

# POLST eRegistry in California: Challenges and Opportunities



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## Table of Contents

Executive Summary	iii
Background	1
Key Interview Findings	3
Conclusion	14
Appendix A: Key Informants	15
References	17

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LifeCourse Strategies prepared this report. LifeCourse Strategies is a health care consulting firm specializing in project management, community-based research, gap analyses, and strategic planning for health and social service organizations serving vulnerable and underserved communities. [www.lifecourse-strategies.com](http://www.lifecourse-strategies.com)

## Executive Summary

Physician Orders for Life-Sustaining Treatment (POLST) is a medical order that provides seriously ill patients with a tool to communicate their medical treatment choices in the event of a medical emergency or serious illness. The POLST form is designed to lead to a thoughtful, high-quality conversation between a patient and a health care provider about the patient's diagnosis, prognosis, treatment options, treatment wishes, and quality of life. California established POLST in state statute in 2009. Since then, there has been steady growth in the use of POLST across the state by patients, families, and health professionals.

As POLST continues to spread in California, a set of new opportunities and challenges has emerged with the development of POLST electronic registries (eRegistries)—systems that collect, store, and exchange POLST orders. The technology was developed to promote easily accessible, accurate, and completed POLST forms for seriously ill patients when they are needed most: during a life-threatening clinical event. A number of major health systems in California are in the process of developing POLST eRegistries, leveraging the rapidly expanding role of health information technology to automate, integrate, and ensure access to health data across healthcare systems and settings.

This report summarizes key findings from phone-based, semi-structured interviews with 18 key informants representing healthcare systems, health information organizations, Emergency Medical Services Authority (EMSA), health plans, subject matter experts, a medical association, and state staff. The purpose of the interviews was to elicit stakeholder perspectives and experiences about the following: POLST value and adoption challenges; POLST eRegistry engagement—motivators and challenges; a long-term goal for POLST eRegistry platforms and services in California; and, the role of the Coalition for Compassionate Care of California (CCCC)—a leader in promoting high-quality, compassionate care for Californians who are seriously ill or nearing the end of life—in supporting a quality POLST ecosystem for California. (POLST ecosystem refers to the interconnected network of POLST elements ranging from POLST implementation, to quality patient-provider goals of care conversations, to interoperable POLST eRegistry platforms.)

The interviews confirmed the value of POLST. POLST offers seriously ill patients a tool to communicate their treatment preferences should they not be able to speak for themselves. For providers, it removes a common burden of not knowing patients' treatment wishes during medical emergencies. It also reduces the risk that providers will give either less or more care than patients desire. Despite the confirmed value of POLST and its spread in California, POLST adoption and implementation challenges remain.

Completion of the POLST form is predicated on providers having thoughtful conversations with their patients, to understand what is most important to them and to document their goals of care. Provider

barriers to using POLST include not feeling comfortable or trained to have quality conversations with patients about their serious illness and corresponding end-of-life treatment wishes, not having enough time to have these conversations, and not understanding the difference between POLST, advance health care directives, and “do not resuscitate orders.” Patient barriers to using POLST include not understanding the form and not having high-quality conversations about it with their healthcare provider.

Key informants were asked about their experiences with POLST eRegistry platforms and services. Nearly all endorsed the development and implementation of this technology. The primary motivators for implementing POLST eRegistries are to ensure a patient’s data is accessible by emergency medical services (EMS) personnel and emergency department (ED) providers, so that patient wishes can be honored; and, to standardize POLST processes to improve quality. Several eRegistry challenges were also cited: developing and implementing POLST eRegistries is expensive and time-consuming, using POLST eRegistries requires significant culture change and workflow accommodations, and the diversity of health system payment structures may slow adoption of POLST eRegistries.

Despite one informant’s expressed concern about the overall value of POLST eRegistries, all informants supported developing an electronic system for statewide exchange of POLST information among qualified medical personnel. However, their approaches to achieving this long-term goal differed. Four possible options emerged:

- ▶ **Develop a standardized electronic POLST form completion process/platform for use statewide**—a standardized input mechanism was seen as a necessary precursor to data sharing via a state repository.
- ▶ **Enhance existing local/regional health information exchange (HIE) systems and POLST registries**, as the primary means for accessing POLST data where and when needed throughout the state.
- ▶ **Create a statewide POLST data repository that enables interoperability**, allowing health care providers to upload standardized POLST data using their registry/method of choice.
- ▶ **Direct California’s POLST efforts to the development of a national POLST form/repository.**

Interviewees unanimously supported convening a task force comprised of key POLST registry stakeholders to study and select the most viable approach to achieving the consensus long-term POLST goal for California, and CCCC to lead the effort.

