



Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment (POLST) Documentation Access through Health Information Exchange (HIE)



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ELECTRONIC END-OF-LIFE AND PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST) DOCUMENTATION ACCESS THROUGH HEALTH INFORMATION EXCHANGE (HIE)

“All Americans should be able to expect that they and their loved ones will receive the care and services they need at the end of their lives.”

— *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*
Institute of Medicine of the National Academy (National Academy of Medicine), 2014

End of Life Care and Treatment Discussions Are Not Common

Recent research reveals that while individuals think it is important to discuss end-of-life treatments, most people rarely engage in such conversations:

- In a survey of nationally representative Americans ages 18+ published in 2013, 90 percent of Americans believe talking with family about wishes at the end of life is important, but fewer than 30 percent have done so.¹
- According to a California Health Care Foundation survey conducted in 2011, 82 percent of Californians said it is important to put their end-of-life wishes in writing, but only 23 percent had actually done it.²
- In that same survey, nearly 80 percent indicated that they definitely or probably would want to talk with a doctor about end-of-life care, but only 7 percent had had such a conversation.³
- The 2017 End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions found 90 percent of those surveyed thought conversations regarding end-of-life treatments were important. However, only 41 percent of respondents within five upstate New York regions (39 counties) have a designated Health Care Proxy.⁴

¹ The Conversation Project. (2013) ([The first national survey on end-of-life conversations is released](#)).

² California Health Care Foundation. (2012, February) ([Final chapter: Californians’ attitudes and experiences with death and dying](#)).

³ *Ibid*

⁴ Excellus BlueCross BlueShield. (2017) ([End-of-life care survey of upstate New Yorkers: Advance care planning values and actions](#)).

Introduction

Despite modern-day advances in medical treatment, everyone eventually faces the end of their life. For some, death is sudden and cannot be planned for in any significant way. For most others, death may come as a result of a serious illness or advanced age and can be anticipated. In these cases, individuals and their families have an opportunity to contemplate their end-of-life wishes for medical care and support.

Research presented in the Institute of Medicine's (IOM) 2014 report "Dying in America" found that patients have two consistent concerns about care near the end of life—the cost of care and being a burden on their families.⁵ While Americans generally affirm the value of discussing end-of-life wishes with loved ones, the number of individuals who actually do have such conversations with their family remains relatively low.⁶

Most people near the end of life lack the ability to make their own decisions. A majority of patients will receive their care during a hospitalization and afterwards in post-acute or long-term care from physicians who do not know them.

Advance care planning supports guidance of medical care in the event a patient is incapacitated and unable to actively participate in decision-making.⁷ This planning process includes learning about the types of treatment decisions that may need to be made, considering those decisions ahead of time and making those preferences known.⁸ The results of such care planning are often formalized in an advance directive, which is a legal document (such as a health care proxy or durable attorney for health care) that states the kinds of medical care a person does or does not want under certain specific conditions. Advance directives also typically identify a family member or friend to act as an advocate (or health care proxy), making decisions on behalf of the individual should they become incapacitated.⁹

The IOM report "Dying in America" encourages states in the U.S. "to develop and implement a Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in accordance with nationally standardized core requirements."¹⁰ The POLST paradigm is for patients with serious illness or frailty whose physician or nurse practitioner would not be surprised if they died within a year. For these patients, their current health status and prognosis indicates the need for standing medical orders that may be changed based on changes in patient goals for care, health status or prognosis.¹¹ These patients may work with their physician or health care professional to translate their end-of-life wishes into a

⁵ Institute of Medicine. (2014). Dying in America: Improving quality and honoring individual preferences near the end of life.

⁶ The Conversation Project. (2013). [The first national survey on end-of-life conversations is released.](#)

⁷ [National Hospice and Palliative Care Organization.](#)

⁸ National Institute on Aging, National Institutes of Health. (2016, August). [What is advance care planning?](#)

⁹ [US National Library of Medicine, MedlinePlus.](#)

¹⁰ Institute of Medicine. (2014). Dying in America: Improving quality and honoring individual preferences near the end of life.

¹¹ The National POLST Paradigm. [About the National POLST Paradigm.](#)

medical document by completing a *Physician Orders for Life-Sustaining Treatment (POLST)* form. The POLST form is a portable medical order designed to support patients transitioning between facilities or who live outside a facility by communicating patient treatment wishes. Medical decision making is often time-critical in medical emergencies. The [voluntary POLST form](#) serves as an immediately available and recognizable order set in a standardized format to aid emergency personnel in honoring the patient’s treatment wishes. As the form is generated after a shared-decision making conversation between the patient and their health care professional, the [POLST](#) reflects that person’s values, beliefs, and goals for care.¹² A POLST can clarify the patient’s wishes regarding specific interventions in certain situations, thereby removing the burden of decision making from both family members and health care providers.¹³

The National POLST Paradigm created the following chart (Table 1) to help consumers understand the differences between advance directives and POLST forms.

Table 1: Differences between Advance Directives and POLST Documentation¹⁴

	POLST	Advance Directives
Type of Document	Medical Order	Legal Document
Who Completes the Document	Qualified Health care professional (which health care professional can sign varies by state)	Individual
Who Should Have One	Any seriously ill or frail individual (regardless of age) whose health care professional would not be surprised if he/she died in the year	All competent adults
What Document Communicates	Specific medical orders	General treatment wishes
Can this Document Appoint a Surrogate Decision-Maker?	No	Yes
Surrogate Decision-Maker Role	Can engage in discussion and update or void form if patient lacks capacity	Cannot complete
Can Emergency Personnel Follow this Document?	Yes	No
Ease in Locating / Portability	Patient has copy a, a copy is in patient’s medical record. A copy may be in a state	No set location. Individuals must make sure surrogates have most recent version and

¹² The National POLST Paradigm.

¹³ Institute of Medicine. (2014). Dying in America: Improving quality and honoring individual preferences near the end of life.

¹⁴ [The National POLST Paradigm](#).

	POLST	Advance Directives
Ease in Locating / Portability cont.	registry (if the state has one).	are encouraged to share a copy with their health care professional.
Periodic Review	Health care professional responsible for reviewing with patient or surrogate.	Patient is responsible for periodically reviewing.

Although the use of POLST forms is becoming more common, the development of POLST registries (either paper-based or electronic) is still relatively new. Because individual states and regions implement POLST programs independently, there are differences in how they are designed, managed and executed. For example, the nomenclature can vary across programs that elect to use terms beyond POLST, including Medical Orders for Life-Sustaining Treatment (MOLST), Medical Orders for Scope of Treatment (MOST), and Physician Orders for Scope of Treatment (POST). The POLST forms vary based on individual state needs and regulations and are therefore state-specific.

The National POLST Paradigm embodies and promotes the essential elements of a POLST Paradigm Program¹⁵ (See Appendix C for more information). Programs may use the term “POLST” or a similar term but they do not represent the fundamentals of the POLST Paradigm until they have been endorsed by the National POLST Paradigm.¹⁶ As recognized by the National POLST Paradigm¹⁷ at the time of this report, two states have developed mature POLST programs (these programs are actively gathering data quality for quality assurance and have considered centralized POLST Paradigm databases), 22 states have National POLST Paradigm -endorsed programs, and an additional 24 states are considered developing programs and are in various stages of implementation. Four states have non-conforming POLST programs and one state has separated from the National POLST organization though it had implemented a mature POLST program.¹⁸ (See Appendix A for a list of states by The National POLST Paradigm with POLST programs by stage of development).

How Do Health Care Providers Access POLST Registries?

To truly benefit the patient and be useful, POLST forms must be accessible to all potential health care providers managing the patient’s care, including emergency medical services (EMS), long-term and post-acute care (LTPAC), physician offices, home health services, assisted living facilities, palliative care, hospice and emergency department (ED) personnel. As POLST orders must be immediately available when and where providers need to make emergency treatment decisions, this document focuses mainly on POLST form access and use by emergency care providers.

Paper POLST form use has increased due to efforts from existing state programs, the National POLST Paradigm, and other community advocacy groups. For patients at home, the patient, their family member or caregiver are responsible for keeping the original copy of the paper POLST form and

¹⁵ The National POLST Paradigm. [About the National POLST Paradigm](#).

