the accessibility of POLST forms and care preference documentation is a critical factor in honoring patients’ wishes. To facilitate states’ development of programs that increase accessibility of POLST forms, The Retirement Research Foundation provided support to examine the development of electronic registry systems for POLST information in seven different states already implementing POLST programs, while the Archstone Foundation provided additional resources to publish and distribute this report.

Respondents from the seven states were self-selected from the Registry subcommittee of the National POLST Paradigm Task Force. Therefore, information collected is not necessarily reflective of all registry efforts underway in the nation. The resulting report, however, provides valuable information about lessons learned in the unique approach followed by each state. We examine common themes that appear to be core elements of program success.

While the specific focus of this report is POLST registries, incidental information about other registry systems, including AD registries, was provided by respondents and is included herein. However, this report does not serve as an in-depth review of AD registries, nor does it include information about states actively operating non-POLST registries.
Methods

The respondents interviewed for this report were drawn from a convenience sample of representatives of the National POLST Paradigm Task Force Subcommittee on Registries. The interview was developed by the authors and included open-ended questions regarding the state's history with POLST, a review of registry status or plans, registry function, collaboration and oversight, and ongoing registry-related activities including operation, outreach and promotion. This examination was done using the framework of a set of Key Components and Timing of POLST Registry Implementation developed by the Registry Subcommittee of the National POLST Paradigm Task, included in Appendix B. Respondents were asked to reflect on lessons learned, including barriers and facilitators to registry development and use.

Interviews were conducted with a variety of registry-related positions, including state POLST coalition chairs, registry data managers, registry developers, and State employees. Members of state respondent groups were interviewed at least once, and as many as four times, between February and August 2012.

Participating States
- California
- Idaho
- New York
- Oregon
- Utah
- Washington State
- West Virginia

Glossary of Terms

Registry:
A secure electronic storage system for POLST Paradigm forms or other advance care planning documents that allows submission of both original and updated information and access to the forms or information to a defined audience through a defined mechanism

POLST:
Physician Orders for Life-Sustaining Treatment. The term “POLST” is used in this report to describe any state POLST paradigm program. POLST programs may have other names such as MOLST, POST, LaPOST, and MOST.

Form:
Refers to POLST form, or other registry content

Patient or Registrant:
The person whose information is held in the registry

Sender:
The person who sends the form or documents into the registry. It may be the patient, the signer, or signer’s representative. It may also be the health care professional completing the form.

Registry User:
A person such as an EMT, physician, other health care professional, or individual who accesses the content in a registry, as well as those adding or updating registry content. Most registries define various levels of users according to need.

EMR/EHR:
Electronic Medical Record or Electronic Health Record

RHIO:
Regional Health Information Organization
Definitions of Electronic Repository Systems

States and regions are developing unique electronic solutions to increase access to POLST orders and other advance planning documents. A variety of registry systems were described throughout these interviews and a number of processes and products were discussed under the heading “registry.” These systems can be grouped into three primary electronic models: Electronic Form Completion Systems, Form Repositories, and Hybrid Form Completion and Repository Systems. These different models also vary in content of the registries, the methods of document submission and the means of access to the information. Each model supports different needs and potentially different users and audiences. A form repository system without some storage capacity would not, using standard definitions, be a registry unto itself, but systems like these were included in this report if they were being used in a responding state. Each model is more thoroughly described below.

Electronic Form Completion Systems
These are software or web-based modules allowing electronic documentation of POLST orders or other advance care planning documents, resulting in printable POLST forms or other forms or documentation. These systems allow hard-coded programming to reduce error and prevent combinations of orders that are not actionable. They can require that certain information be captured, reducing data errors or incomplete data. They can also be programmed to “walk” users through form completion, prompting with information or education. Guides for the conversation between health care professionals and patients, including potential scripts, can be built-in. These systems may be stand-alone, or integrated into an electronic health record or accessible through a health information portal or exchange. Users are largely registered through health systems or provided access through existing electronic systems to which they may already have access. While forms can be printed for patient or health professional signatures, electronic signatures are feasible. Efforts to effectively and efficiently capture patient signatures on electronic forms are under consideration by a number of health information technology groups.

Form Repositories
Repositories are databases, either stand-alone or web-based, designed to store forms, form content, or both, and to make that information available when needed. There are a wide variety of content options for repositories since this model primarily supports document storage, regardless of type. Repositories into which data is manually entered from forms have larger development needs than do simple form storage systems. Repository systems presented in this report include one or more of the following content types: POLST forms, ADs including living wills, durable medical powers of attorney, and other (usually state-specific) forms. Repositories can also be integrated into EMR or EHR systems and have a variety of submission routes and access mechanisms. Individuals can submit their own documents via mail, fax, or in person while health care professionals may submit directly through their hospitals, health systems, clinics, or other care environments. The National POLST Paradigm Task Force has adopted recommended standards for EHR systems to facilitate the rapid location and retrieval of POLST forms (see Appendix C). Access to repository-stored information is made available through call centers, web-based portals, RHIOs, and other electronic health record routes.

Hybrid Electronic Form Systems with Repository Functionality
A hybrid system combines the two systems described above, allowing electronic form completion with form storage functionality or, alternatively, with automated submission to a related repository. These systems can also be stand-alone or integrated into other portals for access. They allow a potentially “seamless” form completion and storage system for users, providing the hard-coded requirements and built-in quality control while also eliminating a lag time for registry inclusion of forms. These systems can also assure that any form that is completed in the electronic system is automatically sent to the repository.
Defining the Registry's Purpose is Vital to Success

Assessing the need for, and expected function of, a registry is essential to its development and long-term success. Respondents repeatedly stressed the importance of creating a well-established POLST program, before considering the development of a registry, in order to assess both the needs of the program and the clear goals for the registry. States that take the time to carefully monitor, and assure wide spread utilization of their POLST program are in a better position both to identify the specific needs the registry must meet (e.g. access to POLST forms in an emergency, or portability of POLST across care settings), and to identify the needs of the registry's senders and users. Clarity in these areas will have a major impact on the registry's development, degree of use, and long-term success.

Several key questions emerged as helpful guides in defining a registry's purpose:

• **What is its proposed function?**
  The most important question to consider when developing a POLST registry is the purpose for which it is intended. Is its primary goal to give patients and families a means to store important medical documents, or is it to give emergency health care professionals 24/7-access to essential information about patients' wishes for care in times of medical crisis? The answer to this question will impact every aspect of the registry's design—who will need access, what search function will be needed to provide that access, where the registry will be housed, and what content needs to be included.

• **Who will have access?**
  If the registry is intended to store medical documents for patients and families, there will be a limited number of senders and users needing access to the system. However, if the registry is intended primarily to provide EMS with POLST orders at a time of medical crisis, one of the most essential elements of the system will be easy and reliable access for health care professionals, in any setting, at all hours of the day and night. The system will fall short, for example, if the only access route requires a single patient identifier that may or may not be with an unresponsive patient; or if a registry is intended to work seamlessly within a health system EMR, but users need to access the system through an external pathway or web address. Further, it is likely to fail if the user needs to remember an infrequently used password or call a number and wait any length of time to get a response. System designers need to take into account whether or not EMS professionals have access to the Internet, cell phones and/or radios. Both the flow of registry information and the workflow of the intended users must be carefully considered to ensure that POLST information will be readily available to those who need it.

• **Where will it be housed?**
  Where a registry is physically (or virtually) housed has long-term ramifications on medico-legal issues such as data ownership, HIPAA compliance, privacy, security, confidentiality, liability, utilization and—eventually—success. For this reason, respondents encouraged other states to identify potential existing “homes” and access pathways (especially those that might already be familiar to a registry's users and senders) early in the process. Form completion systems housed within health systems may be proprietary, or may limit access to users within that system only. State-run systems have been housed in vital-statistics departments, health departments, EMS and trauma departments, and contractually through HIT vendors or self-built systems. Considerations for registry ownership will impact whether or not registries comply with HIPAA, and may help define when and to whom information can be released. Maintenance and storage policies and practices may also hinge on registry ownership, as well as long-term maintenance costs.