## Background

Ensuring that individuals experiencing a serious illness or medical emergency toward the end of life, who are unable to speak for themselves, receive medical care and treatment concordant with their wishes is essential to preserving the dignity of all human beings. POLST (Physician Orders for Life-Sustaining Treatment) was developed to enable patients to communicate these wishes. As both a physician order and patient-driven document, the POLST form is designed to lead to a thoughtful, high-quality conversation between a patient and a health care provider about the patient's diagnosis, prognosis, treatment options, treatment wishes, and quality of life. POLST was developed to complement, not replace, an advance directive. Designed for seriously ill individuals, POLST translates an individual's values and wishes expressed in the advance care directive into actionable medical orders that can be readily understood and followed by healthcare providers.

POLST was developed in Oregon in 1991 and became part of California state law in 2009 through Assembly Bill (AB) 3000, (Wolk, Chapter 266, Statutes of 2008). POLST was designed to be a standardized, easy-to-access, readable, and portable medical order. Once the form is completed and signed by a physician, nurse practitioner, or physician assistant and the patient or her healthcare decisionmaker, it travels with the patient and must be honored by healthcare providers across the healthcare continuum. Access to an accurate POLST form for health care providers treating patients during a medical emergency honors patient wishes, and improves care provided by emergency medical services (EMS) personnel, emergency department (ED) providers, skilled nursing facility (SNF) clinical staff, and hospital-based providers.

Gaining immediate access to a complete and accurate paper (bright pink) POLST form during an emergency, however, can be challenging for many health care providers and systems in California. Paper forms are easily lost or may not be available when needed most. Some POLST forms may contain conflicting orders or lack required signatures, making them invalid. Patients may also have multiple POLST forms completed over a period of time, with differing dates and orders, making it hard to determine desired treatment. In response to these difficulties with the POLST form, a number of health care organizations around the country are exploring or developing electronic POLST registries and platforms. Registries store the POLST data and enable users to query and retrieve patient POLST forms.

In 2015, California passed Senate Bill (SB) 19 (Wolk, Chapter 504, 2015), which required the state's Emergency Medical Services Authority (EMSA) to establish a pilot project to operate a POLST electronic registry (POLST eRegistry) with non-state funding. With financial support from the California Health Care Foundation (CHCF), the pilot was conducted from 2016-2018. To test the feasibility, functionality, quality, and interoperability of a POLST eRegistry and inform development of statewide electronic access to POLST, two communities with different health information structures were selected for the pilot.<sup>1</sup>

One pilot was implemented in the city of San Diego because of the presence of an active health information exchange (HIE) infrastructure through San Diego Health Connect. The other was implemented in Contra Costa County, which does not have an HIE. The lead for the Contra Costa pilot was the Alameda-Contra Costa Medical Association. Overall project management was provided by the Coalition for Compassionate Care of California (CCCC). Leadership, and project oversight were provided by EMSA, CHCF, and CCCC. While the two communities had different POLST eRegistry pilot experiences and results, a core group of lessons learned emerged from the pilot. For detailed information about the pilot and pilot outcomes, see [California's POLST Electronic Registry Pilot: Lessons for All States](#).

Building on the POLST eRegistry pilot, CCCC, CHCF, and EMSA identified a next phase to the project, which included identifying motivators and facilitators to successful POLST eRegistry platforms and services in California via interviews with stakeholders. Eighteen phone-based, semi-structured interviews were conducted in September and October 2019 with key informants representing healthcare systems, health information organizations, Emergency Medical Services Authority (EMSA), health plans, subject matter experts, a medical association, and state staff (see Appendix A). The goal of the interviews was to gather stakeholder perspectives on POLST and POLST eRegistries in California.

The qualitative research method of thematic content analysis was used to analyze interviewee responses to questions in four defined thematic categories: POLST value and adoption challenges, POLST eRegistry engagement—motivators and challenges, a long-term goal for POLST eRegistry platforms and services in California, and the role of CCCC in supporting a quality POLST ecosystem for California. (POLST ecosystem refers to the interconnected network of POLST elements ranging from POLST implementation, to quality patient-provider goals of care conversations, to interoperable POLST eRegistry platforms.) This report summarizes key findings from the content analysis of these thematic categories.

## Key Interview Findings

### POLST Value

The first thematic category explored the value of the POLST form. Understanding how providers and organizations think about and integrate POLST into their workflows proved a necessary foundation for subsequent conversations about POLST eRegistries and platforms. Prompts for this discussion included questions such as, “How does your organization think about or use POLST?”