¹⁶ *Ibid.*

¹⁷ *Ibid.*

¹⁸ The National POLST Paradigm. (2018, April).

providing it to EMS. For patients in LTPAC or hospital facilities, the original POLST form must travel with the patient and a copy is typically maintained in the medical record. In some cases, paper POLST forms are not readily available, may become lost during transport of the patient from home to the hospital or may not be included during discharge/transfer from LTPAC facilities or hospitals.

POLST forms need to be current, accurate, and rapidly accessible to be helpful in an emergent situation. To provide centralized and faster access, some states have adopted registries where POLST forms can be filed and referenced by physicians and emergency care providers. Although the completion of a POLST is voluntary, as use of POLST becomes more widely adopted, these registries can grow and become increasingly valuable to practitioners and patients. HIE organizations can play a central role in facilitating the necessary immediate access to this information.

Several states have been developing electronic POLST registries to enable EMS providers to have view-only access to POLST forms. Some states are implementing bidirectional functionality to enable submission of completed POLST forms digitally from an electronic health record (EHR) system to the electronic POLST registry. Each state has taken a slightly different approach to POLST registry implementation. Table 2 provides an overview of the approaches used. Some states provide access to POLST forms through web portals. Others enable emergency care and hospital personnel to access the POLST forms in the state POLST registry either from directly within the EMS Electronic Patient Care Record (ePCR) system or from a hospital's or LTPAC facility's EHR system. Others allow all providers access to the POLST registry by integrating it with a local or state HIE organization. Each approach has different implementation benefits and challenges. Appendix B contains detailed profiles for the POLST registries and implementation experiences in California, New York, Oregon, and West Virginia.²⁰

Health Information Exchange Organization

An entity that oversees or facilitates the secure and timely exchange of health information among a diverse group of stakeholders within and across regions, according to nationally recognized standards.¹⁹

Table 2: Electronic Provider Access to POLST Registries: Characteristics of Different Approaches

POLST Registry Access Approach	Benefits	Challenges
Web-Portal Access	<ul style="list-style-type: none"> Requires only an internet connection Potentially requires less IT resources/investment that would be needed to integrate distinct data systems Accessible wherever the patient is, and is not dependent on EHRs 	<ul style="list-style-type: none"> Requires an internet connection (may be a challenge in rural areas) May require an additional login if the systems are not integrated as single sign on Use of a separate system may require more time and effort to integrate into emergency care provider workflow

¹⁹ ONC. Health information exchange and behavioral health care: What is it and how is it useful?

²⁰ At the time of the initial draft report in 2016, these states were identified by subject matter experts and others as moving towards electronic availability of POLST documents.

POLST Registry Access Approach	Benefits	Challenges
ePCR/EHR Integration	<ul style="list-style-type: none"> Ease of integration for communities that have one or two dominant EMS ePCR or health system EHR vendors 	<ul style="list-style-type: none"> Requires coordination and funding to establish registry connections from registry to each ePCR or EHR Requires point-to-point integration with each ePCR or EHR
HIE Integration	<ul style="list-style-type: none"> Minimizes interfaces and connections for communities with stable and operational HIE organization 	<ul style="list-style-type: none"> Dependent upon maturity of the HIE organization Requires EMS ePCR and EHR vendors to have capabilities and functionality required to integrate with HIE organization

How Are Communities Implementing Electronic Access to POLST Documents?

Table 3 provides a brief overview of how programs in four states have implemented electronic access to POLST forms through registries.

Table 3. Profiles of States Using Electronic POLST Registries

	California	New York	Oregon	West Virginia
Start Year of POLST Registry	2017	2011	2009	2009
Organization Managing Electronic Access to POLST Registry	<i>California Emergency Medical Service Authority (EMSA)</i>	<i>Excellus BlueCross BlueShield, a not-for-profit insurer in upstate New York</i>	<i>Oregon Health & Science University Department of Emergency Medicine through a contract with Oregon Health Authority</i>	<i>West Virginia Center for End-of-Life Care, a program funded by the West Virginia Department of Health & Human Resources</i>
Method to Access POLST Registry	EHR and ePCR integration with optional web-based portal for upload; back-up call center for EMS; bidirectional transmission available; HIE integration in one county	Web-based portal with optional EHR and HIE integration; bidirectional transmission available	Web-based portal and call center-based system, bidirectional transmission available, HIE integration complete	Began with web-based portal, currently accessed through fax only

	California	New York	Oregon	West Virginia
Funding Source(s)	Philanthropy: <i>The California Health Care Foundation</i>	A New York State grant provided seed funding; <i>Excellus BlueCross BlueShield</i> provides full support	Oregon Government	West Virginia Government until 2018, then WV University Health Services
Number of Counties Participating	2 of 58 counties	All 62 counties	All 36 counties	All 55 counties

These states also identified lessons learned and best practices around developing POLST registries to share with other communities considering implementing electronic access to POLST forms. State information in this report is current as of May 2018. We encourage readers to reach out to states for the most current information available on their projects, visit www.polst.org/technology, or go to www.polst.org/map and click on the state for the appropriate contact information.

Emerging Success Factors from the Field to Establishing Electronic Access to POLST Documents

The following are a list of emerging success factors identified by the states and communities in Appendix B to establishing electronic access to POLST documents. Communities interested in community access to current and legally valid POLST documentation may want to reference some of the critical success factors when working to provide hospitals, EMS, LTPAC, and other emergency health care providers with access to POLST forms. Interested communities or facilities are encouraged to connect with their state POLST Program when starting this process.

Precursors to POLST Registry Success

Promote Engagement between POLST Program Leaders and a Physician

Active engagement between state POLST program leadership and physician champions leads to a strong, unified voice to promote the POLST agenda. Having a physician leader and EMS staff involved in communicating the value of POLST conversations and documentation is essential to public understanding and acceptance of POLST as a way to improve the quality of end-of-life care and reduce unnecessary, unwanted care. Obtaining a POLST form is tied into a conversation with a health care professional. It is not a decision that can be completed independently from a physician, such as organ donation. Health care providers need to be actively encouraged to initiate these conversations and are often more receptive to persuasion from physician leadership.

Focus on the Emergency Provider Audience for Electronic POLST Registry Adoption

Based upon discussions with the states listed in Appendix A, EMS and LTPAC providers appear to be the primary users of electronic POLST registries, although ED staff use is rising. EMS and LTPAC provider adoption should be the primary focus of a registry rollout, since these providers must make quick decisions about care.

Higher Volumes of POLST Forms Prior to Promoting Provider Access Promote Registry Success

A robust database of completed POLST forms is a common precursor to the success of an electronic POLST registry. Registries that contain a large volume of POLST forms allow for better results when a provider searches for a patient's record. If there are not enough POLST forms in the registry, emergency care providers will discontinue accessing the registry when they repeatedly cannot locate any POLST information during emergency patient care. In the past, states that have developed registries with a "build it and they will come" approach have fallen short of meeting provider adoption goals. Even the best designed registry is not useful without a significant POLST form data set. In some cases, providers needed to use a paper POLST form to initiate the conversation between the provider and the patient and established the provider workflow.

POLST Registry Implementation Considerations

Ensure POLST Registry Technology and Workflows Meet Provider Needs

Several states that have had success with widespread adoption of registries focused on the needs of EMS and LTPAC providers in their initial pilot efforts, ensuring access methods met their workflow needs. These states worked to engage providers from EMS and LTPAC in the process to help consider how to best address errors, timeliness and updates in the workflow process. The states stressed the need to integrate the registry technology and processes to access patient POLST forms electronically with existing workflows for EMS, LTPAC and ED providers. States noted that if these providers cannot easily access the POLST forms from the registry, they will probably not use it. For example, workflows should consider integrating single sign-on (SSO) functionality into the ePCR or EHR systems, as it reduces the burden of multiple system logins for providers and saves time which is critical in a medical crisis.