Critical questions to ask when considering registry placement include:

• Who will secure the registry?
• Will data be made available for other activities such as research or evaluation? If so, who will provide it and through what routes?
• Who will authorize access to a registry?
• How easy is it to access the registry as part of EMS/other health care professionals' daily workflow—is the registry integrated into a system they already use, or is it outside the clinical care system and thus requiring a special number? Does it require web access?
• Can the database be searched using multiple patient demographics or must a unique identifier be used to locate the patient (a significant problem when the patient is found down and the identifier is unavailable)?
• Who will be responsible for outreach and education related to the registry?
• Will the registry’s “ownership” be sustainable?

• **What will it contain?**
  The careful consideration of content is another vital element for registry development. While each state reported a need for accessibility of documents as a primary reason for registry development, the content of each system is unique. Guided largely by legal and charting requirements, each state developed a system to meet the individual needs of their users and owners. For the registries documented in this report, Table 1 outlines content variety.

<table>
<thead>
<tr>
<th>State</th>
<th>Registry Content (by State)</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>n/a</td>
</tr>
<tr>
<td>Idaho</td>
<td>POST forms, Combination Living Will/Durable Power of Attorney for Healthcare</td>
</tr>
<tr>
<td>New York</td>
<td>eMOLST forms, MOLST Chart Documentation Form (includes goals for care discussion and legal requirements)</td>
</tr>
<tr>
<td>Oregon</td>
<td>Oregon POLST forms</td>
</tr>
<tr>
<td>Utah</td>
<td>ePOLST forms</td>
</tr>
<tr>
<td>Washington</td>
<td>POLST forms, Advance Directives, Additional related forms</td>
</tr>
<tr>
<td>West Virginia</td>
<td>Advance directives, POST forms, Surrogate Selection Checklists, Combined Medical Power of Attorney and Living Wills, Miscellaneous related documents</td>
</tr>
</tbody>
</table>

*The Washington state registry ceased operations in 2011.*
The National POLST Paradigm Task Force Registry Subcommittee guidelines reflect Pathways to POLST Registry Development:

A mature, widespread POLST program will already have in place a strong network of collaborative partnerships with those of other important members of the POLST coalition. These partnerships should be as multi-disciplinary and as inclusive as possible. And respondents observed that caution should be exercised in approaching potential partners whose political agenda or belief system might be in conflict with those of other important members of the POLST coalition.

POLST forms can be updated at any time to reflect changes in patient wishes or health care status. A 2010 study reported that 6% of original POLST forms had been modified within 60 days in long-term care settings in three states. The National POLST Paradigm Task Force Registry Subcommittee guidelines reflect the need to allow a means for registrants to update registry-stored materials. It is, therefore, important to develop a system to identify forms that need to be updated, and confirm that older orders will not be shared with registry users—even if new orders have not yet been entered. States have described a number of methods for this “updating,” including patient-applied “red flags” for forms with orders no longer consistent with their wishes, and patient-level identifiers allowing all documents relating to a patient to be available through one route.

The POLST form itself is also subject to change. Through different review mechanisms, states usually modify the POLST form every few years. Registries implementing a model of data abstraction and manual entry of POLST data or orders will need to allow scalability of a registry system to accept data from multiple form versions, or will need to “map” newer forms to older form versions when possible (re-ordering of form, but no change in content). Working closely with regional and statewide POLST coalitions and other advance care planning stakeholders will be of great advantage in assisting a registry to identify potential form or other content changes as part of continuous quality improvement.

A Mature POLST Program Supports More Rapid Population of a POLST Registry

A mature, widespread POLST program will already have in place a strong network of collaborative partnerships that are uniformly described by respondents as a vital ingredient in registry planning and development. These partnerships support more cohesive goal setting and planning, better registry design, and more widespread education and implementation. The result is more rapid registry use and population.

The theme of collaboration emerged throughout this study, with great emphasis placed on the importance of engaging all stakeholders in early discussions about registry development. This means identifying all active regional and statewide parties in end-of-life care, including coalitions, task forces, health care professionals (both senders and users), hospice, long term care, palliative care programs, legislators, EMS, hospital systems and the public. These partnerships should be as multi-disciplinary and as inclusive as possible. And respondents observed that caution should be exercised in approaching potential partners whose political agenda or belief system might be in conflict with those of other important members of the POLST coalition.

Respondents also noted the advantage of building on past legislative relationships. Several states’ POLST programs, or at least POLST forms, are authorized legislatively. And, although the process of legislative advocacy can be daunting, respondents thought that the effort was well rewarded because lawmakers can authorize registry funding and provide good faith immunity. A legislative mandate can also assure that forms are submitted to the registry (unless the patient wishes to opt out). Such a mandate satisfies specific HIPAA requirements, facilitating submission rates and serving as a key component of success. One caution: if the form content itself is mandated, legislative action will be needed to change the form in the future.

Strong Leadership is Essential to POLST Program Outreach

The need for strong and effective leadership to oversee registry outreach and education is another consistent theme that emerged from the study. Ongoing education and outreach are critical to a registry’s success because, if the intended audience is not aware of both its existence and its function, the registry simply cannot succeed. In addition, registry senders and users may need to be trained, registered, and encouraged to access the system effectively.

States with successful registries have drawn heavily on collaborative relationships with diverse community leaders to ensure that their registry is both visible and accessible for its intended senders and users. Partnerships with multi-disciplinary and broad-based leaders, including POLST task forces and end-of-life or advance care planning coalitions, ensures statewide dissemination of essential information about the POLST registry and its use. The broader and more inclusive the leadership base, the more effective the outreach into diverse population groups throughout each state.

An effective model for distributing education and outreach programs throughout the state is the “train the trainer” approach, in which networks of trainers have previously been trained and are experienced in building POLST awareness. This group can then be given specific training and materials to educate specific groups of both senders and users of a newly-developed registry. This model depends on strong leadership, both to launch the training system and then to administer its dissemination broadly throughout the state and within different health systems.

Some states have shown notable initiative in seeking grant funding and developing creative programs to promote their POLST registry. Such initiatives require robust leadership and vision, as well as extended and careful oversight of the outreach and education programs once they are developed. Without effective leadership, even the most creative ideas can languish.

Integrating a Registry into Existing Health Care Systems Increases Use and Economizes Resources

One of the important factors to consider when determining where to house a POLST registry is whether there is an existing health care agency, organization, system, or coordinated program in the state that can effectively accommodate the registry. This approach can offer significant advantages both in terms of leveraging economic resources and increasing use of the registry.
For example, if the goal of the registry is to make POLST information accessible to EMS in the field, states with statewide, coordinated EMS systems will have the potential to create instant statewide penetration by integrating their registry or its function with the existing EMS system. Emergency health care professionals throughout the state will then have easy access to POLST information because they will already be familiar with the system and will have no need to learn new phone numbers or codes for system access. Easier access for users greatly increases the likelihood that POLST orders will be requested in times of medical crisis, and building on existing systems can be a very cost-effective means of establishing highly effective statewide presence.

Regional Health Information Organizations or Health Information Exchanges can offer similar opportunities to piggyback on existing systems that already have an established presence within a community and—as with statewide systems—there are cost-saving advantages to working with an existing system that has access routes that are familiar to its users.

Integrated Health Systems Can Serve Some Registry Functions, if EMR is Designed to Locate Forms

In an age of rapid development of medical records technology, where electronic medical records are becoming the standard for hospital and health systems, there is a marked increase in federal and state funding for coordinated health technology solutions. These technologically integrated EMR systems can serve some functions of a POLST registry within a specific health system if that system has the capacity to locate POLST forms rapidly and discretely (see Appendix C).

A number of EMR systems, such as GroupHealth in Washington and Intermountain Health in Utah, have been successfully designed to rapidly locate POLST forms. This is a cost-effective means to achieve a component of the access a registry would provide (so long as the forms can be easily and quickly located within the EMR system) and ensures easy access for health professionals within that health system. It is important to note, however, that this approach is limited by the size of the health system and the likelihood that the patient will receive some of their care outside the health system. The smaller and less integrated the system is, the higher the potential becomes that POLST orders will not be accessible to those who need them in times of medical crisis.