“Organizationally, where do you see POLST having its intended impact?” “Is it falling short of its intended impact? If yes, why?” or “Does your organization have specific goals related to advance care planning and/or POLST discussions? If yes, are these goals an organizational priority?” and “Is your organization thinking about how patient POLST information travels across care settings?”

Key informants uniformly asserted that the POLST form was inherently valuable to both patients and providers. For patients, it was described as a culture-changing document. It offers seriously ill individuals an opportunity to have a high-quality conversation with their medical providers about what is important to them in the context of their diagnosis, prognosis, and available treatment options. Based on these discussions, patients’ treatment preferences regarding cardio-pulmonary resuscitation, medical interventions, and artificially administered nutrition are documented in the POLST, which guides care if the patient is no longer able to speak for herself. Healthcare providers also benefit from the POLST. It removes a burden common to those who provide care for seriously ill or frail patients: not knowing what care the patient wants in a medical emergency or at the end of life. It equally reduces the risk for patients of receiving either less or more care than they desire.

*“I see the value of POLST in information exchange at the point of care. We want to have the right care for patients concordant with their wishes at the end of life. Not honoring those wishes is not what patients or providers want.”*

– State Staff

*“The quality agenda around this is the most important. It is incredibly linear. If we spend time educating doctors and patients about the importance of POLST—what it is and who it is for—and clear up that it is not a replacement for a “do not resuscitate” order or a de novo form [a new POLST form]. The latter is a paradigm that some skilled nursing facilities use for every admission that has to go away. Then we will have the right document for the right people. POLST is the physician’s way to be with the patient at all times.”*

– Healthcare System

## System-Wide Engagement

With the value of POLST affirmed by interviewees, a subtheme emerged for key informants representing major health care systems, health plans, and a medical association: systemwide engagement with POLST. Many in this group reported tying their system's advance care planning and palliative care strategies to POLST. Sutter Health, for example, has a broad strategy around advance care planning and goal-directed care, which enabled them to link POLST to their Advanced Illness Management and palliative care programs.<sup>2</sup> Kaiser launched a comprehensive initiative, entitled Life Care Planning to educate patients and providers about advance care planning and POLST.<sup>3</sup> Providence Health uses a tiered whole person approach across the life span. Their framework involves 1) promoting advance care planning for all patients age 18 and older; 2) using the Serious Illness Conversation Guide for all patients with a serious illness; and 3) initiating quality conversations and POLST discussions with all patients with advanced illness in the last year or two of life.<sup>4</sup>

*“Our system is currently looking at developing an electronic POLST. We have paper POLST forms scanned into our medical record and we have a system where providers across multiple settings can access the information. We are very excited for electronic POLST to help us with quality to ensure there are correct responses and to increase efficiencies around getting the document signed by providers.”* –Healthcare System

## POLST Adoption Challenges

While the value of the POLST form was highlighted by interviewees, so too were barriers to using the form effectively and efficiently. The most common reasons reported for why **providers** do not use POLST or fail to have high-quality POLST conversations with patients include:

- Not feeling comfortable or trained to have quality conversations with patients about their serious illness and corresponding end-of-life treatment wishes.
- Not having enough time to have these conversations (average medical visit is 15-20 minutes)
- Not getting feedback on patients who used POLST during a medical emergency.
- Not understanding the difference between POLST, advance health care directives, and “do not resuscitate orders (DNR),” and which forms are appropriate for which patients.

*“There is a bit of an assumption that education is key to making quality conversations. That is a false assumption. Is it more about making a feedback loop that is persuasive—but you can also do education, incentives, and workflow changes.”* –Health Plan

An additional obstacle for providers is ensuring accurate completion of the POLST form with the required signatures. (In California, the POLST must be signed by a physician, nurse practitioner, or physician assistant AND the patient or her healthcare decisionmaker.) One interviewee explained this challenge: some health care providers and systems use social workers, nurses or other health care team members to initiate the POLST conversation with patients, but afterwards have difficulty obtaining the appropriate health care professional's signature on the POLST form. Without this signature, the POLST is invalid.



While most interviewees reported that there were few patient barriers to using POLST once patients and families understood its purpose and had open and educative conversations with their providers about their condition and treatment choices, one small segment of the patient population was identified as expressing resistance to POLST. This population was loosely defined as individuals who believe that recent California legislation involving serious or end-of-life care (e.g., POLST, California End of Life Option Act) represented efforts to “push them into foregoing care.” It was suggested that providers be aware of and sensitive to patients who may have this belief, or who have had health care experiences that reinforce this belief, so they can address their concerns and provide important clarifying information.