Educate Both the Community and Health Care Providers

Both health care providers and the public should be aware of the importance of having an up-to-date advance directive and POLST form for seriously ill and frail patients (these two documents should be consistent in supporting the same type of treatments). Community health care leaders must continuously promote the value of advance directives and POLST to families to ensure there is an identified surrogate and that their loved ones receive the treatment they want.

Funding and Sustainability

Ensure Adequate and Sustained Funding for Both Technology and Education

Technology development and refinement can be expensive, but it is just one aspect of implementing an electronic POLST registry. Continuous community outreach and education as well as sustainable physician and clinician training to ensure shared decision making that is well informed are also very important and require significant and sustained funding. Organizations must budget for and secure adequate funding to fulfill present and future needs.

Consider State & Local Level Outreach

Outreach mechanisms at the state and local level may have resources available to raise awareness around health care professional submission of POLST forms to a state registry and can be an important tool in adopting widespread paper and electronic access to POLST forms. Such support can add legitimacy to outreach efforts, encourage physician adoption and provide sources for long-term financial sustainability.

Development of Electronic Access to POLST Registries

For a POLST registry to be successful, counties, communities and states may want to strive for widespread adoption of POLST forms to ensure all individuals at the end stages of life have discussed and documented their preferred treatment wishes with their health care provider. At the same time communities should also begin exploring how best to provide providers with access to registries. Access methodology may change over time as technology improves and human interactions with technology become more comfortable and normalized. States interested in starting or expanding their existing POLST programs to include electronic access to POLST registries can learn from robust programs in other states.

States and communities interested in identifying potential funding sources can now explore how Health Information Technology for Economic and Clinical Health funds can support POLST registry development. The Centers for Medicare & Medicaid Services (CMS) [State Medicaid Director's Letter 16-003](#) updates guidance on the availability of CMS 90/10 funding that may be used to support POLST registry development and integration with HIE organizations. Letter 16-003 expands the scope of expenditures eligible for the 90-percent matching rate and supports the goals of "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Version 1.0,"²¹ published by the Office of the National Coordinator for Health Information Technology (ONC) on October 6, 2015 (See Appendix C for more information). State end-of-life care advocacy groups should consider working with State Medicaid Directors to apply for CMS 90/10 funding to pilot POLST registries and achieve Promoting Interoperability (formerly known as Meaningful Use) objectives.

²¹ ONC. [Connecting health and care for the nation: A shared nationwide interoperability roadmap](#).

Appendix A: Current POLST/MOLST Programs Stages of Development by State

Source: The National POLST Paradigm as of April 2018²²

Program Type	Description
<p>Mature Programs = 2</p> <p>California West Virginia Oregon²³</p>	<p>Used by 50% or more hospitals, nursing homes or nursing home resident population and hospices. These programs are actively gathering quality assurance programs and have considered or implemented centralized databases or registries.</p>
<p>Endorsed Programs = 22</p> <p>(includes Mature Program States) California, Colorado, Georgia, Hawaii, Idaho, Indiana, Iowa, Kansas, Louisiana, Maine, Missouri, Montana, New Hampshire, New York, North Carolina, Oregon, Pennsylvania, Tennessee, Utah, Virginia, Washington, West Virginia (La Crosse Region only)</p>	<p>States that have implemented POLST programs that meet The National POLST Paradigm standards, have become standard components of advance care planning in the community and have developed strategies for ongoing implementation and quality assurance.</p>
<p>Developing Programs = 24</p> <p>Alabama, Alaska, Arizona, Arkansas, Connecticut, Delaware, Florida, Illinois, , Kentucky, Michigan, Minnesota, Mississippi, New Jersey, New Mexico, Nevada, North Dakota, Ohio, Oklahoma, Rhode Island, South Dakota, South Carolina, Texas, Wisconsin, Wyoming</p>	<p>States that are in the process of developing a POLST program, ranging from initial design of the POLST form to active use of POLST forms statewide. POLST programs in this phase are evaluating and addressing sustainability strategies.</p>
<p>Non-Conforming Programs = 4</p> <p>Maryland, Massachusetts, Vermont, Nebraska</p>	<p>States that have developed POLST-like programs that are not in alignment with, or have not yet met The National POLST Paradigm requirements based on implementation, development of the form, or for legislative reasons.</p>
<p>Exploring or Planning Programs = 1</p> <p>District of Columbia</p>	<p>In the initial planning stages, or have not yet begun development of a POLST program.</p>

²² [The National POLST Paradigm](#). (2018, April).

²³ Oregon separated from the National POLST organization in June of 2017; Oregon confirms that they exceed the Mature Program requirements.

Appendix B: Community POLST Profiles

CALIFORNIA

Background

The California POLST form and program were introduced in 2008 through California state legislation. POLST is in widespread use in California. The key challenge that California has encountered has been making sure that the paper POLST form consistently travels with patients as they interact at various points with the health care system, including during emergency care.

The California State Legislature passed [Senate Bill 19 \(SB-19\)](#) on October 15, 2015, to establish a pilot test of a POLST registry. SB-19 supports development of a pilot POLST eRegistry to help identify the requirements for EMS, long-term care and hospital workflows necessary to establish a permanent operational statewide electronic POLST registry. SB-19 identifies the California Emergency Medical Service Authority (EMSA) as the entity responsible for implementing the POLST form throughout the state. Other POLST registry projects in states that did not have a mandate to submit forms to the registry found that their submission rates were low.

The pilot project is coordinated by the [Coalition for Compassionate Care of California](#) (CCCC) and the California EMSA. SB-19 requires use of non-state funds to develop the POLST eRegistry pilot and evaluate its effectiveness. The California Health Care Foundation (CHCF) provided \$3 million to support the pilot efforts and is an advisor in the implementation effort. The legislation sunsets January 1, 2020. The pilot's three phases include:

- **Phase 1: Technology and Workflow Development (January 2016-December 2016).** Stand up the registry technical platform, select pilot sites and prepare for pilot implementation.
- **Phase 2: Testing (January 2017-December 2018).** Conduct testing and refine workflows; conduct independent evaluation to identify benefits, outcomes and POLST data trends.
- **Phase 3: Evaluation and Planning (June 2018-February 2019).** Complete independent evaluation and planning for how to broaden electronic access to POLST forms statewide sustainably.

In January 2016, CHCF established an advisory group to help plan and implement the POLST pilots. The advisory group included representatives from California EMSA, CCCC, CHCF, project management and IT consultants. This group participated in the development of the Request for Proposal for a technology vendor, identifying an appropriate independent evaluator and selecting the two pilot sites. Two initial communities, Contra Costa County (no HIE organization) and San Diego (mature HIE organization), are participating in the POLST eRegistry pilot.

Key Features

San Diego Health Connect (SDHC) has contracted with Stella Technology as the vendor to implement an electronic POLST registry that integrates directly with SDHC's health information exchange²⁴. The Contra Costa County pilot uses Vynca as the technology vendor.

For areas participating in the pilot study, the California legislation makes it mandatory for providers to submit POLST forms to the state registry. POLST forms are scanned and uploaded into the registries at both San Diego and Contra Costa County pilot sites, or optionally may be completed electronically within the EHR in Contra Costa County. San Diego and Contra Costa County work with their technology vendors to ensure basic information is populated in the forms, and the forms are matched with patient demographics in EHRs where available. Health providers in the emergency department, acute care, EMS, and skilled nursing facility settings access forms through their EHR/ePCR, displaying an indicator should a POLST form exist when a patient record is pulled up. In San Diego health providers use the access established through the HIE, including integration with EHRs and ePCRs. Optionally, providers may also upload scanned paper forms through a web-based portal. Registries at both pilot sites allow access to providers only; neither registry has access for patients to upload or use POLST forms.

Current Activities

Connectivity has been established and tested at both Contra Costa County and San Diego pilot sites. POLST forms and other related data are being collected electronically. Data collection for the pilots end at the end of 2018.

In Contra Costa County, EMS access to the POLST database has completed functionality testing. As of April 2018, it is not yet open for widespread EMS access. The EMS in San Diego currently accesses the HIE through an existing system with which the POLST registry has been integrated, therefore no additional testing is required. When a patient's record is viewed, EMS will be able to determine if a POLST form is available. A back-up call center is available to EMS should connectivity at the patient location not be available.

