California HealthCare Foundation

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Issue Brief

Information in a Heartbeat:
Readiness Assessment for Establishing a POLST Registry in California

The medical treatment that Californians want at the end of life is often out of sync with what they receive. While 70% of Californians say they would prefer to die at home, only 32% do.[1] How can individuals make sure their end-of-life care wishes are known and honored?

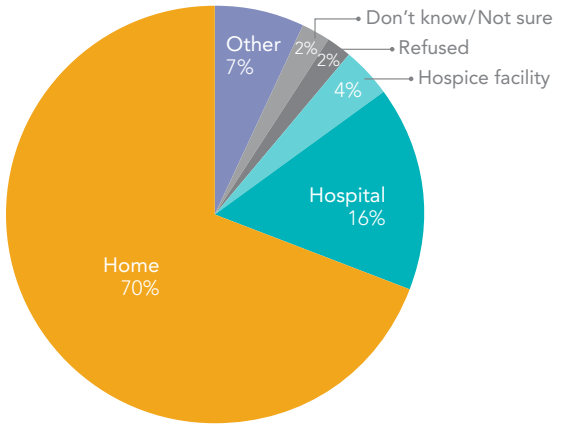
Physician Orders for Life-Sustaining Treatment (POLST) allow individuals to articulate their wishes and have more control over their end-of-life care. POLST is a form that captures a conversation between individuals, their family members, and their physician regarding choices for end-of-life treatment.

However, completing a POLST form isn't enough; it must be easily accessible during a crisis. How will emergency responders know a patient's treatment wishes if that person's POLST form or medical record is not available?

One solution is an electronic statewide POLST registry, which would securely store patients' POLST information and make it accessible by medical personnel at any time.

This brief examines the landscape for a POLST registry in California, looks at models and lessons learned from other states, and outlines possible next steps to successful implementation and adoption of such a registry in this state.

Figure 1. Preferred Location of Death, California, 2011



Note: Segments do not add to 100% due to rounding.

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adults.

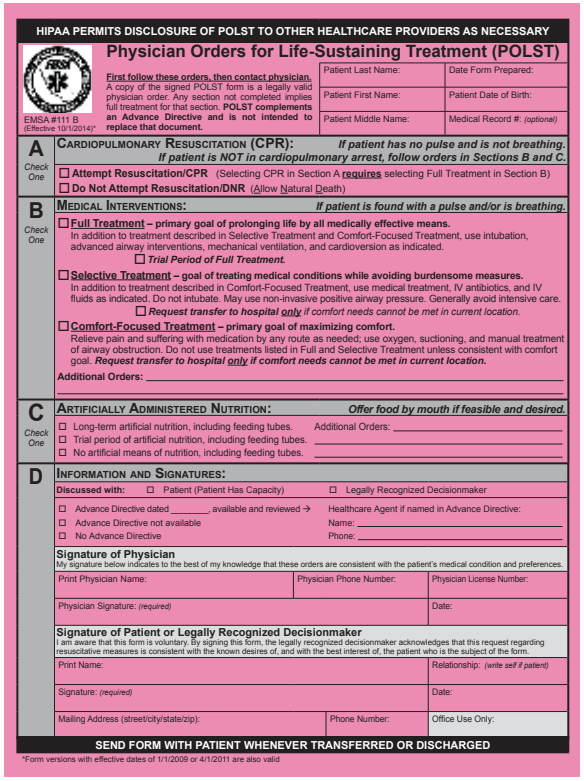
Background

California's POLST allows individuals to record their choices about life-sustaining treatment, including cardiopulmonary resuscitation, intensity of medical interventions, and artificially administered nutrition. Produced on a bright pink paper for easy recognition and signed by the physician and patient, POLST is a physician order recognized throughout the medical system. POLST is designed for people with a chronic progressive illness or serious health condition, or who are medically frail.

The form is intended to travel with the patient across care settings. "The information contained in a POLST form is as critical to our approach to patient care as information on allergies to medications," said Tami Gash-Kim, MD, an emergency physician at Marin General Hospital. "It's the first thing we look for when we see a patient in the end stages of advanced illness."

After more than 20 years of use in Oregon, where POLST originated, research shows that POLST is a successful process for documenting and honoring end-of-life treatment wishes.[2] A 2014 study of Oregon's registry data compared treatment wishes listed in POLST forms to location of death and found that the end-of-life wishes outlined in the forms were honored, whether these wishes involved full treatment or limited care.[3] Moreover, in a 2012 *Cleveland Clinic Journal of Medicine* study, authors found that "POLST more accurately conveys end-of-life treatment preferences for patients with advanced chronic illness and for dying patients than traditional advance directives and yields higher adherence by medical professionals."[4]

Figure 2. POLST



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

EMSA #111 B (Effective 10/1/2014)*

Patient Last Name: | Date Form Prepared:
Patient First Name: | Patient Date of Birth:
Patient Middle Name: | Medical Record #: *(optional)*

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR):** *If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A **requires** selecting Full Treatment in Section B)
☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B Check One — **MEDICAL INTERVENTIONS:** *If patient is found with a pulse and/or is breathing.*

☐ **Full Treatment – primary goal of prolonging life by all medically effective means.** In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
☐ *Trial Period of Full Treatment.*

☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.** In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
☐ *Request transfer to hospital only if comfort needs cannot be met in current location.*

☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.** Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. *Request transfer to hospital only if comfort needs cannot be met in current location.*

Additional Orders: _____

C Check One — **ARTIFICIALLY ADMINISTERED NUTRITION:** *Offer food by mouth if feasible and desired.*

☐ Long-term artificial nutrition, including feeding tubes.
☐ Trial period of artificial nutrition, including feeding tubes.
☐ No artificial means of nutrition, including feeding tubes.
Additional Orders: _____

D **INFORMATION AND SIGNATURES:**

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _____, available and reviewed → Healthcare Agent if named in Advance Directive: Name: _____ Phone: _____
☐ Advance Directive not available
☐ No Advance Directive

Signature of Physician
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician Name: | Physician Phone Number: | Physician License Number:
Physician Signature: *(required)* | Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the patient who is the subject of the form.

Print Name: | Relationship: *(write self if patient)*
Signature: *(required)* | Date:
Mailing Address (street/city/state/zip): | Phone Number: | Office Use Only:

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009 or 4/1/2011 are also valid

Source: The Coalition for Compassionate Care of California (CCCC) www.capolst.org.

POLST in California

State policymakers considered and adopted the POLST form for use in California in 2008. Assembly Bill 3000, championed by Senator Lois Wolk, received bipartisan support. It was signed by Governor Schwarzenegger and became law in California, effective January 1, 2009.[5]

The Coalition for Compassionate Care of California (CCCC), the lead agency for POLST in California, is focused on implementing POLST as a community standard of practice. Formed in 1998, the CCCC is a statewide collaborative of more than 200

Advance Directives and POLST: What's the Difference?

POLST complements, but does not replace, advance directives. With an advance directive, individuals can appoint their surrogate — the person they want to speak on their behalf. While an advance directive also allows people to provide a broad outline of their wishes relating to end-of-life care, these documents usually do not address specific treatment issues. Because advance directives are not signed by physicians, they do not carry the weight of a physician order.

POLST is designed for seriously ill individuals, and identifies patients' specific wishes on specific medical decisions. A POLST is a physician order, and must be honored by emergency responders. These forms are designed to travel with a patient from one medical setting to another.

	ADVANCE DIRECTIVE	POLST
For who?	Every adult	Seriously ill
What does it include?	Broad outline	Specific wishes, actionable physician orders
Names a surrogate?	Yes	No

organizations and individuals — including health care providers, consumers, and regulatory agencies — working together to improve care for seriously ill Californians. CCCC works with more than 25 local POLST coalitions around the state to conduct outreach and education activities in their communities.

Legislative Landscape

In early 2014, legislators in both California's Assembly and Senate introduced bills to establish a statewide electronic registry for POLST.

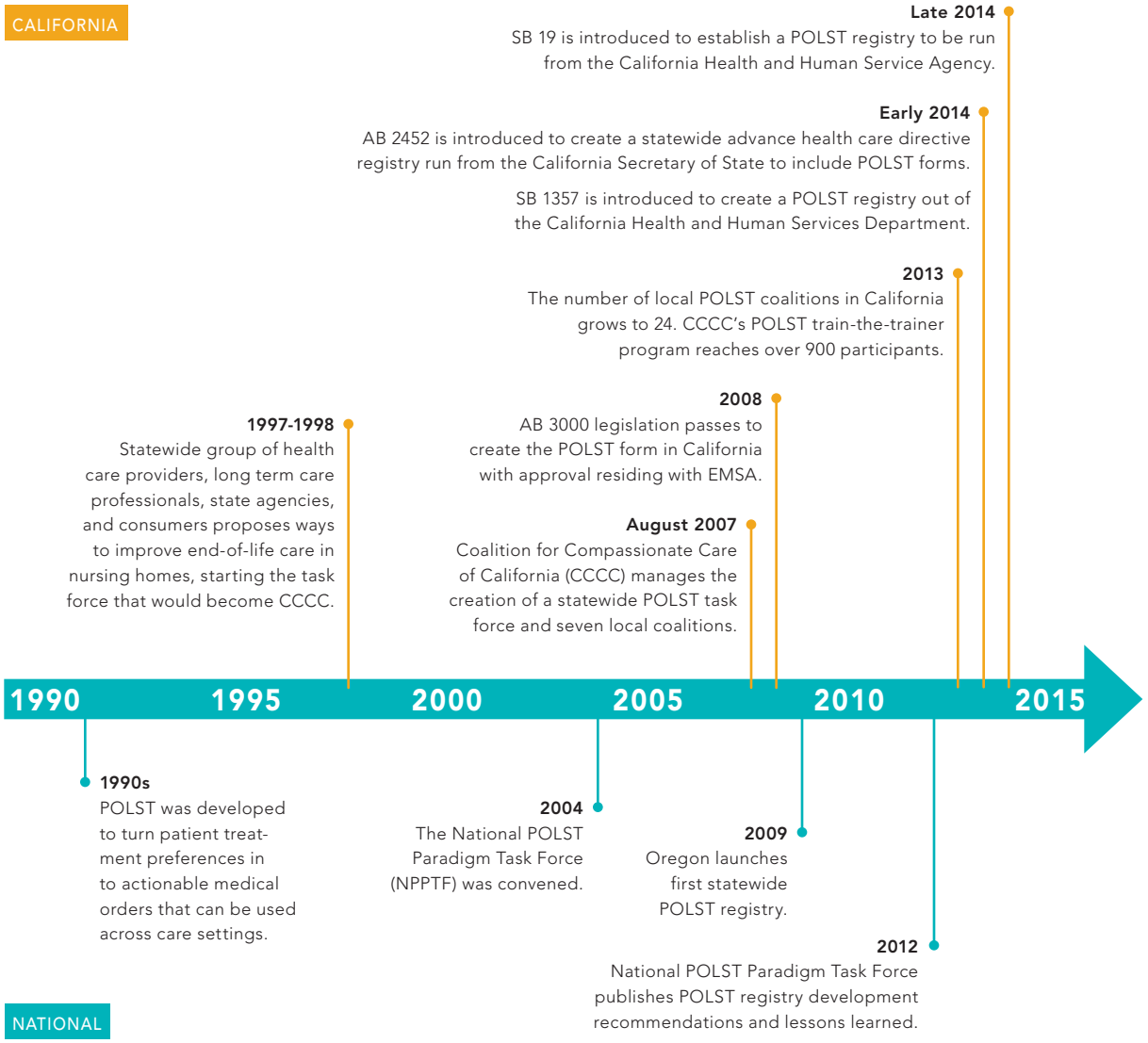
Assembly Bill 2452 (AB 2452 Pan) proposed creating a statewide advance health care directive registry that would include POLST forms.[6] Administered by the California Secretary of State, this bill would have digitized the state's existing paper-based advance directive registry and added POLST forms.