*“There are still so many problems around filling it [POLST] out correctly, having conversations about it, completing advance care planning. I also think there is some suspicion or reluctance on the part of some people about POLST. They feel there is a push to forego care. So, I think there is still a lot of education that needs to be done to accompany conversations around the form.”*

*–State Staff*

## **POLST eRegistry Engagement**

Technology affects all aspects of daily life today, including health care. Groundbreaking technological developments have occurred in how medication is dispensed, surgery is performed, disease progression is tracked, and health records are maintained. POLST is no exception. The spread of POLST coupled with the growing need for easily accessible, complete, accurate, and shareable POLST forms in emergency medical situations has contributed to the development of POLST electronic registries.

Currently, POLST eRegistries are operational in at least five California communities. Each registry uses a different technology platform and is managed by a different organization. In light of these developments and because several other California communities are at the threshold of developing their own POLST eRegistries, key informants were asked about these electronic registries. Providers and organizations involved with or in the process of implementing a POLST eRegistry were asked questions about their electronic registry experiences, such as “Discuss your organization’s reasons for investing in the POLST eRegistry,” “What level of leadership or buy-in did you need to move forward with the eRegistry?,” and “How is the eRegistry currently used within and across your organization?”

Providers and organizations without a POLST eRegistry were asked to “Describe if your organization has taken any steps to explore developing or implementing a POLST eRegistry? If not, please describe any barriers or challenges to these steps,” and “What would motivate (incentivize) your organization to invest in technologies to improve access to POLST across care settings? What would you need to know or have happen to prioritize this?”

Key informants representing health systems reported being engaged with a POLST eRegistry, albeit in different phases of organizational readiness. Some are in the development phase, studying the resources, workflow issues, and culture change efforts needed to implement a registry. Others are in



standardized to facilitate the integration of POLST into current workflows and EHRs. Last, registries offer a structure to incorporate clinical practice standards (e.g., mandating electronic documentation of quality patient-provider conversations prior to POLST completion) and data analysis. One interviewee noted that the data can be used to identify providers submitting incomplete POLST forms who may need POLST training.

*“We are working on the electronic POLST but don’t have that yet. Epic [EHR] is following the national POLST conversation and ideally wants that in place. I am working with EPIC directly. One of the limitations is that the signature block is not reducible, so patient and healthcare provider signatures might override some of the surrounding text. We hope to resolve it soon.”*  
–Healthcare System

## POLST eRegistry Challenges

Despite consensus regarding the value of POLST eRegistries, key informants cited multiple challenges transitioning from the paper POLST form to POLST electronic registries.

- **Developing and implementing POLST eRegistries is expensive and time-consuming.** Engaging a registry vendor or customizing an existing EHR system to host the exchange of POLST information takes significant financial resources and time. The latter requires a dedicated and often extensive setup, installation, and testing period to ensure hardware and software synchronization, and a platform that is integrated into existing workflows—for some systems, this may need to be done across multiple departments and settings.

*“As informaticists we develop data platforms and interfaces for clinicians, so they make sense to them. For example, clinicians provide a workflow packet (current and future state workflow) and we link it to clinical best practices. In that sense we know we have to have technology platforms that are easy to use, understand, and give people the information they need quickly. At the same time, we need to respect the principles of adult learning (andragogy) and the need for a multimodal approach. Users need compassion and time to adjust to and use the technology.”* – Healthcare System

- **Using POLST eRegistries requires significant culture change.** Motivating providers and health systems more broadly to use POLST eRegistries is challenging.

*“You need to get physician buy-in on development of the eRegistry to promote adoption. If the registry is not designed with clinical workflows in mind, it is burdensome (busy work) and there is no value-producing work.”* -- Medical Association

Key informants reported that healthcare providers and systems without a multi-prong POLST eRegistry engagement strategy may be reluctant to make the technological, workflow, and financial investment in POLST eRegistries. To engage these stakeholders in the change process, they suggested the following strategies:

- **Offer health care providers** (including medical residents) education and training on POLST and how to have quality conversations with seriously ill patients.