How Forms Are Submitted, And By Whom, Impacts Submission Rates

Respondents noted that, given the frail state of health of the patient population for which POLST was developed, it is unlikely that there will be high levels of self-submission from this group—especially given the dynamic nature of the POLST form, which needs to be updated as often as necessary to reflect patients’ changes in treatment preferences as they become less capable.

Only one state, Oregon, has a legislative mandate for signers to submit completed POLST forms to the Registry—unless a patient opts out—and this mandate is an effective means of increasing submission rates, while also satisfying HIPAA requirements. Currently, the Oregon POLST Registry receives 3,500-4,000 POLST forms per month, a significantly higher number than other states.

Overall, the most consistently reported challenge for registries included in this report is education and outreach, both of which have significant bearing on the number of forms submitted. This underscores the need described above to work collaboratively with other stakeholders to develop a robust statewide POLST educational program prior to registry implementation. Building on a preexisting foundation of POLST knowledge makes it easier to rapidly raise awareness about a new registry, and to train both users and senders in how to utilize the system effectively.

Launching Registries Prematurely Diverts Important Resources

All states that have operated, or are operating, active registries or form repositories noted the need for patience when developing a registry, pointing out that the premature launch of a registry can divert important resources (both financial and volunteer) from education and other programs. It is critical during the early development of a POLST program to devote resources to quality form completion based on rich conversations between health care professionals and their patients. And, when the time is right to consider a registry, it is important to devote time and energy beforehand to assessing the registry’s need and utility and building collaborative partnerships, as well as establishing clear goals for the registry. The result will be a more successful registry and a more sustainable use of resources.

Sustainable Funding is Vital to Long-Term Success

Just as it is essential to have clarity about a registry’s purpose before launching into its development, it is equally critical to have sustainable funding in place at the outset to ensure its long-term success. There are two aspects of long-term funding needs to consider—operations and education—and they may not come from the same source.

Once the registry is up and running, it will be challenging to find grant funding for the essential, but not very glamorous, functions of ongoing operations that include entering forms, verifying and updating information, reports, and making forms available. Several states have successfully secured state government funding to sustain these operations long-term.

Funding for ongoing education programs will be equally vital to the long-term success of a registry because of the evolving populations of both senders and users. Senders will not only need to be aware of the registry’s existence, but also be well trained in how to have conversations with patients about their advanced care needs and wishes. Users meanwhile will need training on how to access the system. Education can also be an important means of building public trust about the POLST program, and—given recent public debate—reassurance that the program has been developed to respect the freedom of persons with advanced illness to have, or to limit, treatment (rather than for cost-saving purposes) is an important element (see Appendix D). For this reason, seeking funding for education from non-governmental agencies, such as a broad coalition of health care professionals and private philanthropy—while integrating ongoing education into each aspect of the health system—will probably be the most effective way of sustaining this ongoing need.
California

In California, POLST is a relatively new program. Developed and piloted in 2007-2008, POLST was authorized in Assembly Bill No. 3000, Chapter 266 on August 4, 2008 and came into effect on January 1, 2009. POLST in California is managed by the Coalition for Compassionate Care of California (CCC), a statewide partnership of healthcare professionals, consumers, and regulatory agencies.

CCC, under the leadership of Executive Director Judy Citko and with the support of the California HealthCare Foundation, has worked to promote POLST since its development. The Coalition serves as the leader for all statewide aspects of POLST, including education, outreach, and form dissemination. CCCC organizes and staffs the statewide POLST Task Force, supports the work of 26 local coalitions; coordinates quality improvement efforts and evaluation; oversees all public policy aspects of POLST; and develops standardized educational messages and training content. POLST forms, which can be downloaded from the group’s website at www.capolst.org, are available in English, Armenian, Chinese, Farsi, Hmong, Korean, Pashto, Russian, Spanish, Tagalog, Vietnamese, and, upon request, Braille.

Because California is such a large and diverse state, statewide coordination including interaction and communication with local health care leaders has been extremely important. CCCC works with community coalitions to generate buy-in and to identify the needs and challenges of implementation. Partnering with key stakeholders—such as physician champions, hospital and nursing home administrators, and medical society and professional association leaders—has yielded success and quick adoption of POLST in California. Ms. Citko notes that this mix of people adds to the depth of understanding about use of POLST on a variety of levels.

CCCC and community coalitions are still focused primarily on quality POLST implementation. An electronic POLST registry, however, is often seen as a logical next step. “There is a lot of interest,” says Ms. Citko. “Everyone, including patients, wants to make sure that emergency responders and emergency departments can access this documentation when it is needed.” Because emergency responders in California are overseen by 32 local emergency medical authorities, rather than a single statewide agency, there is no logical centralized home for the registry.

The desire to share health information is larger than POLST. And in California, the state of health information technology is in flux. “We want to create a registry that is consistent with and interfaces with future health information technology. So we are looking at building the functions of a POLST registry into health information exchanges that are still developing at the local level or leveraging QR code technology to create a registry,” Ms. Citko adds.

Idaho

A 2002 Robert Wood Johnson Foundation report gave Idaho a grade of “D” for end-of-life care, highlighting, amongst other measures, a lack of advance care planning/advance directive laws.

With the intent of changing the end-of-life landscape in Idaho, a statewide end-of-life coalition was formed in 2003. A Better Way Coalition: Life on Our Own Terms includes representatives of professional medical organizations, citizen groups, individuals, academic centers, long-term care and nursing facilities, and local end-of-life groups. Promoting legislative advocacy (a 2004 revision of the Idaho Natural Death Act) and serving as a resource center, the coalition is currently led by President Cheryl Simpson-Whitaker, MSW, who also serves on the National POLST Paradigm Task Force.

During the 2005 legislative session in Idaho, Medical Consent and Natural Death Act was amended to authorize the use of a combined Living Will and Durable Power of Attorney for Healthcare. This same act created a Health Care Directive Registry (Title 39, Chapter 45, Section 15) and, in 2007, defined a “directive” as a “document meeting the requirements [of Idaho code], and/or a “Physician Orders for Scope of Treatment (POST)” form signed by a physician. In Idaho, a valid POST needs a physician signature and the individual’s signature (and/or that of their agent acting under a durable power of attorney). The POST form was not actually introduced until July, 2007. Authorized in 2006, the registry needed a home. The Secretary of State’s Office was approached to house the project, with the intent of keeping costs low. A provision to allow the office to charge $10 for maintaining registered documents was written into the law, but has not yet been invoked. Guided by an active group of stakeholders, led by the A Better Way Coalition, the Idaho Health Care Directive Registry started receiving forms in January, 2007.

Unlike several registries described in this report, the Idaho Registry is housed completely within a State office, and was built by State Information Technology staff. According to Miren Artiach, Deputy Secretary of State and Health Care Directive Registrar, the fact that the system is all “in-house” is a big benefit, allowing ease in updating or modifying the system. The project has no specific line item for staffing, but does have a small budget for materials and equipment.

The End of Life Coalition has drawn on the strength of its members to implement broad education initiatives for the registry, including an innovative contest entering new registrants for a chance to win a trip.

There are three types of registrant in the Idaho system—those with POST forms only, those with the combination living will/durable power of attorney, or those with both. Individuals submit forms themselves or through attorney or legal surrogate, primarily by mail. There is no prohibition regarding electronic submission, but it is not encouraged and is the least utilized route for submission. Forms for submission can be accessed electronically through http://www.sos.idaho.gov/general/hcdr.htm.
This site also includes guidance for completion of forms and submission to the registry. Registrants receive copies of the registered documents, a wallet-sized plastic registration card (Figure 2), and additional information about the registry. In May 2012, the Idaho Health Care Directive Registry housed documents for over 11,000 people. Documents can be amended at any time, and the Registrar notes that 15-20% of documents received are updates or amendments. For users to access the registry they would need Internet access and the codes provided on the registration card. They need not be registered beforehand. It is important to note that registries utilizing a system with patient codes required for searching face barriers for emergency health care providers, who may not know about the registry and would not look for a card, or who may encounter patients unable to respond who do not have the card with them.