Challenges

A major issue encountered is prioritization of POLST registry workflow by health systems. Establishing a registry and seamlessly connecting to health systems will foster adoption. The pilot may make recommendations for a fully-integrated or state-wide registry upon completion.

Funding

The California POLST pilots conclude on December 31, 2018. However, evaluations will continue through February 2019. Once the pilots are completed, the funding for both pilot sites will cease as well, but sites plan to continue independently contingent on development of alternative funding sources.

²⁴ CHCF to Fund Pilot Project to Develop an Electronic POLST Registry in California, [San Diego and Contra Costa Counties to be pilot site locations](#), July 29, 2016.

Evaluation

A critical part of the California POLST eRegistry pilot is the evaluation process. The evaluation team will evaluate whether the POLST pilots achieved the goal of providing access to POLST documentation for patients with serious illnesses and/or end-of-life patients. The evaluation will also include details on how nursing homes used the POLST forms and how EDs received and incorporated electronic POLST forms into the patient's EHR. To evaluate the POLST eRegistry, California will:

- Assess the volume of forms that go into the registry at each pilot site.
- Identify the number of forms that were “registry ready” and did not require corrections.
- Identify the numbers and types of providers submitting POLST forms to the eRegistry (e.g., general geriatric, hospice, long-term care, social worker, hospital providers) as well as any trend data.
- Determine the number of community educational sessions, EMS provider and ED provider trainings conducted.
- Identify additional metrics to help determine success factors.

Currently each pilot site provides data (e.g., access, information flow, EMS usage) to contribute to the evaluation and reporting at the conclusion of the pilot. In addition to this information, the evaluation report will provide recommendations, best practices, guidelines, and funding options for implementing a community POLST registry.

Contact Information:

Priscilla Rivera, Manager Standards Unit
EMS Authority
Priscilla.rivera@emsa.ca.gov, 916-431-3707

NEW YORK

Background

The MOLST program began as a community initiative in Rochester to improve end-of-life care in 2001. The Community Conversations on Compassionate Care program was launched in 2002 to support New York MOLST as part of the community initiative. The program supports early advance care planning discussions and completion of advance directives, particularly health care proxies, for everyone 18 years of age and older. After working from 2001 to 2003 on the creation of the Medical Orders for Life-Sustaining Treatment (MOLST) form and program, MOLST was launched in the Greater Rochester Region in 2004, followed quickly by adoption in Syracuse and the surrounding area. The New York State Department of Health (NYSDOH) approved use of MOLST in all health care facilities in 2005, prompting use in all counties. In order to permit EMS to use a MOLST to follow Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders in the community, legislation was required to modify New York State Public Health Law (NYSPL). After a successful community pilot (2005-2008), NYSDOH approved MOLST for statewide use in all settings in 2008. MOLST became a NYSDOH form in 2010. The MOLST form is the only form approved by NYSDOH for both DNR and DNI orders and is now in statute. NYSDOH directs all health care providers to follow MOLST orders in all settings, including the community.²⁵ New York was one of the first states to adopt a POLST or MOLST program and is a founding member of the National POLST Paradigm.

New York's [eMOLST system](#) incorporates MOLST form completion and documentation of a standardized communication process, including patient health status, prognosis, goals for care and the ethical-legal requirements while also serving as the registry of MOLST forms for New York State. The eMOLST system allows physicians and nurse practitioners to create a set of medical orders that accurately defines which life-sustaining treatment the patient wants to receive or avoid. Other health care professionals can participate within scope of practice. eMOLST allows providers to print forms to include with paper records. Health systems can also electronically integrate eMOLST with an EHR. The system allows physicians to sign MOLST orders electronically. The process-oriented nature of eMOLST ensures accuracy and consistency to achieve the triple aim of quality, patient safety, and harm reduction. eMOLST provides 24/7 access to forms for any credentialed provider who wishes to access the system. eMOLST caters to providers interested in improving clinical outcomes, legal outcomes and provider satisfaction and meets the needs for a systems-based solution for health systems.

New York's eMOLST program is a secure web-based application that allows physicians to complete an electronic MOLST form, print the form to provide a paper copy to the patient, store the form in electronic format in the provider's EHR and automatically include the eMOLST form in the New York state registry for access from other clinical settings.

The original eMOLST program began in 2008 with seed money from a health information technology Health Care Efficiency and Affordability Law (HEAL) grant secured by the Rochester Regional Health Information Organization (RRHIO). In collaboration with the RRHIO, Excellus BlueCross BlueShield (EBCBS) led a clinician planning group to develop the initial design of an electronic MOLST web-based completion system and registry. In 2010, New York implemented a significant change in public health

²⁵ Bomba, P.A. Honoring patient preferences: [The role of MOLST medical orders for life-sustaining treatment in advance care planning](#). Excellus BlueCross BlueShield.

law to allow surrogates to make end-of-life decisions when a health care agent was not named or was not available. The MOLST form was revised as a plain language form and became a NYSDOH form. NYSDOH, together with the Office for People with Development Disabilities (OPWDD), created seven checklists²⁶ to ensure that the quality of the process and the ethical-legal framework for end-of-life decisions (this framework is required for any order to withhold/withdraw life-sustaining treatment in New York and is not specific to MOLST), was followed. These changes required significant modification of eMOLST.

In 2011, Dr. Pat Bomba, eMOLST Program Director, and Katie Orem, M.P.H., eMOLST Administrator, both employed at EBCBS, conducted site visits with physicians and other representatives from long-term care facilities, hospitals, hospices and EMS to understand the best methods to promote eMOLST adoption as part of their general practice. Based on clinician feedback, eMOLST was revised to include the 8-Step Protocol,²⁷ the NYSDOH and OPWDD Checklists. By following the protocol and checklists, practitioners can complete the NYSDOH eMOLST form and the appropriate MOLST Chart Documentation Form and file them with the registry.

As a result, physicians and clinicians in all settings that utilize eMOLST have instant access to the most current eMOLST form as well as a copy of the discussion that preceded completion of the forms in all settings. As the patient's health status, prognosis and goals change over time, or at the time of a care transition, or if the patient changes their mind, providers can quickly and easily update the eMOLST form. The system is designed to ensure that the most recent eMOLST form is always easily accessible to providers; updates to a patient's eMOLST form voids any previous documents, although the older forms are retained in the registry.

The original plan was to build and implement eMOLST in the region served by RRHIO and then replicate the implementation in other counties. With the growing interest outside the RRHIO service area, the RRHIO and EBCBS decided to work with early adopters of eMOLST and implement the program statewide. As of 2013, eMOLST has been available to providers from all counties across New York. The eMOLST team solicits ongoing feedback from users about the functionality of the website, including feedback about the ease of online process to complete the eMOLST form. The process is designed from a clinician's standpoint, with regard to the communication with the patient. The eMOLST team has also enhanced the system to include clinical workflow tools, which ensure the eMOLST form and documentation are available and shared easily among multiple providers in support of an individual patient treated and followed by multiple physicians and other clinicians. The application also includes rich administrative reporting capabilities that provide access to operational and use statistics. The current eMOLST system continues to be enhanced based on user feedback.

The eMOLST program is more than just a registry. The online completion system supports a standardized clinical process and provides the ethical and legal framework to document personal values, beliefs and goals for care that drive choices around life-sustaining treatment and patient wishes regarding care to receive and/or avoid. eMOLST includes embedded educational links and videos that physicians and other clinicians can use as part of the discussion. Quality assurance is built in with

²⁶ New York State Department of Health. (2013, May). Medical orders for life-sustaining treatment.

²⁷ Compassion and Support at the End of Life. (2011, March). Medical orders for life-sustaining treatment (MOLST): 8-step MOLST protocol.

logic-based coding to ensure an eMOLST form created on the website is completed with 100 percent accuracy.