- **Build the POLST eRegistry** around provider workflows—include feedback loops for health care providers with patients whose POLST forms were accessed during a medical emergency or at the end of life.
- **Establish an audit system** to monitor the quality of POLST forms and conduct education and training for providers whose POLST forms are incomplete.
- **Ensure bidirectional (upload/retrieval) access** to POLST eRegistries for stakeholders that is easy and not burdensome.
- **Report on POLST outcomes** for patients whose POLST forms were accessed, e.g., were treatment preferences honored, etc.
- **Ensure the POLST eRegistry system design is interoperable**, i.e., has the potential to interface with local HIEs and a potential POLST state repository.

**Note:** Financial incentives were not identified as either a successful or effective mechanism for encouraging providers to use POLST eRegistries. To motivate payers and health systems to develop registry implementation plans and consider sharing or matching registry costs across regions and systems, several interviewees recommended developing a business use case for the electronic registry.

- **Diversity of payment structures across hospital and health systems may slow adoption of POLST eRegistries.** Key informants noted that because health care systems across California operate with different payer mixes (some function as integrated and capitated health care systems, others have a mix of payers, e.g., Medicare, Medi-Cal, commercial insurers), support for financing the development of electronic registries is variable, especially among smaller hospitals and health systems. To address this area, interviewees recommended understanding and addressing the motivations for hospitals and health systems *to engage or not to engage* in POLST eRegistry platforms based on diverse payment structures.

*“We need to understand that motivations to implement POLST and a POLST eRegistry may differ across hospitals and health systems in part because of the diversity of payers and payer mixes.”*  
 –Healthcare System

One concern regarding POLST eRegistries identified by one interviewee that merits mentioning is that the registries may have unintentionally shifted the locus of POLST control away from patients and onto emergency responders and ED providers.

*SB 19 made a monumental shift in the way we look at end-of-life decisions. It proposed to change the [POLST] model from a consumer-mediated document to a query-based system model. It made the shift from an individual responsibility to a system responsibility. We have yet to have a full understanding if that makes sense even to this day.”*  
 –State Staff

Most key informants affirmed that POLST eRegistries by definition and function are consumer-focused, because they honor patient wishes by ensuring access to complete, accurate, “single source of truth”<sup>9</sup> POLST forms during medical emergencies.

## Long-Term Goal for California POLST eRegistries

Key informants were asked, “What would be an appropriate long-term goal or big picture vision for POLST eRegistry platforms and services in California?” Despite one informant’s expressed concern about the overall value of POLST eRegistries, all informants supported developing an electronic system for statewide exchange of POLST information among qualified medical personnel. But approaches to achieving this long-term goal differed. Four possible options emerged (Table 1 profiles these approaches with accompanying advantages, disadvantages, and considerations):

- ▶ **Develop a standardized electronic POLST form completion process/platform for use statewide**—a standardized input mechanism was seen as a necessary precursor to data sharing via a state repository.  
**Support:** One interviewee representing a health plan endorsed this option as a discrete approach; however, all of the interviewees who supported a statewide data repository supported developing a standardized electronic POLST form as part of the repository.
- ▶ **Enhance existing local/regional health information exchange (HIE) systems and POLST registries**, as the primary means for accessing POLST data where and when needed throughout the state.  
**Support:** Three interviewees representing EMSA, a healthcare system, and state staff supported using local/regional HIEs and POLST registries to increase access to POLST.
- ▶ **Create a statewide POLST data repository that enables interoperability**, allowing health care providers to upload standardized POLST data using their registry/method of choice.  
**Support:** Twelve interviewees supported creating a statewide repository: six healthcare systems, two state staff, one health plan, two health information organizations, and one subject matter expert.
- ▶ **Direct California’s POLST efforts to the development of a national POLST form/repository.**  
**Support:** One interviewee representing a health plan endorsed this option; however, several interviewees (subject matter expert, healthcare system) recommended trying to tie in or coordinate California efforts on a statewide POLST registry with efforts to develop a national POLST form and repository.

Goal 3, “Create a statewide POLST data repository that enables interoperability, allowing health care providers to upload standardized POLST data using their registry/method of choice,” garnered the most support among informants.

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<sup>9</sup> Single Source of Truth refers to having either a single centralized database, or at least a distributed synchronized database, which stores all of an organization’s data in a consistent and non-redundant form.

*“There needs to be a big registry in the sky. If you have POLST at Kaiser and Sutter where is the EMS provider going to query? You don’t want to have them looking at three different systems. That is why you have a single source of truth. It would mean a larger investment. This [state] administration is very keen on health care so it could be funded through general funds or the state could generate special funds or they could charge a small fee for all the POLST generated in the state and that money could be used to fund a data technical provider.”*

*–State Staff*

More than half of interviewees who endorsed the statewide repository approach said provider participation in the repository should be mandatory, several recommended it be voluntary, and several did not voice an opinion. The chief reason cited for the mandatory approach is that it requires providers and health systems to participate in the repository, which eliminates resistance to a voluntary approach. Additional benefits to the mandatory requirement are that it would make the system work as intended, because all stakeholders, not a select few, would participate, and collected patient data [de-identified] could be used by health systems to assess patient needs and improve patient care.