Challenges for the registry have included a lack of funds for outreach, education, and promotion, but stakeholder groups have creatively sought out partnerships for these efforts, including with the AARP. The End of Life Coalition has drawn on the strength of its members to implement broad education initiatives for the registry, including an innovative contest entering new registrants for a chance to win a trip. In 2010 the Coalition received the Regence Blue Cross Sojourns Award for leadership in advancing quality palliative and end-of-life care in Idaho, and more recently received additional grant funding to support promotional efforts for POST and the Health Care Directive Card, or who may encounter patients unable to respond who do not have the card with them.

Figure 2: Idaho Health Care Directive Registration Card

### New York

In New York, the POLST Paradigm Program is “Medical Orders for Life-Sustaining Treatment,” or MOLST. Given the state’s complex surrogacy laws and documentation requirements, the implementation of MOLST required thoughtful planning and collaborative efforts. These efforts were initially driven by the Community-Wide End-of-Life/Palliative Care Initiative, a regional coalition based in the Rochester area, led by Dr. Patricia Bomba, vice president and medical director, geriatrics, Excellus BlueCross BlueShield.

Initiated in 2001, the group’s efforts led to the creation of the first regional MOLST form in late 2003. This form was adopted for regional use in January 2004. The New York State Department of Health approved a revised MOLST form for DNR and life-sustaining treatment documentation in any health care facility in October 2005. Legislation in 2005 and 2006 authorized a three-year MOLST pilot project, allowing MOLST to be used as a non-hospital DNR and DNI form in two New York counties. After successful completion of the community pilot, MOLST was approved through legislation for statewide use.

In 2010, New York State passed the Family Health Care Decisions Act (FHCDA), enabling a patient’s surrogate to make health care decisions when a patient is unable to do so and has not designated a health care agent. When FHCDA went into effect in June 2010, the original MOLST legislation was repealed and a new law governing non-hospital DNR forms, including MOLST, was put into place. The MOLST form was revised to include the FHCDA’s decision-making standards and became a New York State Department of Health Form (available from http://www.health.ny.gov/forms/doh-5003.pdf). Since 2010, oversight for MOLST has resided with the MOLST Statewide Implementation Team.

Recognizing that pathways can be complicated and slow to traverse, the measured approach used in New York has yielded both a short-term highly functional system and a long-term plan for electronic integration and access to MOLST education, documentation, and orders when and where they are needed.

 Consideration of electronic medical records and digital version of the MOLST form was given reasonably early in MOLST implementation and utilization. As in the paper world, documentation of the discussion must be included in the medical record. eMOLST simplifies the process by including the goals for care and legal requirements to produce MOLST Chart Documentation Forms for adults, minors and persons with developmental disabilities who lack decisional capacity. Dr. Bomba, in partnership with community stakeholders, applied for and was awarded a 2008 New York State Department of Health HEAL (Health Care Efficiency and Affordability Law) Phase 5 grant, to initiate both a New York State Registry for ADs and MOLST forms aiming to improve quality, legal outcomes, provider satisfaction and accessibility. The purpose of HEAL Phase 5 health information technology grants was to advance interoperability and community-wide EHR adoption.

The AD registry is accessible through the patient portal in Rochester’s Regional Health Information Organization (Rochester RHIO). This was the first RHIO in the country that allowed individuals to scan and attach ADs to their electronic health records.
The eMOLST system is separate and distinct from the AD registry in both submission and utilization practices. eMOLST is a hybrid tool allowing electronic completion of MOLST forms and associated documentation, quality assurance and analytics, and accessibility of completed forms in the eMOLST registry. eMOLST is a secure, web-based application allowing providers to complete and electronically sign eMOLST forms, even from mobile devices. The form can be printed, saved as a pdf, stored in an EMR, and automatically included in the eMOLST registry. The application walks senders through the discussion and the form, provides documentation for charting, allows users to document time spent in discussion (useful for reimbursement), and provides guidance on clinical steps, legal requirements and capacity determination. When FHCDA changed the MOLST process, the eMOLST system flexibly expanded its functionality to include documentation of the discussion and new legal requirements. While the eMOLST servers are currently housed at the Excellus BlueCross BlueShield data center, they will ultimately be held by the New York State Department of Health.

Institutions using eMOLST enroll users into one of four clinical roles, and one of four administrative roles. The clinical roles include:

1. Form creator, non-signer: these users can create and edit MOLST forms, document goals for care and legal requirements, but cannot sign the eMOLST form.
2. Form creator, signer: these users can create and edit eMOLST forms, document goals for care and legal requirements and can also sign the eMOLST form (only physicians can be assigned this role based on New York State Public Health Law).
3. Form reader: a role designed for clinicians who only need access to view the eMOLST form; this is ideal for EMS and other providers who need to follow MOLST orders, but are not allowed to change the form.
4. No clinical role: designed for eMOLST users who never need to see identifiable patient data, but need access to the system, and will be assigned an administrative role.

The four administrative roles include:

1. Quality assurance/quality improvement: provides access to aggregate, de-identified data in the eMOLST system.
2. HIPAA-covered Entity Administrator: allows a user to enroll other users and create facilities under their health system entity without seeing QA/QI data or any patient data.
3. HIPAA Entity Auditor: available for individuals who need access to the audit log data, but can't do other administrative tasks in eMOLST.
4. eMOLST Administrator: only available to the administrators of the eMOLST program for NYS. These users can create HIPAA-covered Entities in the eMOLST application and assign eMOLST administrators for a health system.

Each eMOLST user is assigned both a clinical and administrative role in the system allowing for dual roles (such as a form creator and signer who also has access to QA/QI information).

Once form creators have a login, they can complete or review MOLST forms, update orders, print forms, and access required documentation forms. The system tracks dates and provides reminders for review and renewal conversations. When a patient's form is completed using the eMOLST system, they receive a printed copy of their form. Other patient-level documentation that will alert health care professionals to the existence of an eMOLST is now under consideration. Currently, data analytics produced by the system show an institutional-level dashboard indicating descriptive aggregate data from the forms and system. An expanded dashboard with more available metrics is in development.

The eMOLST system was contractually developed by Fusion Productions and overseen by the community stakeholder group that included health care professionals (including EMS), representatives from the Rochester RHIO and the New York State Department of Health. Given the rapidly shifting legislative landscape, the product needed to be flexible and scalable enough to support a phased development and implementation cycle.

Implementation of eMOLST is occurring along two tracks. Health systems and facilities across New York State are being encouraged to begin using the eMOLST system as early adopters. At the same time, integration of eMOLST with the Rochester RHIO continues. Integration with the RHIO means that a completed eMOLST form will be available and viewable through the RHIO's document registry to all participating health systems and providers, including EMS. Creating eMOLST and a MOLST registry just made sense in New York State, according to Dr. Bomba. eMOLST creates legible, valid forms, eliminates incompatible orders, integrates quality improvement and research, and provides an electronic registry.” However, Dr. Bomba is quick to note that both timing and collaboration are all-important. Her team asked eMOLST providers to provide reflection on the proposed eMOLST process before implementation and she describes this as a "critical step that was very helpful for gathering information across a broader mindset, multiple patient populations, and different sites of care, while also building up excitement and buy-in." This inclusive approach, along with site visits after the system launched, helped the team to appreciate the complexity of eMOLST use and need. Site visits resulted in the addition of documentation of the clinical process and legal requirements in the application and generation of the MOLST Chart Documentation forms. While this delayed the launch, inclusion of these features meets the long-term vision for the MOLST program.

Currently, there is no charge for eMOLST software or service for institutions. The future vision for eMOLST is seamless transition to a state level service and maintenance of the intact eMOLST system as part of the Statewide Health Information Network of New York (SHIN-NY). Recognizing that pathways can be complicated and slow to traverse, the measured approach used in New York has yielded both a short-term highly functional system and a long-term plan for electronic integration and access to MOLST education, documentation, and orders when and where they are needed.
Beginning in 1991, EMS and ethics leaders in Oregon became concerned that the treatment preferences of patients across the state were not being honored because of lack of documentation of actionable medical orders. To address these issues, they brought together a broad-based coalition of representatives from long-term care, hospital systems, EMS, hospice and other health professionals from around the state. This coalition eventually became the Oregon POLST Task Force. With the intent of converting patient preferences regarding life-sustaining treatments into signed, portative medical orders that could be honored across care settings, including emergency care, the coalition created a document called the Medical Treatment Coversheet, which was renamed “Physician Orders for Life-Sustaining Treatment” or POLST in 1995. POLST evolved into a national model, and the POLST Paradigm is now one of the most widely used and studied models for documenting and honoring patient preferences and guiding medical treatment for people with advanced, chronic medical conditions or frailty.