The eMOLST team consults with health systems on integration of eMOLST access into EHRs. Options for system integration include Security Assertion Markup Language (SAML)-based single sign-on (SSO) with or without patient context. Web services API have been implemented that allow organizations such as Regional Health Information Organizations (RHIOs) or health systems to pull eMOLST documents and specific orders into their patient record. eMOLST is offering RESTful web services to provide access to current forms, orders and other information directly to other health systems. These features can be used to enrich the experience in the EHR by indicating that a patient has a MOLST form and offering the capability to both navigate directly to the patient's record in the eMOLST registry or to show medical orders and the entire form inside the EHR itself.

Key Features

eMOLST includes a nationally recommended approach for making end-of-life decisions; these ethical standards are also incorporated into NYPHL, which is different from other states' POLST programs.²⁸ The 8-Step MOLST Protocol was developed in 2005 to support a standardized approach to completion of the paper MOLST. The Protocol was revised in 2011 to comply with new NYSPHL. New York's MOLST form is reviewed annually with the NYSDOH and has been refined over the past decade based on clinical use and feedback from physicians in all clinical settings, as well as EMS and ED providers based on the data they need most during an emergency. The first page of the eMOLST form documents resuscitation preferences in the event of a cardiac and/or pulmonary arrest (i.e., natural death); page two includes an explicit section on intubation and mechanical ventilation, the information most critical for EMS providers when a patient experiences acute cardiac and/or pulmonary insufficiency, as well as patient preferences for hospitalization. With the emergence of community paramedics, other portions of the MOLST form are gaining attention (e.g., preferences for artificial hydration and antibiotics).

Paper MOLST or POLST forms often have quality gaps and patient safety concerns associated with incomplete, erroneously completed or conflicting forms. By encouraging the transition from paper MOLST to eMOLST, New York is helping to eliminate these issues. The eMOLST form completion algorithm ensures that all forms are completed correctly and without conflict.

The eMOLST program has integrated with a variety of EHRs, enabling providers to see a patient's eMOLST status with a single click. The SAML-based SSO + patient context process instantly logs them in, gives them the correct level of access based on their clinical and administrative roles and searches the registry for the selected patient. If an exact match is found based on eMOLST number then the provider is taken directly to that record and the current eMOLST orders. If multiple matches are found the provider is offered pertinent information to decide which patient is theirs. RHIOs, HIEs and EHRs may store the unique eMOLST number in their own patient profiles to guarantee exact match and to utilize API features. One-click access has supported provider adoption and use. If a patient's form exists, the user can attest that they are treating the patient and immediately see both the eMOLST orders with the option to see additional, detailed information about patient goals as well as other legal and ethical documentation.

²⁸ Bomba, P.A., Kemp, M. & Black, J.S. (2012, July). POLST: An improvement over traditional advance directives. *Cleveland Clinic Journal of Medicine*, 79(7), 457-64.

eMOLST's SAML-based SSO + patient context is a tool for health systems and vendors to incorporate into their EHR. Numerous organizations — including hospitals, nursing homes and physician practices — have seen the value of using eMOLST even when they use paper charts or have an EHR but do not have high-level electronic integration.

Current Activities

Funding & Sustainability

HEAL NY Phase 5 — “Advancing Interoperability and Community-wide EHR Adoption in New York State” grant funding enabled the eMOLST program to become operational. Current funding for New York’s MOLST and eMOLST programs is from Excellus BlueCross BlueShield, a not-for-profit health insurer in upstate New York. Part of their mission to improve the health of the members and the communities they serve. Excellus BlueCross BlueShield views the eMOLST program as a public health initiative.

New York’s has effectively implemented MOLST and eMOLST programs. Successful implementation requires a multidimensional approach. Sustainability of the efforts is a key activity of New York’s program director. To be successful, eMOLST implementation must also be coupled with ongoing clinician training and public education.²⁹ A successful program requires:

- Culture change
- Professional training of physicians, clinicians and other professionals
- Public advance care planning education, engagement and empowerment
- Thoughtful discussions and shared, informed medical decision-making
- Care planning that supports MOLST
- System implementation, policies and procedures and clinician-friendly workflow
- Dedicated system and physician champions

In the future, a sustainable payment stream may be based on improved compliance with person-centered goals, preferences for care and treatment, as measured by improved patient/family satisfaction and reduced unwanted hospitalizations.

Legislation

The eMOLST team is deeply involved in the legislative process, playing a major role in creating and drafting relevant legislation. In the current 2018 legislative session, Bill A9063 proposes changes to public health law so that the words “Medical Orders for Life-Sustaining Treatment (MOLST)” will exist in public health law. The bill also establishes the eMOLST registry in statute. This bill would require practitioners who complete a MOLST form to submit it to the eMOLST registry within 14 days. In addition, A9063 would require the department of health to create a health care proxy registry. In addition, new legislation going into effect May 28, 2018 allows nurse practitioners to more fully participate in the process and sign medical orders to withhold/withdraw life-sustaining treatment under a number of scenarios. New legislation will necessitate updates to not only the MOLST form, DOH

²⁹ Bomba, P.A. & Karmel, J.B. (2015). Medical, ethical and legal obligations to honor individual preferences near the end of life. *Health Law Journal*, 20(2), 28-33.

Checklists and supporting implementation tools and resources, but also the eMOLST system. The New York eMOLST system is nimble enough to accommodate such changes quickly as well as incorporate the necessary education.

Integration With EHRs and RHIOs

The eMOLST team consults with EMS agencies and health systems on integration of data from the eMOLST registry into ePCRs/EHRs. eMOLST will ultimately serve as the data source and registry for the Statewide Health Information Network for New York (SHIN-NY), similar to the organ donor and immunization registries. SSO is available with several RHIOs. Newer integrations are focused on web services that allow organizations such as EMS, RHIOs and health systems to pull eMOLST documents and specific orders into their patient record. EHRs have querying capabilities into the system, while RHIOs and HIE also perform patient matching using the registry. eMOLST is offering RESTful web services to provide access to current forms, orders and other information directly with other health systems. These can be used to enrich the experience in ePCR/EHR by indicating that a patient has a MOLST form and offering the capability to both navigate directly to the patient's record in the eMOLST registry or to show medical orders and the entire form inside the ePCR/EHR itself. As new interfaces are developed, the new functionality is shared with systems ready and able to adopt.

Physician Payment for MOLST Conversations

In 2009, Excellus BlueCross BlueShield was the first health plan in the country to develop a reimbursement model for trained providers (physicians, nurse practitioners and physician assistants) to have MOLST conversations within their scope of practice. The health plan utilized existing current procedural terminology (CPT) codes and implemented a time-based program for providers to bill for MOLST discussions and documentation for all appropriate members, for all lines of business and in all sites of service. Inclusion as a provider allowed to bill for these discussions was tied to specialty qualifications in hospice and palliative medicine or having completed training provided by the New York MOLST program. New York was able to quickly demonstrate the value of eMOLST to both physicians and their patients, which helped adoption. The model was cited in the IOM Report "[Dying in America](#)" and by multiple media outlets preceding CMS' endorsement of reimbursement for advance care planning. In January 2016, the model was discontinued and replaced with the new CMS-approved CPT codes for advance care planning discussions that include MOLST.

Challenges

One of the biggest challenges in New York was ensuring all stakeholders were on board with and ready for electronic registry implementation. Clinical care settings (prehospital, hospitals, nursing homes, hospices and physician practices) were in different stages of adoption of ePCRs and EHRs. Multiple EHRs existed and still exist in New York. Many health systems were in the midst of converting from one EHR to another. They faced a community where the nursing home wanted to implement MOLST, but the health systems were not ready and/or care settings did not have resources to support the program development. Currently there is no legislation mandating submission of completed MOLST forms to the eMOLST Registry in New York; clinicians have suggested that they would appreciate such legislation to encourage quicker adoption among health systems. The proposed legislation in the current legislative session is described above.

Success Factors

One critical success factor is the need for all parties to focus on partnership and collaboration. New York focused on partnering and coordinating with many state and local groups to engage the community and health care providers, to help educate them on the benefits of eMOLST and to support their provider education and adoption. Similarly, because New York does not have mandatory submission of these forms to the state registry, the team in New York has focused their efforts on partnering with high performing organizations that are prioritizing patient-centered care as these places are more likely to adopt eMOLST.