Senate Bill 1357 (SB 1357 Wolk) was introduced to create a statewide POLST registry under the auspices of the California Health and Human Services Agency.[7] This bill would have required the submission of POLST form data, unless the patient did not want it submitted.

Neither bill was approved by the legislature. AB 2452 was held in Senate Judiciary committee; SB 1357 was held in Senate Appropriations.

In December 2014, Senator Wolk introduced Senate Bill 19, the California POLST Registry Act, which proposes the establishment of a state POLST registry to be operated by the California Health and Human Services Agency. SB 19 is currently under consideration.

Figure 3. Evolution of POLST



Source: BluePath Health, Inc.

This grassroots approach is one of the hallmarks of California's successful POLST adoption. There are more than 1,200 skilled nursing facilities, 393 acute care hospitals, over 7,000 assisted living facilities, and numerous physician offices in California.[8] The most up-to-date data available, from 2011, just two years after POLST was launched, show that more than 100,000 POLST forms had been completed by residents in California's nursing homes alone.[9]

POLST awareness and use is growing among California's care providers: A 2010 survey of 546 nursing homes found that 82% of skilled nursing facilities in California have participated in training sessions about POLST.[10] "We are training the nurses in skilled nursing facilities to consult the resident's completed POLST form for guidance and not call emergency services for a patient that does not want to be transferred to a hospital," explained Karl Steinberg, MD, certified medical director and current secretary of the California Association for Long-Term Care Medicine.

But because POLST is most appropriate for people with serious illnesses, the general public is largely unaware of this tool.

"The value of POLST is that it reaches across the entire continuum of care: from emergency services

California's POLST Leadership

These organizations and state entities are involved in the strategy, policy, communication, and regulatory efforts for the use of POLST.

The nonprofit **Coalition for Compassionate Care of California (CCCC)** promotes high-quality, compassionate care for Californians who are seriously ill or approaching the end of life. CCCC is the lead for POLST in California. In that role, CCCC oversees and coordinates all aspects of POLST, including convening the POLST Task Force, and working closely with community coalitions around the state working to promote POLST locally.

Local coalitions have raised awareness of POLST among their community's health care professionals and within the general population. Each coalition includes a physician champion who also serves on the POLST physician leadership council, which provides guidance to the POLST effort from the physician perspective. The local POLST coalitions include:

- Alameda-Contra Costa POLST Coalition
- Antelope Valley Care Transitions Collaborative
- California Central Valley Coalition for Compassionate Care
- Central Coast Coalition for Compassionate Care
- Coalition for Compassionate Care of San Mateo County
- Compassionate Care Alliance (Monterey Area)
- Greater Bakersfield Better Care Coalition
- Humboldt POLST Coalition
- Inland Empire Palliative Care Coalition
- Journey Project Coalition (Sonoma County) and My Care, My Plan — Speak Up Sonoma County
- Marin County POLST Coalition
- Mendocino POLST Coalition
- Orange County POLST Coalition
- Paradise POLST Project (Chico Metropolitan Area)
- Sacramento POLST Coalition
- San Diego POLST Coalition
- San Francisco Community-Based Palliative Care Initiative
- San Gabriel Valley End-of-Life Care Coalition
- Santa Barbara POLST Coalition
- Santa Clara County POLST Coalition
- Santa Cruz County Make Your Wishes Known Initiative
- SPA 2 POLST Coalition (San Fernando/Santa Clarita Valley Area)
- Stanislaus POLST Coalition
- West Los Angeles POLST Coalition
- Yolo POLST Coalition

The **POLST Task Force** is convened by CCCC and is comprised of members who represent a constituency. Members include representatives from stakeholders across the continuum of care, including physicians, hospitals, nursing homes, assisted living providers, first responders, and consumers. The task force provides input on all statewide aspects of POLST, including public policy, education, communication, form content, and quality.