**Support:** Seven interviewees supported mandatory provider participation in the statewide repository: six healthcare systems and one health information organization.

*“I think it should be mandatory from the state perspective. The challenge is going to be what are the data elements that are required for it? When I talk to other EHR-based ePOLST folks they don’t really have the mechanism or necessarily the infrastructure to convert paper forms into discrete elements. Whereas if you complete it [POLST] online then you can do that. We have done that to an extent in our system. We don’t have ePOLST but through a series of document types I can tell in our system how many POLST forms we have that are do not resuscitate compared to full code. To do this at the state level you need to account for the process you use and the staffing. But without a mandate, hospitals won’t do this universally.”*

*–Healthcare System*

Those in favor of a voluntary-use approach reported that incrementalism is a better way to advance big change. Given the complexity of using a statewide POLST repository, they recommended “a start slow and bring others along” approach. They also noted that if participation were mandatory, a significant number of stakeholders (small health care systems and hospitals, individual providers, SNFs, etc.) would incur prohibitive costs. Several interviewees expressed that some stakeholders unhappy with the mandatory requirement might pursue counter legislation, which could derail a statewide POLST data repository.

**Support:** Three interviewees supported voluntary provider participation in the statewide repository: two state staff, and one subject matter expert.

*“This is such a sensitive topic that requires the right amount of time and the right kind of conversation. It should not be another obligation that you check off the list, which is why I like the idea of having some broad parameters or guidelines or some loose requirement, or incentives even to encourage wide adoption of the use of the form and*

*then working toward submitting it into a registry as quickly as we can. That said, we need a plan with some benchmarks to keep us moving forward.” --State Staff*

A solution to the mandatory-voluntary dilemma was to make participation in the repository initially voluntary, for a set period of time, before making it mandatory.

**Table 1. Options for Achieving an Electronic System for Statewide Exchange of POLST**

OPTIONS	ADVANTAGES	DISADVANTAGES	CONSIDERATIONS
<p><b>Option 1: Develop a standardized electronic POLST form completion process/platform for use statewide—a standardized input mechanism was seen as a necessary precursor to data sharing via a state repository.</b> Promote an electronic POLST standard across all health systems and providers (including SNFs).</p> <ul style="list-style-type: none"> <li>▶ Develop a POLST electronic form</li> <li>▶ Set standards for the electronic POLST, include branching logic and other mechanisms to prevent conflicting orders, lack of required signatures, etc.</li> <li>▶ Consider coordinating development efforts with national POLST efforts</li> <li>▶ Do a phased state roll-out</li> </ul>	<ul style="list-style-type: none"> <li>▶ Patients and providers sign the electronic form on a tablet/computer — patients are then given a paper POLST to keep</li> <li>▶ Reduces completion errors</li> <li>▶ Increases access to recent/accurate POLST</li> <li>▶ Standardizes the electronic POLST form across health systems</li> <li>▶ Can potentially coordinate California efforts with national efforts to create an electronic POLST form</li> <li>▶ Sets up future opportunity for statewide registry because of standardized electronic POLST form</li> <li>▶ Provides time for key stakeholders (health care providers, systems, SNFs, and others) to develop capacity to use the standardized electronic POLST form before sharing POLST data via a statewide repository</li> </ul>	<ul style="list-style-type: none"> <li>▶ Transitioning systems to electronic POLST takes time, money, and culture change</li> <li>▶ Requires engaging with stakeholders across the POLST ecosystem, including SNFs</li> <li>▶ Coordination with national POLST efforts to promote electronic POLST may be difficult</li> <li>▶ Need to develop incentives to support voluntary stakeholder transition to electronic POLST form</li> </ul>	<ul style="list-style-type: none"> <li>▶ Review approach with diverse group of stakeholders to assess interests</li> <li>▶ If stakeholders support developing a standardized electronic POLST form, establish consensus-driven plan to implement this option</li> </ul>
<p><b>Option 2: Enhance existing local/regional HIE systems and POLST registries, as the primary means for accessing POLST data where and when needed throughout the state.</b> In lieu of developing a single statewide registry, develop current local and regional health information systems.</p> <ul style="list-style-type: none"> <li>▶ Organize access by region so EMS/others search a limited set of databases</li> <li>▶ Set criteria for access</li> <li>▶ Coordinate enhancement of local/regional systems</li> </ul>	<ul style="list-style-type: none"> <li>▶ Cost effective—builds on and leverages existing HIEs and other POLST eRegistry platforms as the information hub</li> <li>▶ Does not encroach on POLST vendor business opportunities</li> <li>▶ May be easier and more accurate to manage patient identifiers within a region (i.e., a smaller population) using existing processes/technologies, than attempting to create a state unique patient identifier system</li> </ul>	<ul style="list-style-type: none"> <li>▶ Need legislation to require that POLST forms be transmitted in a secure way to one or more locations, and that once they get to the designated location, they are shared with HIEs, e.g., queryable</li> <li>▶ Every form must be visible/interoperable</li> <li>▶ Need policies, procedures, and mechanisms governing access to regional health information exchanges</li> </ul>	<ul style="list-style-type: none"> <li>▶ Review approach with diverse group of stakeholders to assess interests</li> <li>▶ If stakeholders support enhancing existing local/regional HIE systems and POLST registries, establish consensus-driven plan to implement this option</li> </ul>