A principle reason for the success of the Oregon POLST program is that members of the Oregon POLST Task Force are committed to representing their constituents and taking POLST information and education back to them. Ongoing education and dialogue, as well as accepting feedback and making changes to meet the needs of all POLST users, is critical to success. The Oregon POLST Task Force continues to meet regularly to review and revise the POLST form and educate about the Oregon POLST program. This past year the Task Force revised its POLST educational videos, patient brochures and Spanish language resources. And POLST education is regularly conducted across the state and incorporated into Task Force members’ conferences and training sessions.

In Oregon there is no legislation in the state directing the use of particular out-of-hospital DNR forms, and health care professionals and their patients can use other methods of documenting DNR and other orders. However, POLST has become the standard of care and is widely recognized throughout the state. Completion of a POLST form is always voluntary, although some facilities have a policy of asking all new residents if they have one or would like to have one completed. Oregon used regulatory change through the Oregon Medical Board to direct EMTs to honor POLST forms and to allow emergency physicians to honor the orders, whether or not the physician who signed the orders has admitting privileges at that hospital.

[Mandating that all completed POLST forms are submitted to the Registry, unless a patient opts out] benefits many patients with advanced illness or frailty who would have difficulty submitting their form, assures submission for most registrants, and builds a large enough repository that users searching the Registry may actually find a match.

After completion and signature by a physician, nurse practitioner or physician assistant, the POLST form is intended to remain with the patient. However, a 2004 study of Oregon EMTs’ experience with POLST found that, when asked about any problems during the last call they had in which the patient had a POLST from, in about 25% of cases the EMTs reported that the form could not be found when they first arrived. Some hospital systems have begun scanning copies into their electronic medical records, which can increase access as long as the patient is treated within that system, but does not help with out-of-hospital calls or if the person is seen in an emergency department that is not part of that health system. Because of these obstacles, the concept of an electronic registry for Oregon POLST forms was conceived.

The Oregon POLST Task Force, the Center for Ethics in Health Care and OHSU Department of Emergency Medicine began development of The Oregon POLST Registry in 2008 with philanthropic funding to develop the database and pilot test it in one county. Although POLST had developed in Oregon through regulation and without legislative change, the Task Force soon realized that—in order for the Registry to comply with HIPAA guidelines without obtaining written consent forms—the Registry needed to be a state registry, and the state needed to mandate that signed forms be submitted to the Registry. It still does not mandate the completion of forms. Thus, Dr. Susan Tolle and Dr. Terri Schmidt worked with the Oregon Legislature to create and fund The Oregon POLST Registry with the passage of House Bill 2009 on July 1, 2009. This legislation created a Registry within the Oregon Health Authority (OHA).

The Registry is operated by the OHSU Department of Emergency Medicine through a contract with the OHA. The OHSU Department of Emergency Medicine already had a 24-hour Emergency Communication Center (ECC) used by EMTs in the Portland area for medical consults and throughout the state for trauma transfers. This created a natural place to receive calls for POLST forms in the Registry. The legislation approved funding for the Registry from the state’s general fund and, perhaps most importantly for the Registry, mandated that all completed POLST forms be submitted to the Registry by the signer unless the patient opts out. This signer mandate benefits many patients with advanced illness or frailty who would have difficulty submitting their form, assures submission for most registrants, and builds a large enough repository that users searching the Registry may actually find a match. The Oregon POLST form was revised in 2009 to include this opt-out option, and was revised again in 2011 with the registry in mind when the opt-out box was moved to the front of the form, along with all signature areas (Figure 4).

The Registry collects signed, valid POLST forms, scans the forms, and abstracts data from the form that is manually entered into a web-based database. This database can then be searched by trained Emergency Communications Specialists within the ECC (Figure 5).
These specialists receive telephone calls from EMS, emergency departments and acute care units, then search the Registry and, if a match is found between the patient and a form, provide the POLST orders to the caller. They may also fax a copy of the form to an emergency department or hospital (see Figure 6).

The OHSU ECC serves a number of roles within and throughout the state, including coordination of patient transfers and physician consults, and serving as medical scribes and pediatric team dispatchers. But its role as the statewide trauma communication center provided a critical access point for the Oregon POLST Registry that was already well known to emergency departments and hospitals across the state as well as regional EMS professionals. By working with a pre-existing and trusted system, the Registry was able to leverage resources and create a plan for utilization that would not be “bulky” or unusual to many planned Registry users. The Oregon POLST Registry subcontracts time from the ECC from its primary state budget. Because the ECC is located at the same institution as the Registry contractor, there are straightforward routes for training and coordination of Registry-related needs between the two groups. Finding and working within these existing systems can strengthen the link between a registry and its users, and subsequently increase adoption and utilization.

The Oregon POLST Registry is funded by the Oregon Health Authority, administratively overseen by the State EMS Medical Director, advised by the Oregon POLST Registry Advisory Committee (PRAC), and operated contractually by the OHSU Department of Emergency Medicine at OHSU. Education and outreach related to the POLST Registry for EMS and other emergency health care professionals are managed by the POLST Registry staff, while education and outreach related to POLST or the POLST Paradigm are managed and coordinated by the Center for Ethics in Health Care, the National POLST Paradigm Task Force and the Oregon POLST Task Force.

The Oregon POLST Registry collects only Oregon POLST forms, and contains no other content. Given the legislative mandate to submit forms, it can be assumed that the Registry receives most of the completed POLST forms. The Registry office receives and processes 3,500-4,000 forms per month (Figure 7), providing direct feedback to senders regarding form validity or inconsistency issues on forms deemed Not Registry Ready (NRR). Registrants receive a letter summarizing their form’s orders, a magnet with a Registry ID#, and several stickers to affix to medical records or identification.

The Oregon POLST Registry was developed to meet specific needs of emergency health care providers, including EMS. Because these providers may have limited information about a patient in an emergency situation, the Registry does not rely on a caller providing a single identifier for a patient, but instead searches using any and all demographic information. A weighted search algorithm, which was developed for the Registry to assign point values to matched information, was validated in a recent study and found to be highly specific and sensitive, allowing no “false positives”
in the study time frame. To access Registry-housed orders, a certain number of data elements must be matched. This allows emergency health care professionals to request POLST orders from the Registry using the limited information available when assessing a patient who is "down." Another recent study interviewing early EMS users and patients found that the registry was easy to access and allowed EMS to find and follow POLST orders.

Ongoing provider education and outreach are key aspects of a registry's success, and the Oregon POLST Registry has been well supported by the Oregon POLST Task Force in this area. Comprised of members representing every major group of senders and users, the Task Force has played a major role both in developing educational materials and ensuring that their constituents receive and learn from them. An educational program—including a video and other materials—was developed to reach every hospice, hospital and long-term care facility in the state, designed to launch at the same time as the statewide registry was signed into statute. This ensured rapid population of the registry and a high level of statewide penetration.

As of July 31, 2012, the Registry had received nearly 120,000 POLST forms for more than 88,000 Oregonians. Oregon has about 31,000 deaths each year. The level of POLST penetration throughout the state is a key factor in ensuring the Registry's success because the higher the level of penetration, the greater the likelihood that EMS will find a match when they call at a time of crisis.

To date, the ECC has received over 1,500 emergent calls for POLST forms, while the Registry back office receives more than 200 telephone calls each month for both POLST and Registry-related education or guidance and non-urgent POLST form requests. While originally developed as an EMS resource, utilization of the Registry by Emergency Departments has also been strong, with 47% of all emergency calls received from this setting. EMS providers (34%) and Hospital Acute Care Units (17%) comprise the balance of callers to the Emergency Communication Center.