The **Emergency Medical Services Authority,** part of the California Health and Human Service Agency, provides oversight for POLST and provides guidance to local EMS agencies on the use of POLST.

California's Advance Health Care Directive Registry

Since 2000, the California Secretary of State's Advance Health Care Directive Registry permits a person who has an advance health care directive, or a similar document, to register it with the California Secretary of State. The registration includes information regarding the location of the advance health care directive or a copy of the advance health care directive itself. The intent of this process is to receive and release specified information from a person who has executed a written advance health care directive to authorized individuals like health care providers, and to charge a fee to cover the costs of establishing and maintaining the registry.

This repository of advance directives contains approximately 4,700 forms.[11] California's current advance directive registry is not searchable, the information cannot be immediately accessed electronically or over the phone, and requests for information can only be made during business hours. Since the registry only includes advance directives, it does not offer information about specific treatment preferences.[12]

The Secretary of State does not conduct any marketing activities for the registry other than the information provided on the website. Secretary of State representatives have indicated that their office is not an obvious place for health care providers to look for the registry.[13]

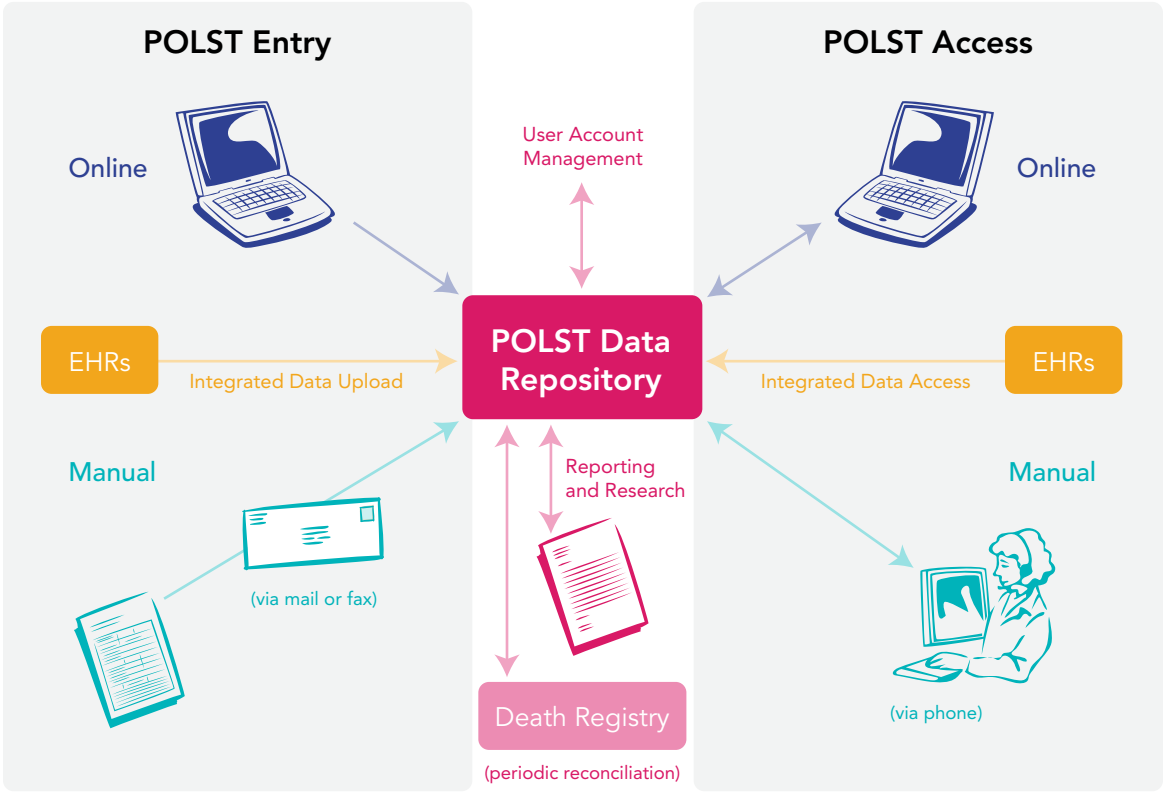
to hospitals and nursing homes, all the way to care provided in the home. It gets all health care providers in California working to improve the way that we discuss, document, and honor patients' treatment wishes," said CCCC's Judy Thomas.

Why Is Immediate POLST Access Important?

During medical emergencies, providers benefit from immediate access to an individual's treatment wishes.

Care providers at skilled nursing facilities and hospitals report that managing the paper POLST form

Figure 4. POLST Registry Technical Overview



Source: BluePath Health, Inc.

across settings of care is a challenge. While the POLST form is meant to travel with patients between care settings, the form can get lost during transfers — or never sent at all.

"If it's late at night and the family isn't there, I want to be able to tap into a registry and see what the patient really wants. For a useful registry, the data have to be high quality and absolutely reliable," explained Larry Stock, MD, of Antelope Valley Hospital.