OPTIONS	ADVANTAGES	DISADVANTAGES	CONSIDERATIONS
<p><b>Option 3. Create a statewide POLST data repository that enables interoperability, allowing health care providers to upload standardized POLST data using their registry/method of choice.</b></p> <p>The repository would be managed by a designated state department; technology entity to manage data and quality oversight.</p> <ul style="list-style-type: none"> <li>▶ Create a task force (comprised of physicians, nurses, consumers, POLST eRegistry vendors, SNFs, other stakeholders) to develop the repository framework and technical design</li> <li>▶ Establish repository requirements (technical, storage, security, patient matching, etc.)</li> <li>▶ Develop a strategic blueprint (goals, timeline) and funding mechanism to implement repository</li> </ul>	<ul style="list-style-type: none"> <li>▶ Creates a central POLST database that end users can access anywhere in the state during a medical emergency</li> <li>▶ Repository requirements and standards will ensure a single source of truth</li> <li>▶ Provides an opportunity to create a standard “push”<sup>Φ</sup> for POLST users (EMS and ED personnel) and feedback loop for stakeholders</li> <li>▶ Removes current practice among EMS personnel of searching multiple registries to find patient POLST forms</li> <li>▶ Enables current POLST registries to maintain current operations; does not prohibit commercial vendors from expanding their business model into new regions and health systems</li> </ul>	<ul style="list-style-type: none"> <li>▶ Requires legislation to establish and fund repository</li> <li>▶ Developing repository requirements including patient matching with identification numbers likely to be difficult</li> <li>▶ Need policies, procedures, and mechanisms governing access to the repository</li> <li>▶ Requires addressing impact of repository on stakeholders, e.g., POLST vendors, SNFs</li> <li>▶ Selection of technology entity to manage the repository will require the state to develop a lengthy and potentially complicated competitive bidding/procurement process</li> <li>▶ Requires a voluntary/mandatory participation decision</li> </ul>	<ul style="list-style-type: none"> <li>▶ Evaluate adding the repository to an existing state registry</li> <li>▶ Explore possible federal funding for repository</li> <li>▶ Evaluate viability of establishing a single statewide HIE or network of networks covering HIEs for the repository</li> <li>▶ Evaluate state dept. to host repository—identify key elements the host dept. should have</li> <li>▶ Develop tech parameters for vendor to manage the repository data plus bidding/funding process</li> </ul>
<p><b>Option 4. Direct California’s POLST efforts to the development of a national POLST form/repository.</b></p> <ul style="list-style-type: none"> <li>▶ Advances in the use of POLST and POLST eRegistries by other states, signal an opportunity for California to lead efforts to standardize POLST forms and develop a national registry</li> </ul>	<ul style="list-style-type: none"> <li>▶ Would obviate the need for a separate California POLST repository</li> <li>▶ Growing congressional interest in lifting the ban on federal funding for a unique patient identifier would help implement a national POLST repository</li> <li>▶ A national POLST would facilitate greater adoption and spread of POLST forms for patients with serious illness unable to communicate their treatment preferences at the end of life</li> </ul>	<ul style="list-style-type: none"> <li>▶ Difficult to coordinate a national POLST form and repository, given diverse state approaches to POLST, POLST eRegistries, and end user access needs</li> <li>▶ Need state/federal legislation, funding, and a voluntary/mandatory participation decision</li> <li>▶ Need standards</li> <li>▶ Need federal entity to provide oversight and manage data</li> <li>▶ Would slow California efforts to create a statewide repository</li> </ul>	<ul style="list-style-type: none"> <li>▶ Next steps for this goal should be informed by the CCCC, given its leadership role working on the National POLST Paradigm</li> </ul>

<sup>Φ</sup> “Push” in this context refers to electronic alert notifications about patient POLST forms that show up on health information platforms.