Research using Oregon POLST Registry data has recently been published, describing the Registry's population (85.9% age 65 or older, 61% Female, and 40.4% residing in a rural area) and reporting that while the majority of patients' POLSTs included a Section A order for Do Not Resuscitate (72.1%), only half of those forms indicated an order for "Comfort Measures Only" in Section B. This bolsters the argument that DNR does not mean "Do Not Treat," and that DNR status should not be used to infer patient wishes regarding care in other circumstances. 23

Terri Schmidt, MD, MS, director of the Oregon POLST Registry and medical director for Clackamas County, summarizes the Registry's role with this description: "The Oregon POLST Registry provides access to POLST orders 24/7 for EMS, emergency departments and acute care units through a preexisting emergency call center familiar to EMS providers throughout the state. In addition, the Registry fulfills hundreds of non-urgent POLST form requests per year for individuals, long term care facilities, clinics, health systems, and others during business hours through the Registry office. It has also become an invaluable quality assurance and research tool. Data from the Registry helps guide POLST-related education for health care professionals. Research using the Registry is providing insight into POLST utilization to facilitate continuous quality improvement."

Using de-identified information, the Oregon POLST Registry generates monthly data reports as well as annual reports of operations. For more information about the Registry, see www.orpolstregistry.org. If interested in learning more about the Oregon POLST Registry, contact the Registry at polstreg@ohsu.edu.

Utah

The path from early Living Wills to a POLST registry in Utah has been characterized by collaboration among individuals and organizations.

POLST first came to Utah in 2002 by way of a hospice nurse who learned about it at a national meeting. At the time, Utah's Personal Choice and Living Will Act had been in place for 17 years, but professional consensus reflected the research suggesting that Utah's traditional format living will and a very restrictive statutory scheme did not help patients to achieve their wishes. POLST was enacted in Utah in 2002 through Department of Health regulations that governed the state's health facilities (R432-31). A variety of health care facility types, professions such as medicine, nursing, and law, and advocates for older adults participated in the process of drafting the form and regulation.

A state-wide coalition funded by the Robert Wood Johnson Foundation Community State Partnerships to Improve End-of-Life Care worked with the Utah Department of Health to provide education on the POLST. Unfortunately, coalition funding ended and it eventually ceased to operate. Although the Bureau of Health Facility Licensing continued to provide education about the POLST to healthcare facilities, many providers, including EMS, remained largely unaware of the form and system. And, when they were aware of the POLST, providers were often unsure about its relevance or legal weight.

After a fall in activity, the Utah Commission on Aging, which was created by the state legislature in 2015, turned its attention to advance health care planning and POLST by forming a special committee. Since its creation, the Commission has been directed by Maureen Henry, JD, who also served as the manager, then director, of Utah's Community-State Partnership to Improve End-of-Life Care. Maureen also serves the Utah representative to the NPFT.

Particularly important in this evaluation process was the knowledge gained from using the POLST for a number of years. More than 200 people were involved in various iterations of this process, from groups at senior centers, to disability rights advocates, to health care attorneys, to providers.

Although the earlier coalition was no longer operational, the Commission pulled together many of those who had been involved in past efforts, as well as new members, to reconsider Utah's advance care planning laws and regulations. The special committee considered what was and was not working, studied the Uniform Health Decisions Act and many state laws, and reviewed the research on advanced care planning and POLST. Particularly important in this evaluation process was the knowledge gained from using the POLST for a number of years. More than 200 people were involved in various iterations of this process, from groups at senior centers, to disability rights advocates, to health care attorneys, to providers.

The special committee's work was reflected in the Utah Advance Health Care Directive Act (Utah Code §75-2a-100 et seq.), which dramatically changed the state's advance care planning system. The statutory language was influenced and informed by providers’ experiences with POLST from its implementation in regulation in 2002.
Once passed, POLST gained recognition as a legal form to be followed by providers, facilities, and EMS. The statute (75-2a-106) used the term Life with Dignity Order to describe medical orders addressing end-of-life care, including POLST forms. It was contemplated that the POLST would be—and it has since become—an authorized Life with Dignity Order (along with the EMS/DNR form that had been in place for many years) and that the Department could authorize additional Life with Dignity Orders in the future. The bill was signed into law in 2007 with an implementation date of January 1, 2008.

Minor statutory amendments were made during the 2008 and 2009 legislative sessions, including expansion of authorized signers of Life with Dignity Orders/POLST to include nurse practitioners and physician assistants, and an expansion of providers authorized to evaluate capacity for the purpose of determining when a surrogate’s right to make decisions on behalf of an incapacitated patient was triggered. Regulations supporting the law (R432-31) were issued in 2009 and implemented in 2010.

Despite a carefully-developed statutory scheme and increasing awareness and use of POLST, the limitation of a paper form remained a barrier to effective implementation of the POLST form. In addition, the Commission on Aging lacked the funding and staff resources to maintain a coalition.

A mechanism to help address both of these challenges came in the form of the Office of National Coordinator for Health Information Technology’s Beacon Community Program. Utah’s successful Beacon proposal, led by HealthInsight, the state’s Medicare Quality Improvement Organization, included funding for the creation of a POLST registry and education and support for POLST. The Utah Department of Health’s Office of Vital Records and Statistics agreed to house the ePOLST registry. This was a good fit because many of the physicians who use the state’s EDEN electronic death registry are likely to use the ePOLST system due to the nature of their medical practice. The system is a hybrid electronic form completion system with repository functionality.

There are three primary user populations:

1. **Form Access:** Can view or revoke forms/form information via secure web-based system (licensed health care providers, including EMS).
2. **Form Preparation:** Can prepare new or replacement forms based on conversations (social workers, nurses, physicians, physician assistants).
3. **Signature/Authority:** Can view, prepare, and sign forms (physicians, nurse practitioners, and physician assistants).

ePOLST is being piloted during the summer of 2012, and is expected to launch statewide by the end of 2012. Figure 8 shows a “screenshot” of one page of the Utah Registry.

The Beacon Community funding provided financial support for the Utah Commission on Aging to increase efforts in educating providers about POLST. This enabled Utah to hold its first state-wide Advance Care Planning and POLST meeting in June 2012. A POLST/ePOLST leadership committee is being formed among attendees at that meeting. HealthInsight will serve as the administrative lead for a new leadership committee and statewide coalition, emphasizing a shared interpretation of POLST and sustainability for ePOLST and the coalition. In addition to ePOLST, 2012 plans also include a revitalized web site for end-of-life care in Utah.
Washington

Washington and Oregon share not only a common border but also some common practices and philosophy, so Washington State was familiar with the POLST program from the beginning. The Washington State Natural Death Act was enacted in 1992 and amended in 2008 to enable Washington’s POLST program. POLST implementation followed a phased approach starting in Spokane before moving to other areas in Eastern Washington and later to the urban areas of Puget Sound.

The geographic roll-out was a practical result of limited resources for training and education. Efforts focused on high-level agreements among leaders of EMS, hospitals, and long-term care centers followed by training of respective "front line" personnel. Piloting POLST in the smaller population centers allowed processes to be well developed before moving to larger centers. Washington health care professionals were accustomed to an existing state-endorsed out-of-hospital DNR form, so moving to the POLST was more an evolution than a revolution. There was some initial disagreement among leaders of state agencies as to the specific role of the POLST program in nursing homes, but these differences were eventually resolved leading to state-wide acceptance in all settings of care.

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The administrative home of the POLST program is the Washington State Medical Association (WSMA) (http://www.wsma.org/patient_resources/polst.cfm). The WSMA sponsors the Washington End of Life Consensus Coalition, which is focused on education. The POLST Task Force is a subcommittee of that coalition that meets primarily to review and revise Washington’s POLST form periodically. While the Washington POLST program benefited from support from many committed individuals and key organizations early on, the infrastructure put into place to maintain oversight, coordination, and integrity of the POLST program over time, is not comprised of representatives from the broad range of stakeholders that were key to the establishment of POLST. In addition, the administrative home for POLST does not serve as the state-wide voice for POLST. Thus, leadership for POLST in Washington can appear fragmented.