Access to end-of-life treatment information is especially important for emergency response personnel, who oftentimes do not have access to paper POLST forms. "Because emergency services are decentralized in California, a POLST registry may provide a service that simplifies and centralizes some of our procedures and protocols. A POLST registry would put crucial information about end-of-life treatment right into the hands of our frontline EMTs and paramedics, who can then honor patients' wishes and their doctors' orders," shared Jay Goldman, medical director of ambulance and emergency medicine services for Kaiser Permanente Northern California.

A registry makes POLST information available to health care providers at any location at any time, either by looking up the information online or by contacting a 24-hour call center. It provides a backup system if the paper POLST form or electronic health record (EHR) is unavailable. With round-the-clock phone and electronic access to POLST information, providers would be able to follow an individual's wishes even during the most stressful times, such as during an emergency department visit.

POLST Registries: Current Models and Lessons Learned

As of March 2015, 17 states had established POLST programs, sometimes under other names such as Physician Orders for Scope of Treatment (POST), Medical Orders for Life Sustaining Treatment (MOLST), and Medical Orders for Scope of Treatment (MOST), and 25 additional states were developing POLST programs. This brief includes details about the Oregon and New York registries, and information about other POLST registries can be found online at www.polst.org/programs-in-your-state.

A 2012 report of the National POLST Paradigm Task Force, which is comprised of key leaders in the development and spread of POLST in their states and nationally, examined the structure and content of POLST registry systems in seven different states.[14]

Several key findings emerged:

- Defining the registry's purpose prior to its development is essential. Questions to address include:
  - 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 rapid adoption of use of a POLST registry.
- Sustainable funding for registry operations is vital to long-term success.
- Strong leadership from an effective statewide POLST 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 emergency medicine system 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 electronic medical record is designed to rapidly locate POLST forms.
- How forms are submitted, and by whom, impacts the volume of submission. Develop easy-to-use processes that integrate into the work flow to support form submission.
- The POLST program needs to be firmly established before launching a registry.

Oregon, a leader in POLST adoption, launched its POLST registry in 2009, with the mission to "connect emergency health care professionals with their patients' POLST orders to facilitate compassionate, desired health care during a crisis; . . . to increase accessibility to POLST orders to support continuity of care across health services platforms; . . . [and to foster] innovation by creating new ways to securely access health information."[15]

New York has also established a POLST registry. Oregon's registry provides a model for successful adoption, and New York offers a model of advanced technology infrastructure.

Oregon POLST Registry: High Adoption Rate

Launched: 2009

Overview: Oregon's registry is seen by many as the standard-bearer for POLST registries given its length of time in operation and wide use; research demonstrating the impact of POLST could only be done because of the access to POLST forms in the registry.

Key Elements

- The Oregon Legislative Assembly House Bill 2009 created the registry within the Oregon Health Authority.
- The registry is a collaborative effort between state entities. State law provides the authority for this state activity and expenditure of funds, the Oregon Health Authority has statutory administrative responsibility, and the Oregon Health Sciences University (OHSU) operates the registry.
- While POLST form completion is voluntary, Oregon requires health providers to submit completed POLST forms to the registry. Forms may be submitted by mail, fax, or secure file transfer, unless the individual chooses not to participate in the registry.
- Providers in Oregon can access the information from the electronic registry at any time by phone. But there is currently no online access to the registry.

The registry focuses solely on POLST forms because the registry users — emergency medical services providers, emergency room and intensive care unit staff — need actionable medical orders. Advance directives do not provide specific medical direction and are not included in the registry.

Use: Since 2009, more than 4,600 calls have been made to the Oregon POLST registry hot link, which is open to emergency medical services (EMS), emergency departments, and acute care facilities.[16] "We strive to ensure that the registry is on every emergency responders' speed dial," said Susan Tolle, MD, director of the Center for Ethics in Health Care at the Oregon Health and Science University.

The Oregon registry includes over 197,000 POLST forms, more than any other state, of which about 78,000 have been matched to death certificate data and archived.[17] An analysis of 2012 registry data showed that the mean age of individuals with active forms in the registry is 76.7.[18,19] Use of POLST forms in Oregon is high. Because POLST is most appropriate for individuals with serious illness and limited life expectancy, many of the approximately 34,000 individuals who die each year in this state could benefit from the POLST conversation and completion of a form. Some people appropriate for POLST may cope with serious illnesses for several years. The target market for POLST conversations and form completion may be estimated as a percentage of those who die each year plus those with serious illnesses.

Impact: During 2010 and 2011, nearly 18,000 people who died in Oregon had a POLST form in the registry, amounting to 31% of all deaths. When matched with information about place of death, researchers found a strong association between scope of treatment orders on the POLST form and the location of death. For example, 94% of individuals who chose "comfort measures only" died outside a hospital setting, while 44% who chose full treatment died in a hospital.[20]

What Works

- The Oregon POLST program, started in 1990, was already in widespread use among stakeholders with a high level of POLST awareness by the time the registry was established.
- Requirement that providers submit all completed forms, unless patients chose not to participate, ensures that the database is populated.
- The registry secured ongoing state funding at its launch, and enhancements have since been funded by both public funding and private grants.
- Locating POLST forms in a single registry allows for research that can demonstrate the impact of POLST on treatment decisions and location of death.
- In 2015, the Oregon POLST registry was linked with OHSU's electronic health record through specially developed software.