New York stressed the need for communities to realize that MOLST forms and registries are not static like advance directives that may not change for years. Medical orders may change over time based on the patient's health status at the time of care transition, if the patient's goals for care change or if the patient simply changes their mind. A successful program requires a standard process to ensure the MOLST form remains current as the patient's health status changes. Helping physicians and nurse practitioners understand the difference between advance directives and MOLST and encouraging them to revisit MOLST orders over time as end-of-life goals may change, is also a key success factor. States should not underestimate the need for ongoing education of staff at all levels to ensure that copies of any MOLST forms completed in the hospital are sent back to a patient's nursing home or return with the patient to their home. New York's electronic system allows the eMOLST form to be printed on pink paper at the time of discharge, while the current eMOLST information is always retained in the registry.

The eMOLST team reports that education is the key to adoption and has developed various tools for success including work plans with time lines and deliverables, provider training, workflow training, conferences, 'train the trainer' sessions, a hands-on eMOLST system exclusively for "training" use, as well as integration guides for EHRs, HIEs and RHIOs.

New York encourages other states in taking an active role in creating and drafting legislation and moving it forward in addition to implementation and integration efforts. New York has also recognized that patient privacy, data security and user accountability must be carefully considered to ensure a successful and smoothly functioning registry. States need to understand the protections and security framework that need to be in place to support, secure, and defend a registry.

Next Steps

New York has securely integrated the business intelligence tool, Tableau, with the eMOLST server. This will allow the team to build on the quality and accuracy of the data, make process improvements and determine education and training needs. If additional funding is secured, New York would like to have a patient portal that would educate patients on shared decision making and prepare them to have quality conversations with their providers.

Contact Information:

Patricia Bomba, M.D., FACP

Vice President and Medical Director, Geriatrics, Excellus BlueCross BlueShield; eMOLST Program Director
Patricia.Bomba@lifethc.com, 585-238-4514

Katie Orem, M.P.H.

Geriatrics and Palliative Care Program Manager, Excellus BlueCross BlueShield; eMOLST Administrator
Katie.Orem@excellus.com, 585-453-6306

OREGON

Background

The Oregon Health & Science University (OHSU) established a Center for Ethics and Health Care in 1989. The POLST Program started in Oregon with [OHSU Center for Ethics](#) serving as the administrative home. The initial development efforts began in 1991 when medical ethics leaders recognized that patient wishes for life-sustaining treatments were not being honored consistently despite the availability of advance directives. The [Oregon POLST Program](#) remains at OHSU. The National POLST Paradigm was administratively housed at OHSU from its inception in 2004 until January 20, 2017, at which time they became a 501(c)(3) under the Tides Foundation. The Oregon POLST Program separated from the National POLST Paradigm in June of 2017.

After years of extensive development and pilot testing, Oregon released its POLST form for statewide use in 1995. Use was adopted into clinical practice with regulatory changes but without legislation. In 2007, Oregon began planning to build a POLST registry. Given widespread use of the POLST forms, the registry was quickly set up and piloted in a single county that benefited from the high community penetration of POLST activity.

In 2009, the Oregon POLST program worked with the state legislature to create the Oregon POLST Registry. The legislation contained the mandate for any physician, nurse practitioner, physician assistant or naturopathic physician (as of 2018) in the state who signs a POLST to submit a copy of the completed form to the registry, unless a patient specifically opts out of POLST registry participation. The Registry was legislatively mandated by the passing of House Bill 2009, and is operated at OHSU through a contract with the Oregon Health Authority. The Registry remains administratively distinct from the Oregon POLST Program.

For more information about the Oregon POLST program, please see the [Oregon POLST](#) website. The website includes a detailed history of the Oregon POLST program as well as the National POLST Paradigm's [Oregon POLST Fact Sheet](#). For additional information about the Oregon POLST Registry, please visit the [Oregon POLST Registry](#) website.

Key Features

The Oregon POLST Registry is a POLST-only electronic form repository. With legislative funding, OHSU was contracted by the Oregon Health Authority for statewide expansion in 2009. [House Bill 2009](#) funded the Registry and also required submission of signed forms by the signing health care professional or their designee unless a patient opts out of inclusion.

The registry functionality includes a three-step process: Validate, Enter and Activate. The validation step includes validating to make sure the form is registry ready (e.g., signed, dated, patient name, date of birth and orders) and all data fields are filled. Once validated, the form is scanned into the Registry, and data from the form are entered into the database. The final step is activation, where another staff member reviews all POLST information extracted and entered against the physical copy of the form.

The Oregon POLST Registry was built to be the backup system for the paper form completed by the physician with the patient and provided to the patient. Emergency personnel called to a patient's home or skilled nursing facility look for the paper POLST form. The system is designed to provide information

to EMS in the field and to be portable across all care settings. Once the patient arrives at the hospital, the patient's EHR also serves as a backup system and often has a copy of the patient's POLST form available. If the form is available in the field or in the hospital's EHR, there is no need to access the registry. Providers call the registry when they cannot locate a POLST form in their EHR system or in the patient's home.

Oregon uses its 24-hour Emergency Communication Center (ECC) for EMS providers to call via phone or radio to obtain POLST information. The ECC releases Sections A and B of the POLST form to medical providers in the field once the call center identifies a patient match. The matching process assigns points to different patient demographic information to ensure there is a correct match. There are two mechanisms for requesting forms: (1) use of a non-public phone number for emergent POLST requests from health care providers and (2) use of the ECC business office during normal business hours for non-urgent POLST requests.

EMS POLST inquiry calls to the ECC can be answered and resolved within one minute. The Oregon POLST Registry releases a [monthly report](#) on its website that shows the number and duration of these calls. Providers can also request the POLST form to be faxed to the receiving hospital, in cases where the patient is being transported. The ECC maintains a registered list of all active and validated hospital ED fax numbers used for POLST transmissions. They have received more than 7,000 calls in the first six years of operation, with an estimated 40 percent of calls resulting in patient match with a POLST form found.

Oregon designed its POLST system to integrate with EMS, EDs and acute care units. Integration with EHRs to enable hospital providers to easily see the patient's POLST orders with a single click from the patient header is functional. The ePOLST system is color coded to immediately notify the provider of the treatment level requested on the POLST form. Oregon found that physicians really like the single sign-on function. They want to be able to easily see, when they log on, if the POLST document is available and do not want to search the EHR for the document.

In 2013, OHSU enlisted the help of a software vendor to develop an EHR-embedded electronic POLST Completion System (ePOLST) that would support delivery of the hospital's POLST forms to the Registry and minimize errors using electronic business rules. OHSU evaluators tested the system with physicians, nurse practitioners, physician assistants, social workers and health information technology staff to iteratively provide feedback throughout the development process. System champions and evaluators reviewed the system and provided feedback on how it could be improved. The vendor and hospital provided extensive mandatory education for residents and fellows at OHSU about advance directives and POLST to support the implementation.

When an OHSU health care professional completes an ePOLST with a patient, it is automatically submitted to the state registry. This process reduces human error by eliminating a manual submission process and ensuring that all completed forms are submitted. The provider then downloads and prints the POLST form for the patient to take home, maintaining both paper and electronic forms. Patients also receive a confirmation packet from the Oregon POLST Registry, which includes a business card-sized pink magnet that has their unique registry identification number on it as well as stickers for chart placement or wallet placement.

In the ePOLST system, the health care provider can pull a significant amount of information from the EHR itself to complete the ePOLST form (e.g., name, birth date, address). The provider documents the patient's wishes in each section, adds any specific additional orders and then signs the ePOLST to complete.

ePOLST systems are now in use in several large Oregon hospitals and health systems and the Registry will continue to identify appropriate, secure mechanisms for transmitting and receiving electronic data. Oregon has a relatively small state population of just over 4 million people, which has allowed the state to develop a tight and easily maintained POLST program. Oregon benefitted from being able to leverage preexisting EMS workflows that required EMS staff to call into the existing and centralized statewide ECC. Integrating the POLST program into the existing EMS system was cost-efficient, minimizing operational overhead and required less funding and training than creating a new program and infrastructure.