The registry itself was not tied to any local or regional group, nor was it connected to a clinical care application or process, which significantly decreased its capacity to build awareness and promote its use.

Interest in a POLST registry led to HB 1244 in 2009, specifically stating, "[t]he Department of Health (DOH) shall maintain the statewide health care declarations registry which contains health care declarations made by residents of Washington. The department shall digitally reproduce and store health care declarations in the registry." Washington's DOH contracted with the U.S. Living Will Registry to produce the Washington State repository. This system is a free-standing, proprietary national repository system in which groups can purchase "blocks" of user registrations and storage space. Designed as a self- or surrogate-submission registry, the Washington Living Will Registry supported the storage of ADs, POLST forms, Durable Powers of Attorney for Health Care, and Mental Health ADs. After registering, patients sent their documents to the registry for scanning.

The DOH supported a staff member to promote provider registrations and oversee submissions and patient confirmation. The registry itself was not tied to any local or regional group, nor was it connected to a clinical care application or process, which significantly decreased its capacity to build awareness and promote its use.

With no internal mechanism for promotion or marketing, the registry had little public visibility, and outreach to providers promoting registration was also difficult. Soon after implementation, the 2010 Legislature reduced the registry's budget by 60%, eliminating funding for the already limited educational and promotional efforts. Skated for complete elimination by June 30, 2011, the Washington Living Will Registry Task Force attempted to identify a new sponsor for the registry, but was unsuccessful in this effort. At the end of two years of operation the Registry had a total of just over 2,000 Washington registrants with 3,700 stored documents (about 500 of which were POLST forms). At that point, the Washington Living Will Registry closed. Registrants were provided with a lifetime membership to the vendor's services, including ongoing document storage. There are currently no efforts to revive a POLST registry in Washington.

Dr. Bruce Smith, co-chair of the Washington POLST Task Force and member of the Washington End of Life Consensus Coalition, observed that “Washington’s POLST registry faced a number of challenges. Our POLST program was already well established before the registry became available, and people already had their routines established. As an ‘opt in’ program, the registry required a significant commitment to participate on the part of both patients and providers. The registry itself was difficult to use as it required a unique patient identifier for access that was often unavailable in a medical emergency. Only a few patients submitted documents to the registry, so even when providers took the time to check they were unlikely to find what they needed. Finally, depending on State funding in a time of financial downturn proved risky. To be successful, I think a registry program should be automatic (‘opt in’) to insure broad participation, easily accessible, and supported by adequate staff with stable funding.”

When asked to provide guidance for other states considering registries, Judy Citko, Chair of the National POLST Paradigm Task Force, noted that a number of themes emerged from Washington’s experience that were also noted by other states participating in this report:

“First, it is impossible to overstate the importance of building a strong coalition of representatives of all the key constituencies—including healthcare professional organizations, hospitals and health systems, EMS, long-term care, hospice, and others—who are deeply committed to the development and dissemination of the POLST Program. When selecting those partners, it is essential to use caution when including members of advocacy groups with a political agenda that might conflict with the key organizations you need to be part of the coalition. Before considering the launch of a registry, assess the commitment and capability of your coalition to develop a statewide educational effort because this is critical to success. And, finally, when structuring a registry, develop a system that is integrated into the existing health care system and doesn’t rely on patients to opt-in.”
West Virginia

The West Virginia Health Care Decisions Act of 2002 was amended to authorize the use of a standardized form, the Physician Orders for Scope of Treatment, or POST. After over a decade of legislative, policy, and institutional efforts advancing end-of-life care in the state, the West Virginia Center for End-of-Life Care was established and funded by the West Virginia Department of Health and Human Resources in 2002.

Under the direction of Dr. Alvin Moss, the Center's goals include improving end-of-life care for West Virginians through education and training, and acting as a resource center for individuals, health care providers, and legislators to ensure that West Virginians have their pain controlled and their wishes respected at the end of life. In addition to his work at the Center, Dr. Moss is the Director of the Center for Health Ethics and Law and a professor of medicine at the Robert C. Byrd Health Sciences Center of West Virginia University and is the Director of the West Virginia Network of Ethics Committees. He also serves as the vice-chair of the National POLST Paradigm Task Force Executive Committee.

In 2009, following registry efforts in other POLST Paradigm Program states, Dr. Moss, along with Cindy Jamison (West Virginia Center for End-of-Life Care Program Manager) and a group of stakeholders—including end-of-life care leaders and government representatives—conceived of a West Virginia Advanced Directive and POST Registry. However, while the concept was supported, there were challenges in how to implement the project. Initially, the West Virginia registry was to be housed in the State EMS Data System, utilizing a communication center model similar to that of the Oregon POLST Registry. However, state personnel changes in late 2009 created obstacles. By 2010, recognizing that there was little movement in the development of an EMS-based registry, the Center established the West Virginia e-Directive Registry through the West Virginia Health Information Network (WVHIN). The WVHIN is a health information exchange funded through federal HIE grants. With a vision of “high quality, patient-centered care facilitated by health information technology,” the WVHIN allows a portal for communication of patient data between providers and care settings, and is web-accessible, even on mobile devices.

The e-Directive Registry holds, with the permission of patients or their surrogates, a variety of documents, including Medical Powers of Attorney, Living Wills, POST forms, DNR cards, Health Care Surrogate Selection appointments, guardianship appointments, and miscellaneous related documents in a web-based electronic registry accessible to patients and providers through the WVHIN portal. The Registry started receiving forms in October 2010 and was announced under the WVHIN with a plan to go live in 2011, but State-level administrative delays created additional obstacles for Registry deployment through the WVHIN. The Registry went live in August 2012.

However, even prior to provider online access through the WVHIN portal, the Center has been operating the e-Directive Registry, receiving approximately 700 forms per month. Registry staff proof-read each form and notify patients or providers of any problems or concerns they find. Forms are received primarily by fax, although forms are also accepted by mail or in-person. The WV Center for End of Life Care updates and revises the POST forms and other forms (available at http://www.wvendoflife.org/Public/Forms). Individuals can sign up for the e-Directive Registry using their already-completed documents, or the new versions of the Registry-eligible documents with checkboxes for patients to “opt-in” to the Registry. This “opt-in” system is completely voluntary. The registry receives forms from clinics, hospitals, nursing homes, hospices, and individuals. Dr. Moss notes that the Public Employee’s Insurance Agency offered a discount with a completed AD, increasing registration numbers. Patients receive a confirmation letter whenever they submit forms as well as an annual letter to ensure that their most current documents are in the registry.

Patients are made aware of the Registry through advertising, including radio and television, and conference exhibits. Professional outreach and training through the Center includes audiences of social workers, nurses, physicians, professional organizations, and statewide and regional networks of ethics committees and EMS medical directors.

The WV Center for End-of-Life Care operates the WV e-Directive Registry under a state contract. Funding for the Center and the Registry is provided through the Bureau for Public Health under the Department of Health and Human Resources by the West Virginia Legislature. The Center has been consistently funded since its inception in 2002. The Center recognizes that the annual funding authorized for the registry will likely be lower than the initial funding given the need for infrastructure and system development.

The e-Directive Registry is able to generate data reports from their system indicating monthly form volume and distribution, and basic POST form content (Section A and B orders). Registered providers are able to access forms held in the e-Directive Registry. The Network’s master patient index is searchable, with a specific tab indicating registry contents. The data manually entered by the Registry staff (including demographic information, DNR orders, Section A and B of the POST form, and ADs with special directives) are shown, and the saved scanned form images are available for review. When forms received by the Registry are found to be invalid for registry storage, the sender receives a letter indicating how the issue can be resolved.

The Registry is overseen by the West Virginia e-Directive Advisory Committee, with membership drawn from health care facilities, state EMS, state government, and other stakeholders. Dr. Moss and his team credit persistence and investing the time to develop strong working relationships with stakeholders and potential funders as critical elements of success. Initiatives to educate and get buy-in from legislators were well worth the effort, notes Dr. Moss. “By working with the system and using relationships developed over many years, we were able to educate the legislators about the value of these forms and a registry.”

Lessons Learned

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- Funding given the need for infrastructure and system development.