Areas for Improvement

- Registry is not accessible via the Internet or other network connections.

New York's eMOLST Registry: Strong Technology Infrastructure

Launched: 2010

Overview: New York State's POLST is known as Medical Orders for Life Sustaining Treatment (MOLST) and is available in paper format and online. The online format, first released in 2010, is eMOLST. eMOLST was developed by Excellus BlueCross BlueShield with initial funding from the New York State Department of Health. The registry is currently maintained, funded, and operated by Excellus BlueCross BlueShield.

Key Elements

- eMOLST was established by a private entity working closely with New York State Department of Health, and not through state legislation.
- This web-based application allows eMOLST orders and documentation of the conversation to be accessed from anywhere with Internet access. The state's eMOLST system is accessible to all users at all times at www.nysemolstregistry.com.
- eMOLST allows health professionals to follow a standard clinical process for the MOLST discussion and guides them through all necessary documentation. The form and documentation elements can be customized to the requirements and laws of any state.
- New York's MOLST forms can be completed online in eMOLST and are automatically included in the registry. A copy can be printed for the patient.
- Because eMOLST does not require or rely on an EHR system or any other technology besides Internet access, uptake can happen quickly and in all care settings, including in the community. eMOLST is also flexible enough to meet the needs of organizations with well-integrated EHR systems.
- eMOLST is operational statewide and is not dependent on facility EHR systems, health information exchange (HIE), or any regional health information organization (RHIO) for use.
- eMOLST currently operates in all browsers and all devices, including on tablets.

Use: eMOLST has thousands of users who access the application and thousands of forms in the registry. Users are from all regions of New York State, including New York City, the Hudson Valley, Upstate and Western New York, the Capital District, and Long Island. Users and forms are added daily.

What Works

- Technology is used to improve the exchange of critical information. Using a web-based platform guarantees instant usability and accessibility in all care settings, and anywhere in the community with Internet access.
- Because eMOLST can be integrated into an organization's EHR system or HIE, the application can be easily incorporated into the existing provider workflow.
- Quality control measures are built into the system. For example, eMOLST does not allow incomplete forms to be submitted and also prevents providers from creating incompatible medical orders or orders lacking documentation. The eMOLST system immediately notifies providers of errors so they are able to make corrections without losing their work.[21]
- Standardized single-sign-on capabilities are built into the application, allowing for quick basic integration with hospital and nursing home EHR systems, HIEs, and RHIOs.
- In 2015, eMOLST is launching a patient importer process and leveraging optical character recognition technology to allow existing paper MOLST forms to be quickly converted to eMOLST. This addition to the system will report paper-based errors and missing information to providers to allow for corrections in the eMOLST system.

"We designed eMOLST as the electronic version of the MOLST form to support and document the end-of-life care conversation between the patient and physician," explained Patricia Bomba, MD, vice president and medical director of geriatrics at Excellus and program director for the eMOLST application. "eMOLST is a tool for providers that guides them through the conversation, capturing patient input accurately and completely in a document that can be shared electronically and printed."

Areas for Improvement

- eMOLST use is not mandated through legislation or health department action. Health systems may choose to mandate its use within their facilities.
- eMOLST use is driven by systems and facilities that see its value and want to use the application. Systems that are resistant to change in their workflow are not required by legislation or regulation to use the eMOLST application at this time.

A POLST Registry in California: What Do Stakeholders Think

In early 2014, a wide range of health care stakeholders and POLST leaders were interviewed so they could share their perspectives about POLST adoption, the benefits of a statewide registry, and the potential challenges in implementing a registry. Interviewees included users of POLST forms to guide treatment decisions, those responsible for having the POLST conversation, and those completing the form who would also be responsible for submitting the form to the registry. Those interviewed included representatives of hospital emergency departments, acute care facilities, hospices, skilled nursing facilities, emergency medical services, and other care providers. See the appendix for a list of interviewees.

The stakeholders interviewed identified several next steps to support the successful implementation of a statewide POLST registry in California:

- Pilot the registry in a community, with the intent to scale rapidly.
- Develop a technology platform for the registry that supports multiple forms of input and output, from paper to fax to mobile devices.
- Expand existing POLST education infrastructure to include education about the registry.
- Engage state administrative leadership and consider development of an independently operated registry, based on the approaches of other successful California health registries, such as the California Cancer Registry.
- Identify funding sources to build and sustain the registry.

Pilot the Registry

Interviewees agreed that piloting the POLST registry would be a critical step toward ensuring that the system works efficiently and effectively for providers and patients across California. They suggested that the pilot be implemented on a future-focused, mobile technology platform and have the ability to scale quickly once it is completed. Stakeholders identified the following goals for a pilot:

- Develop and test product features, including integration with electronic health records and tablet-based input and access.
- Integrate electronic registry submission with current workflows in appropriate facilities, such as skilled nursing facilities and acute care facilities.
- Develop a financing model and commitment from public and private stakeholders.
- Confirm budget assumptions.