## Coalition for Compassionate Care of California

Leading up to and following the legislation which established POLST in California in 2009, the Coalition for Compassionate Care of California (CCCC) and partners launched a POLST implementation initiative. In the first five years of the initiative, the partnership:

- ▶ Sponsored legislation establishing POLST in state statute
- ▶ Supported 27 community-based coalitions working on POLST at a local level
- ▶ Created a nationally recognized standardized two-day curriculum on the POLST conversation
- ▶ Developed POLST educational materials in a range of languages
- ▶ Launched a statewide taskforce of POLST stakeholders and a POLST website.

These efforts resulted in significant POLST spread in California. In light of CCCC's role in advancing POLST adoption and implementation throughout the state, informants were asked to discuss, "What role now and in the future should the CCCC play in supporting a quality POLST ecosystem?"

CCCC was universally acknowledged by key informants as the linchpin for POLST spread in California. Interviewees strongly supported CCCC continuing to serve as the preeminent POLST thought leader, visionary, educator, legislative advocate, and lead for POLST implementation (includes standardization, education, quality control, and systems integration).

## Conclusion

California has made substantial progress educating health care providers, patients, and families about POLST. While more work needs to be done to continue the spread of quality POLST implementation, the growing interest in and use of POLST eRegistries and platforms presents the state with a joint challenge and opportunity: *to find the best way forward using POLST eRegistry technology to preserve the integrity of the POLST form as a person-centered tool for communicating end-of-life health care treatment preference, while ensuring easy statewide access to accurate POLST information during medical emergencies.*

Interviewees recommended California accept this challenge and opportunity. They further recommended that CCCC, a leader in supporting a quality POLST ecosystem for California, convene a task force of POLST eRegistry stakeholders to study and select the most viable approach to developing an electronic system for statewide exchange of POLST information.

## Appendix A: Key Informants

- **Bonnie A. Arndt**, MSN, BSN, RN, Manager, Clinical Informatics Department, Clinical Informatics, Adventist Health
- **Terri Boughton**, MHA, Policy Consultant, California State Senate, Committee on Health
- **Scott Christman**, MS, Deputy Director and Chief Information Officer, California Health and Human Services Agency, Office of Statewide Health Planning and Development
- **Robert Cothren (Rim)**, PhD, Principal, A Cunning Plan, Executive Director, California Association of Health Information Exchanges
- **Torrie Fields**, MPH, Senior Manager, Advanced Illness & Palliative Care, Healthcare Quality & Affordability, Blue Shield of California
- **Matthew Gonzales**, MD, Chief Medical Information Officer, Institute for Human Caring, Providence St. Joseph Health
- **Kathy Graham**, MS, Health Services Researcher, Paramedic
- **Joseph Greaves**, Executive Director, Alameda-Contra Costa County Medical Association
- **Beth Mahler**, MD, Vice President, Clinical Integration, Sutter Health
- **True McMahan**, MD, Medical Director, Garden Grove Hospital Emergency Department
- **Bob Moore**, MD, MPH, MBA, Chief Medical Director, Partnership HealthPlan
- **Carlo Reyes**, MD, JD, MBA, President and Chief Executive Officer, Health-e-MedRecord
- **Linette Scott**, MD, MPH, Chief Medical Information Office, California Department of Health Care Services
- **Dan Smiley**, Chief Deputy Director, California Emergency Medical Services Authority
- **Elizabeth Steffens**, Executive Director, SacValley MedShare
- **Karl Steinberg**, MD, Chief Medical Officer, Mariner Healthcare Central
- **Melissa Stern**, MBA, Managing Director, Supportive Care Services, Kaiser Permanente Northern California; **Rosalba Carrillo-Vassel**, Program Manager, Epic Application Integration Specialist, Kaiser Permanente; **Hannah Whitehead**, Regional Clinical Practice Leader, Kaiser Permanente

- **Finly Zachariah**, MD, Medical Director, Informatics & Value-based Supportive Care, City of Hope;  
**Valerie Rhea**, MPA, Director Health Care Services and Advance Care Planning, City of Hope

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