Oregon highly advocates and stresses the need to design systems that easily locate the POLST (separately from advance directives) with a single click. Oregon attributes the widespread use and adoption of the Oregon POLST Registry (with over 250,000 forms submitted) largely due to the legislative mandate to submit all POLST forms to the registry. This requirement enabled the registry to amass a high volume of POLST forms. The Registry's success is also largely attributable to the fact that it was designed to meet the access and workflow needs of both EMS providers in the field and acute care providers.

Current Activities

In 2016, Oregon implemented one bi-directional ePOLST exchange with OHSU where the Registry is accessed through the EHR using web application programming interface (API) calls. OHSU receives data from the Registry via a third-party system that updates ePOLST. With state approval and support, Oregon has successfully implemented bi-directional access within EHRs where the EHR is connected to the Registry and the information from the Registry is available to the EHR in systems outside of OHSU. Currently, one vendor's ePOLST system can query the Oregon POLST Registry so that health care professionals can see POLST orders completed in any care setting that have been submitted to the Registry.

Oregon is collaborating with the Emergency Department Information Exchange (EDIE) to alert health care organizations of when a person has a POLST on record. As they expand HIE integration with the Emergency Department Information Exchange, every hospital in the state (except Veterans Administration (VA) hospitals) will have electronic identification of patients with forms registered in the POLST Registry, regardless of where they were completed, with forms provided at Emergency Department registration in near real-time.

Oregon has three mechanisms to access POLST forms: a 24/7 call center, API-based EHR bi-directional access, and the EDIE system. Acute care units, emergency departments, and hospitals are allowed access to the 24/7 call center, which remains the predominant method of requesting POLST forms. Over half (51%) of calls received at the call center are from emergency departments. The registry updated its system to allow entry of the newest Oregon POLST form in January of 2018.

Challenges

The development of ePOLST systems and increased awareness and training of health care professionals regarding advance planning documents has likely led to the significant increase in volume of POLST forms handled by the Registry. In 2017, the Registry received over 61,000 POLST forms, and is on track to process 65,000 forms in 2018. Validation of the forms is one of the most important and time-consuming processes for the Registry. About 20% of the forms submitted are non-registry-ready. The process for correcting POLST forms is a challenging, and exacerbated with increased volume. The Registry continues to send out POLST packets to patients to ensure information is updated.

Next Steps

One of the largest focus areas for the Oregon POLST registry is to manage the significant increase in volume. The team is revisiting the system structure to improve the processing speed and efficiency of forms. Some of the enhancements under consideration include: direct raw data transfer into the registry, using patient matching algorithms, redesign for accessible APIs, and integration with other information exchanges. A new POLST form may be developed within the next one or two years. The Registry will continue to work with additional EHR vendors, and will continue Registry enhancements.

Contact Information:

Dana Zive, MPH/Abby Dotson
Director, Oregon POLST Registry
POLSTReg@ohsu.edu, 503-494-5096

WEST VIRGINIA

Background

In 1999, West Virginia was awarded a Robert Wood Johnson Foundation Community-State Partnership grant to improve end-of-life care, which included implementing a Physician Orders for Scope of Treatment (POST) program. By the end of the grant period in 2002, West Virginia had established the Center for End-of-Life Care, an organization devoted to ensuring that the medical treatment wishes of West Virginians were known and respected. This group was very receptive to the concept initiated in Oregon to build a state POST program modeled after Oregon's POLST program.

State agencies, health care institutions and community groups were able to come together and identify and overcome barriers to POST implementation. The West Virginia Network of Ethics Committees and the West Virginia Center for End-of-Life Care worked with the state legislature to update legislation regarding advance directives and end-of-life decision-making in the [West Virginia Health Care Decisions Act](#), passed in 2000. The legislation was amended in 2002 to include the POST program as well.

Similar to Oregon, West Virginia required the POST form, when available, to be sent with the patient during transport. West Virginia then implemented a new process so only a photocopy of the original form accompanied the patient. In 2009, as the POST program continued to evolve, many patients had a POST, but were not sure how to locate it. Many forms were getting misfiled or misplaced, as West Virginia's experience was similar to Oregon's experience in that approximately 25 percent of all paper forms were lost. West Virginia determined that they could maximize the value of the program with a central POST data repository and adopt a registry similar to that of Oregon. As a result, the [West Virginia e-Directive Registry](#) was established.

In 2010, West Virginia received a \$7.8 million federal grant from the State Health Information Exchange Cooperative Agreement Program. This grant developed the [West Virginia Health Information Network](#) (WVHIN). The West Virginia e-Directive Registry determined that it could best achieve its goal of providing 24/7 access to West Virginians' advance directives and medical orders (including POST) to treating health care providers by becoming a node on the WVHIN portal. With this funding, the West Virginia e-Directive Registry worked with WVHIN's vendor to design an online portal to receive POST and other medical order and advance directive documents and a process to manually review and assess the quality of the completed documents. This was an augmentation of the paper POST form system. Due to recent funding constraints, West Virginia has had to curtail some of the electronic upload aspects of the program, but plans to revisit this decision and restart electronic uploads with new partnerships.

Key Features

Providers can either fax POST forms in via a toll-free fax number, or send them using US mail. POLST documents are then converted into PDF. Occasionally, information is incomplete or conflicting, and the West Virginia e-Directive Registry must contact the patient, his or her representative or the physician, to verify information. The provider submission process includes a special cover sheet for providers to complete when patients have dementia or other sensitive situations. This cover sheet provides instructions to contact the provider or patient's legal representative directly in cases where the patient could be alarmed by receiving a verification notification. The review process confirms that the form:

- Includes signatures from both the physician and the patient (or his or her legal representative).

- Is signed by a provider who is licensed in the state of West Virginia.
- Has a date and time of completion.
- Does not include conflicting order information.

If the orders in Section A and Section B of the form are contradictory, the registry sends the POST form back to the provider as invalid with an explanation as to how to correct and resubmit the form. A second member of the registry staff reviews the form to confirm and verify the patient's name, address, date of birth and last four digits of the patient's Social Security number (SSN).

The program sends a letter and a wallet card to every patient so that the patient has documentation of forms in the registry. When there is conflicting demographic information or suspected typos identified in the verification process, letters are also sent to correct this information. Occasionally, the spouse or child mistakenly enters their own SSN and not the patient's SSN, which requires correction.

West Virginia has refined the review process over time and is now able to verify and upload approximately 1,000-1,500 POST forms per month; 150 requests for POLST forms per month are by treating health care providers, and the POST forms sought are retrieved 20-30% of the time. The registry currently has approximately 85,000 advance directives, DNRs, and POST records.

After three years of operation, the West Virginia registry received feedback from providers that their fax was frequently busy. They resolved the issue by implementing a fax server with a toll-free number with unlimited fax receiving capabilities. They now receive 30 to 80 forms per day, and providers never receive a busy signal. One of the biggest challenges with the current process is the poor quality of faxed forms submitted with older fax machines used by practices that still are using paper charts. Additionally, West Virginia received feedback from EMS that they wanted clear legal protection when making care decisions based on POST forms accessed via the registry. An [interpretive rule](#) was adopted by the West Virginia Department of Health and Human Resources so that EMS has this legal protection.

The POST program also has a working agreement with the West Virginia Vital Statistics Center to obtain cause of death and site of death information and merge it with the registry administrative data sets to monitor quality outcome measures. They also use the death statistics information for practical reasons to identify POST forms for deceased patients and retire them from the active registry. This eliminates the potential for family members of deceased loved ones to receive letters addressed to the decedent.

Given that there are a wide variety of clinics and small practices without EHRs, the current semi-automated paper POST system is both cost-effective and works.

Current Activities

In June 2016 and 2017, new laws authorized advanced practice registered nurses (APRNs) and physician assistants (PAs) to sign the medical order forms that indicate preferences for end-of-life care, including POST³⁰. West Virginia has developed video decision aid for POST and end-of-life directions which will be pilot tested in fall of 2018.

³⁰ National POLST Paradigm. [West Virginia POLST Paradigm Program \(POLST\) affects place of death for advanced cancer patients.](#)

Due to redistribution of funds by the state, funding for the POST program continues through the end of this year for West Virginia but is eliminated from the budget in 2019. However, West Virginia University Health Sciences Center has pledged to continue funding for the program.