Stakeholders talked about the importance of conducting the pilot in a community that is ready for such an effort, and that has the following characteristics:

- Providers committed to participating in registry development efforts.
- An active POLST coalition to provide education and to promote adoption in the local community.
- A population that is able to generate a reasonable number of POLST forms, to populate the registry within the pilot timeframe.
- The ability to integrate POLST with an acute care hospital's established electronic health record system.
- The desire to work with public and private funders and state regulators to explore opportunities to finance and sustain the POLST registry.

Develop a Future-Focused Technology Platform

Interviewees discussed the ideal technology platform for the registry and stressed that it must be flexible to enable updates based on regulatory changes and link to other public registries to support population health and other research needs.

Key technology elements identified for a modern, mobile registry platform include the following:

- Support for web-based data entry as well as input from paper-based documents and output to paper. Electronic data entry is critical for controlling data quality, and input from and output to paper are still a necessity for many users.
- Use of tablets and smartphones. With more than 83% of providers using smartphones and tablets, providing mobile device support is an important component of stakeholder adoption.[22]
- Offer cloud-based access so that any provider with Internet connectivity can access the registry.

Stakeholders highlighted the importance of having the registry's technology support the workflow of its users. They pointed to New York's eMOLST form, a portion of which can be filled out by a non-physician, saved, and then completed and signed electronically

by a physician. The form's feedback system won't allow non-physicians to complete any part of the form that requires physician completion. In this way, the electronic system mimics the paper workflow that has already been adopted by providers.

Two technical challenges that were identified include how individuals and providers will sign the electronic POLST forms to validate them, and what kind of system to implement for the unique identification of individuals with a form in the registry. New York's eMOLST allows for digital signatures and also assigns a unique MOLST number identifier to each patient. While the provisions of the California Uniform Electronic Transactions Act do not prohibit the use of electronic signatures for POLST, more legal analysis is needed to ensure that electronic signatures can be used. In addition, the registry requires a robust patient matching system to ensure that providers can accurately and reliably match patients to their most recent POLST form.

Educate Stakeholders

Stakeholders emphasized that a strong outreach and education effort targeting both providers and patients will be necessary to ensure widespread adoption. The CCCC's statewide and grassroots infrastructure was acknowledged as a ready-made distribution framework for reaching the appropriate consumer and provider audiences with messages on the requirements, use, and benefits of a statewide POLST registry.

Stakeholder membership organizations, such as the California Association of Health Facilities, were also identified as potential venues for reaching patients and providers. A state partnership with the POLST Task Force was discussed as an important way to reach these membership groups to speed adoption and increase the reach and impact of the registry.

Stakeholders acknowledged the diversity of emergency response providers in California, and the flexible approach to integration and adoption that will be required of EMS once a statewide registry is in place. Because communities typically have multiple fire substations, 911 responders, and medical transporters that operate under largely independent local policies and procedures, a POLST registry will be most successful if it is integrated into each of these unique workflows. Stakeholders expressed confidence about overcoming the challenges they recognized that are likely to arise with EMS integration.

Develop Expectations and Rules About POLST Registry Use

Oregon's registry development and adoption was cited as a clear example of how a state requirement led to adoption. Stakeholders agreed that regulation will be a key driver for success in California as well. "We need a mandate, or something with a regulatory feel, to accelerate the adoption of new steps into our workflow," said Jocelyn Montgomery, RN, of the California Association of Health Facilities, a long term care association.

Stakeholders also confirmed that state-supported regulation should focus on requiring providers to submit completed and signed POLST forms to the registry. They agreed that it is just as important to allow patients who are completing the forms to decide not to have their POLST forms submitted to the registry.

Engage State Leadership in Pilot and Statewide Spread Stages

Many stakeholders interviewed believe that strong state leadership, stakeholder engagement, and a requirement to populate the POLST registry will be required to drive adoption. "The hard work for this registry is not the software. The hard work is leadership and stakeholder involvement," explained Robert Moore, MD, of Partnership HealthPlan of California.

Interviewees recognized that a statewide effort, particularly one with a regulatory requirement, will need strong state executive and legislative engagement. Initiating and adopting a California POLST registry will require a multi-stakeholder effort, similar to the initial POLST education effort, with goals and outcomes clearly defined.

Consider Operating Models

The administration and operation of a POLST registry could be provided through an independent organization or be a governmental function. Oregon is an example of a registry run by a state entity, OHSU. New York is an example of a registry run by a non-governmental entity, Excellus BlueCross BlueShield. In California, several statewide health registries were established to support the mission and goals of specific government agencies and departments while under the operation and administration of independently operated organizations (see Figure 5 on the following page).

Figure 5: Select California State Health Registries

	GOVERNMENT ORGANIZATION	OPERATOR	PURPOSE
California Cancer Registry	California Department of Public Health	UC Davis Institute for Population Health Improvement	Collection and collation of cancer patient data for research and program development
California Organ and Tissue Registry	California Department of Motor Vehicles	Donate Life California	Information on organ and tissue donation wishes
Controlled Substance Utilization Review and Evaluation System (CURES)	California Department of Justice	Atlantic Associates	Prevention of drug abuse and diversion through accurate and rapid tracking of controlled substances

Explore Funding to Build and Sustain the Registry

Interviewees agreed that public and private funding sources should be explored to sustain the registry. The launch of Oregon's registry, for example, was funded through its state budget. The registry's general administration continues to be supported through the state's general fund, and research and outreach efforts are funded through private sources.