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Appendix A: 2011 California POLST form

Appendices
Timing of implementation is key to effectiveness and ultimate success of a POLST registry. Early experience demonstrates that having the right model, adequate resources and support from health care professionals and public policy makers is essential for a new registry. The following document developed by the National POLST Task Force Registry Subcommittee includes recognized key components of a POLST registry. It is expected that these components will be refined as additional experience with registry implementation is gathered.

Form Entry and Update
1. A searchable database to maintain forms.
2. A mechanism to assure that a large percentage of existing forms are entered into the registry.
3. Timely entry of the forms into the registry.
4. A mechanism to assure accurate entry into the registry.
5. Unique identifier.
6. A mechanism to update the form for a person in the registry when the person voids a present form and completes a new one.
7. A mechanism to identify a deceased person’s forms, archive them, and remove them from the searchable portion of the registry.

Access to the Forms
1. 24/7 access to the information in the registry by health care professionals such as EMS and acute care hospitals who need them at the time of a crisis.
2. Non-urgent access for other health care professionals who are members of the patient’s care team.

3. A mechanism that protects the information from unauthorized access.
4. A mechanism that assures correct match of the patient and the form so that the wrong information is not provided.
5. Mechanism for patients, signers and others, as needed, to access information about forms in the registry.

Quality Assurance and Research
1. A quality assurance program that assures that the key components are monitored.
2. Ability to produce de-identified reports about forms in the registry.

Initial and Ongoing Education about Use of the Registry
1. EMS/ED/Acute Care hospital professionals (users).
2. A mechanism to provide all health care professionals who counsel, complete and sign POLST Paradigm forms (senders) about entry into the Registry.

Legal Considerations
1. Assurance that the form is HIPAA-compliant.
2. A mechanism to assure data security.
3. Definition of who is authorized to enter forms.
4. Review of specific state requirements.
5. Consideration of medical legal concerns for risk management.

NPPTF Recommendations for Electronic Health Records and Physicians Orders for Life Sustaining Treatment (POLST) Paradigm Forms

Preamble:
The National POLST Paradigm Task Force has developed the following recommendations to foster the conversion from paper based state POLST Paradigm Forms to electronic POLST forms stored in a variety of Electronic Health/Medical (EMR) Systems. State specific e-POLST electronic templates are usually developed, approved and updated by state coalitions and/or state agencies. For more information on the POLST programs, go to www.POLST.org.

These recommendations specifically address recommendations for integrating the POLST Paradigm form into the EMR and do not address the important separate issues of storage or retrieval of advance directives and other types of advanced care planning records.

Recommendations:
1. The EMR system offers access to an external POLST form database and/or system via a secure, authenticated portal, interoperable data exchange standard or link— so that a state specific POLST Paradigm e-POLST document could be accessed while the health care professional is still working within the EMR system. We prefer no additional log on.
2. The EMR system has the ability to rapidly receive and accurately store and display the external document within that patients’ EMR.
3. The POLST Paradigm forms will be in a unique POLST field/tab and can be accessed instantly preferably within one click. The tab can be marked with a yes or no box, so that the provider can see if a form exists before opening the tab.
4. State specific e-POLST electronic templates developed, approved and updated by state coalitions and/or state agencies and standards for wording and printing would be set and changed only by POLST coalitions and/or state agencies.
5. As POLST Paradigm updates occur, the EMR system accepts and stores the updated forms, form definitions [electronic templates].
6. The unique POLST filed within the inpatient and outpatient EMR contain only POLST medical orders.
7. As allowed by state law or regulation, The EMR system should allow export of POLST paradigm forms to a regional or statewide database/system/register for storage and authorized access of forms; using accepted interoperability standards; when such a statewide or regional system exists.
Appendix D: NPPTF POLST Goals Statement

## The National POLST Paradigm Task Force

The National POLST Paradigm Task Force (NPPTF) was convened in September 2004 to establish quality standards for POLST Paradigm forms* and programs and to assist states to develop such programs. At that time only a few states had such programs. The NPPTF includes one representative chosen by each state that has met the requirements to be an endorsed POLST Paradigm program.

## Goals of the POLST Paradigm Program

In the early 1990s the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program was developed to improve patient care and reduce medical errors by creating a system that identifies patients’ wishes regarding medical treatment and communicates and respects them by creating portable medical orders. The system focuses on a growing segment of the United States population, those seriously ill patients with advanced, chronic progressive illness. While the NPPTF supports the completion of advance directives, clinical experience and research demonstrate that these advance directives are not sufficient alone to assure that those who suffer from serious, advanced, progressive chronic illnesses will have their preferences for treatment honored unless a POLST form is also completed.

A key component of the system is thoughtful, facilitated advance care planning conversations between health care professionals and patients and those close to them to determine what treatments patients do and do not want based on their personal beliefs and current state of health. In these conversations patients are informed of their treatment options and, if they wish, their health care professional completes a POLST form based on the patient’s expressed treatment preferences.

A number of states have implemented the POLST Paradigm, and most others have expressed interest in doing so. POLST research shows that POLST use results in treatment consistent with patients’ wishes more than 90% of the time, significantly reduces unwanted hospitalizations, and decreases medical errors.

The NPPTF is continuing to conduct research and develop quality measures to further assess the impact of the POLST Paradigm Program on patient outcomes. The goal of the NPPTF is to assure that the wishes of those with advanced illness and frailty are elicited, recorded, and honored.

*The POLST Paradigm form is called by differing names depending on the state. For example, in New York it is called a MOLST form and in Indiana, Tennessee, and West Virginia a POST form. In this statement the form will be referred to as a POLST form.

Approved 8/23/2012

## Registry Matrix

<table>
<thead>
<tr>
<th>Active Registry or Electronic form Completion System?</th>
<th>California</th>
<th>Idaho</th>
<th>New York</th>
<th>Oregon</th>
<th>Utah</th>
<th>Washington</th>
<th>West Virginia</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

| Registry Structure and Content                        | Active Registry | No registry currently identified for Health Information Exchange with POLST availability | Form repository: POLST forms, Combination Living Will + Durable Power of Attorney for Healthcare | Hybrid form completion system with repository functionality: POLST forms and associated materials. Separate self-submit advance directive registry. | Form repository: POLST forms only. | Hybrid form completion system with repository functionality: POLST Forms only. | Form repository: Advance directives, POST forms, Surrogate Selection. Combined Medical Power of Attorney and Living Will, and miscellaneous related documents |
|------------------------------------------------------|----------------|-------------------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|
| Who submits materials?                                | N/A            | Individuals, legal representatives, authorized surrogates | Providers complete ePOLST with automatic submission to repository. Individuals submit advance directive through RHIO patient portal. | Health Systems, clinics, hospitals, long-term care facilities, hospice, and individuals. | Form preparers and signers | When operational, individuals, or legally authorized representatives submit advance directive materials. Materials submitted to the Washington Registry are still available online through a national vendor. |
| Users                                                 | IF POLST available through HIE, providers and individuals could access | Health care providers access form content through web-based interface. Requires patient identifying codes from wallet card. | Providers using RHIO, as well as those using eMOLSTUIsers have access to the medical records through eMOLST linkage. | Oregon EMS providers, Emergency Departments and Hospital Acute Care Units have 24/7 emergency access via a call center. Long-term care facilities, hospice, and other users access POLST forms through the Registry back office (M-F, 8-4). | Health care systems, providers access content through a web-based interface. | When operational, materials were accessed through a web-based interface, requiring patient identifiers. After the Registry ceased operations, registrants’ materials were maintained on the site and are accessible using already provided patient identifiers. |
| ePOLST Functionality                                  | N/A            | No                                               | Hybrid system guides provider completion of eMOLST forms and automatically submits to form repository. | ePOLST system currently being developed by Oregon POLST Program. Registry plans upgrade to receive ePOLST data. | Yes                                         | Yes                                         | No                                     | No |

The NPPTF POLST Goals Statement aims to ensure that patients’ wishes regarding medical treatment are communicated and respected by creating portable medical orders that are easily accessible and easily understood by healthcare providers.
Pathways to POLST Registry Development: Lessons Learned


Pathways to POLST Registry Development:
Lessons Learned

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