WVHIN has recently joined with the Chesapeake Regional Information System for our Patients (CRISP) HIE. The registry will become part of CRISP, and its data will become part of the WVHIN portal which will be accessed through CRISP using a single sign on. The registry information will be found on the patient's Unified Landing Page. There are also plans to allow for an online upload of forms through CRISP at a later date.

West Virginia has been successful in tracking the upload locations of POST (and other advance treatment or end-of-life care) forms, though published information is available at this time. Most frequently, these forms are submitted by osteopathic physicians, medical directors of nursing homes, physicians treating patients in their clinics, and nurse practitioners signing forms in palliative care settings and hospices.

While West Virginia has not yet completed cost-benefit or return on investment analysis regarding potential cost savings, observations indicate that people who had POST forms in the registry were twice as likely to die at home vs. people who did not have forms in the registry or people who only had advance directives in the registry. Anecdotally, they project that terminally ill patients with POST comfort measures orders who are not transported would have incurred expenses of, on average, \$11,000 for transport, admission and a short hospital stay prior to death. West Virginia estimates that the registry saved \$45 million to West Virginians on end-of-life care charges. Given that over half of all POST forms the West Virginia registry receives have orders for comfort measures, registry staff believe the POST program enables patients to receive the end-of-life care they desire and provides better value to the overall health delivery system.

West Virginia plans to run robust analytics through CRISP allowing them to institute quality improvements and increase use across the state. West Virginia will be able to monitor submitters and requesters of POST forms and can follow up with the hospitals, hospices, and other care organizations to make the process easier for users.

West Virginia is also a frequent presenter at national meetings on their research findings that POST forms provide more usable information to health care professionals than advance directives or DNR orders, and that cancer patients with POST forms are twice as likely to die outside the hospital and twice as likely to be admitted to hospice as patients with advance directives. They hope their research findings continue to improve the POST program and the way patients are treated at the end of life.

Contact Information:

Alvin H. Moss, M.D.
Director
West Virginia Center for End-of-Life Care
AMoss@hsc.wvu.edu

Evan Falkenstine, BS BA
Data Manager
West Virginia e-Directive Registry
EFalkenstine@hsc.wvu.edu, 877-209-8086

Appendix C: Additional POLST Resources

[The National POLST Paradigm](#)

The National POLST Paradigm Office supports the work of the National POLST Paradigm Task Force and serves as a resource to all POLST Programs. The National POLST Paradigm is a voluntary approach to end-of-life planning that emphasizes eliciting, documenting and honoring the treatment preferences of seriously ill or frail individuals using a portable medical order called a POLST form. The **National POLST Paradigm** website contains resources about POLST for patients and healthcare professionals including FAQs, information about state programs, conferences and relevant news items.

[The National POLST Paradigm Technology Consensus Project](#)

The National POLST Paradigm launched this project in May 2018 to conduct diligence on what is currently being done their POLST Programs, invite vendors to share their solutions, and work with experts (technology, security/privacy, EHRs, HIEs, registries, legal, patient communications) to identify best practices and provide guidance to help POLST Programs effectively harness the promise of technology³¹. This project aims to develop a thorough and helpful best practices guide, identify technology-related priorities, and help align technology product development. This year-long project will include webinars, a conference in October 2018, and conclude with findings documented within a white paper to be published in 2019.

[A Creative Plan That Could Help Providers Ineligible for Meaningful Use Not Get Left Behind In the Paper World](#)

A Health Affairs article that discusses the Centers for Medicare & Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC) action in February 2016 to make federal funding available at a 90-percent matching rate for state expenditures to promote health information exchange for providers ineligible for Meaningful Use incentives. This funding is geared toward long-term care, public health, mental and behavioral health and ancillary service providers that are not eligible for Meaningful Use incentives and includes development of registries to meet Meaningful Use objectives.

[Advance Care Planning \[PDF\]](#)

Tips from the National Institute on Aging on advance care planning.

Advance Care Planning - A Population Approach

Sister sites supporting a population approach to advance care planning emphasizing thoughtful discussions, the differences between advance directives and medical orders and the need for a 24/7 palliative care plan to support seriously ill patients and families, as recommended by Dying in America.

- [CompassionAndSupport.org](#)
- MOLST.org

³¹ [National POLST Paradigm Technology Consensus Conference Overview.](#)

[**Bridging the Healthcare Digital Divide: Improving Connectivity Among Medicaid Providers**](#)

A blog, co-written by CMS and ONC, that discusses the CMS and ONC action in February 2016 to make federal funding available at a 90-percent matching rate for state expenditures to promote health information exchange for providers ineligible for Meaningful Use incentives.

[**Connecting Health and Care for the Nation A Shared Nationwide Interoperability Roadmap \[PDF\]**](#)

The Roadmap identifies near-term (i.e., by the end of 2017) actions and roles that health IT stakeholders should perform to make immediate progress and impacts with respect to interoperability.

[**Conversation Starter Kit**](#)

Guide for engaging loved ones in conversation regarding end-of-life wishes.

[**Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life**](#)

Evaluates strategies to integrate care into a person- and family-centered, team-based framework and makes recommendations to create a system that coordinates care and supports and respects the choices of patients and their families.

[**Dying in California: A Status Report on End-of-Life Care \[PDF\]**](#)

“Dying in California” serves as a snapshot of the state’s progress in end-of-life care, as measured against the recommendations made in the Institute of Medicine’s 2014 report “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.” The report was prepared by the Coalition for Compassionate Care of California.

[**Electronic Medical Orders for Life-Sustaining Treatment \(eMOLST\) Program Manual \[PDF\]**](#)

MOLST is a clinical process that emphasizes discussion of the patient’s goals for care and shared medical decision-making between physicians and nurse practitioners and other health care professionals and patients who are seriously ill or frail, who their physician predict could die within the next year. All health care professionals, including Emergency Medical Services, must follow MOLST orders in all clinical settings, including the community. eMOLST is an electronic form completion and process documentation system for the MOLST form.

[**End of Life: Helping With Comfort and Care**](#)

Provides an overview of issues often faced by people caring for someone nearing the end of life. The information provided does not replace the personal and specific advice of the doctor or other experts, but gives a framework for making care decisions.

[**February 29, 2016 State Medicaid Director Letter With Funding Opportunity \[PDF\]**](#)

A CMS letter indicating the availability of Health Information Technology for Economic and Clinical Health Administrative Matching Funds to help professionals and hospitals eligible for Medicaid Electronic Health Record Incentive Payments connect to other Medicaid providers.

[**Health Decision Resources \[PDF\]**](#)

A collection of advance planning resources from the American Bar Association.

[**Information on New York’s eMOLST secure web-based application**](#)

A website that includes overview information on New York’s eMOLST.

[New York eMOLST Overview \[VIDEO\]](#)

A video overview of New York's eMOLST.

- [New York State Department of Health Attorney's Perspective on eMOLST \[VIDEO\]](#)
- [Advantages of New York eMOLST: A Nursing Home Physician's Perspective \[VIDEO\]](#)

[New York MOLST - REVISED 2015 \[VIDEO\]](#)

A 28-minute educational video on New York state's approach to implementing MOLST to expand upon the traditional Do Not Resuscitate orders for individuals living in long-term care facilities, seriously ill individuals, as well as individuals with significant disabilities.

- [Thoughtful MOLST Discussions: Hospital & Hospice Settings \[VIDEO\]](#)
- [Thoughtful MOLST Discussions: Nursing Home Setting \[VIDEO\]](#)

[POLST: Advance Care Planning for the Seriously Ill \[PDF\]](#)

An article that clarifies misconceptions about POLST and its relationship to advance directives and addresses the differences between the two end-of-life documents.

[Understanding POLST \[VIDEO\]](#)

The Oregon POLST Task Force created the "Understanding POLST" video to explain POLST to patients.

[POLST: When is the Right Time? \[VIDEO\]](#)

The Oregon POLST Registry created this new video that integrates a patient story with how the Oregon POLST Registry functions from a patient perspective.