In addition to state funding, there are several federal programs for health information technology investments that could be explored to support the development of a POLST registry. Stakeholders concurred that plans, providers, and state leaders should work together to explore and maximize access to these opportunities.

Next Steps

A statewide POLST registry will ensure that in times of crisis, emergency responders can immediately access treatment wishes so that people get the treatment they want — and equally important — they do not get the treatment they do not want.

What are the next steps?

People and partnerships. Strong leadership and a broad, committed, and sustainable coalition are common themes among successful POLST programs, as well as successful registries. California already has much of the necessary structure and leadership in place with its existing POLST program. The state will need to identify a capable technology partner. There may also be a consulting role for groups that have experience with successful POLST registry systems.

Voluntary and mandatory. The POLST itself is rooted in the belief that the form's completion should always be voluntary for patients, but that it should be mandatory for providers to take reasonable steps to ensure that the POLST form is honored. A registry system should follow the same format: voluntary for patients, but mandatory that providers submit the forms to the registry, unless the patient chooses otherwise. One of the primary reasons the Oregon registry has been so successful is the provider mandate. Without such a requirement, the registry would likely not be a reliable resource, as many forms would never be submitted.

Legislation. Enacting legislation would make it mandatory for providers to submit completed POLST forms to a registry, unless the patient elects not to have the form submitted.

Technology. Because of California's size and complex health care system, existing registry systems may not meet this state's needs for a transactional registry, where data can be both submitted and retrieved in real time. A system that is developed should be flexible to evolve as health-related IT evolves. It should be developed to adapt with the current workflow of health care providers, and dovetail with the larger community-based grassroots approach of POLST.

Governance structure. California's POLST program has long operated under a successful public-private partnership model. The California Emergency Medical Services Authority is the official home of the POLST form and approves the form's content and any revisions. The nonprofit Coalition for Compassionate Care leads the coordination and delivery of POLST education to health care providers, oversees stakeholder engagement activities, and coordinates local implementation efforts. The two organizations work cooperatively to promote POLST.

About the Authors

BluePath Health is a California-based consulting firm that partners with government agencies, public health organizations, health information technology companies, providers, and payers to develop policies and strategies that improve the delivery of patient care and build community health.

The Coalition for Compassionate Care of California is a statewide collaboration of health care providers, consumers, and regulatory agencies working to improve care of seriously ill Californians.

About the Foundation

The California HealthCare Foundation (CHCF) is leading the way to better health care for all Californians, particularly those whose needs are not well served by the status quo. We work to ensure that people have access to the care they need, when they need it, at a price they can afford.

CHCF informs policymakers and industry leaders, invests in ideas and innovations, and connects with changemakers to create a more responsive, patient-centered health care system.

For more information, visit www.chcf.org.

Appendix: Interviewees

California Ambulance Association
June Iljana, executive director

California Association for Nurse Practitioners
Karen Ayers, ACNP

California Association of Health Facilities
Jocelyn Montgomery, RN, clinical affairs program director

California Association of Long-Term Care Medicine
Karl Steinberg, MD, CMD

California Emergency Medical Services Authority
Sean Trask, chief of EMS personnel
Lisa Witchey, manager, EMS Personnel Standards

California Hospital Association
Patricia Blaisdell, vice president, Post-Acute Care Services

California Medical Association
Alicia Wagnon, legal counsel

Center for Medicare & Medicaid Services
Betsy Thompson, chief medical officer, CMS Region IX

Coalition for Compassionate Care of California
Judy Thomas, JD, chief executive officer

Emergency Medical Services Administrators' Association of California
Dan Burch, president

Excellus BlueCross BlueShield
Patricia Bomba, MD, vice president and medical director, Geriatrics

HealthInsight
Deepthi Rajeev, biomedical informaticist

Inland Empire Palliative Care Coalition
Tarek Mahdi, MD, chair

Kaiser Permanente
Jay Goldman, MD, ED physician, EMS liaison

Mendocino POLST Coalition
Mark Apfel, MD

Oregon Health & Science University
Susan Tolle, MD, director of the Center for Ethics in Health Care

Oregon POLST
Jenny Cook, project liaison
Dana Zive, senior instructor

POLST Task Force, POLST Registry Committee
Robert Moore, MD, MPH, Partnership HealthPlan of California

UC Davis, Institute for Population Health Improvement
Rim Cothren

UC Davis School of Medicine
Michael Hogarth, MD, associate professor

Utah Commission on Aging
Anne Palmer, executive director

Utah Department of Health
Janice Houston, director, Bureau of Vital Records

Vynca
Ryan Van Wert, MD, founder

West Los Angeles POLST Coalition
Poonam Bhatla

West Virginia University
Evan Falkenstine, data administrator
Cindy Jamison, program manager, West Virginia Center for End-of-Life Care

Yolo POLST Coalition
Joanne Hatchett, MSN, FNP
Jeffrey Yee, MD, Dignity Health

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