



California's POLST Electronic Registry Pilot: Lessons for All States

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This report describes a pilot test of the feasibility of a statewide POLST (Physician Orders for Life-Sustaining Treatment) electronic registry designed to make patients' end-of-life treatment wishes immediately available to all health care providers regardless of time or place.

POLST Background

Toward the end of life, when seriously ill or frail people cannot communicate their medical treatment choices, they risk receiving care that is inconsistent with their wishes. The [National POLST Paradigm](#) aims to ensure that people get the medical treatments they want, and avoid those they do not want, when they cannot speak for themselves in a medical emergency or due to serious illness. It encourages patients and their health care providers to talk about potential medical interventions, considering their diagnosis, prognosis, treatment options, and goals of care. These conversations should bring out what is most important to the patient and what they think makes a good quality of life.

If the patient desires it, their wishes are then formalized on a POLST form, which is a portable medical order that emergency personnel and other medical care providers can follow whenever and wherever the patient has a medical emergency and is unable to communicate. POLST forms can indicate wishes to receive all treatments aiming to prolong life, or comfort-focused treatment, or specific selective treatments. The patient has full control over what the POLST form says and can change or void it at any time.

POLST conversations and resulting medical orders are appropriate for people with advanced serious illness or frailty who are considered to be at risk for a life-threatening clinical event, where standing medical orders are warranted. Healthier people who want to document their general preferences for future medical interventions and to identify a surrogate decisionmaker would use an advance directive, which is a legal document that provides general guidance, not a medical order.

In California, POLST forms must be signed by the patient (or legally recognized health care decisionmaker) and the provider — a physician, nurse practitioner, or physician assistant. Typically, the signed POLST form is given

to the patient so that it can (in theory) travel with the patient across care settings; the signing provider keeps a copy as well. In California, most POLST information is documented in paper format; these are bright pink POLST forms maintained and issued by the [California Emergency Medical Services Authority \(EMSA\)](#) and distributed by the [Coalition for Compassionate Care of California \(CCCC\)](#) through direct download from their [California POLST website](#), or purchased in bulk from [MedPass](#).

During an emergency, when POLST information is needed urgently, it may not be readily available, hindering care or resulting in treatment that is against the patient's wishes.

During an emergency, however, when POLST information is needed urgently, it may not be readily available. This could hinder care or result in treatment that is against the patient's wishes. In the absence of a POLST indicating other preferences, emergency medical services (EMS) personnel are required by law to do everything possible to save a patient's life, including CPR and putting the patient on a breathing machine. In California, [2008 legislation](#) requires medical providers to treat in accordance with the orders outlined in a patient's POLST and gives immunity to providers honoring a POLST document in good faith. Currently, 45 states have adopted POLST or similar programs.¹

Electronic Registries

To meet the challenges of rapid retrieval of POLST forms across clinical care settings and during medical emergencies, interest in the use of electronic registries to store and retrieve patients' documented wishes is gaining momentum. This approach enables health care providers to search for and retrieve POLST information specific to their patient.

The first POLST electronic registry was established in Oregon in 2009; by 2015–16, 45% of people who died in Oregon had an active POLST form in the Oregon POLST Registry (OPR) at the time of death. Eighty-seven percent of that cohort had "do not resuscitate"

orders, and 88% specified either comfort measures only or limited treatment,² indicating preferences other than the standard of care for emergency medical treatment. Another analysis of OPR data found that people with advanced illness or frailty who had a POLST form in the registry had their wishes honored 94% of the time.³

Given the potential to impact care quality and ensure that patient wishes are honored, a small number of states are in various stages of developing electronic registries to store, manage, and provide access to POLST forms. Some of these efforts are described in Table 1.

Table 1. Examples of POLST Electronic Registry Activity

	CALIFORNIA (2017–18 pilot activities only)	NEW YORK	OREGON	WEST VIRGINIA
Year POLST Registry Started	2017 (pilot)	2011	2009	2009
Single or Multiple Registries	Multiple	Single	Single	Single
Organization Providing Registry Oversight	California Emergency Medical Services Agency had coordination responsibility for pilot; co-led by Coalition for Compassionate Care of California and California Health Care Foundation	Excellus Blue Shield, a nonprofit insurer	Oregon Health & Science University Department of Emergency Medicine through contract with Oregon Health Authority	West Virginia Center for End-of-Life Care, initially funded by the West Virginia Department of Health and Human Resources and currently funded by West Virginia University
Document Completion	Paper form upload and electronic form completion available for some organizations	Electronic form completion	Paper form upload and electronic form completion	Paper form upload and electronic fax submission
Method of Access to Registry	Electronic health record (EHR) and electronic patient care reporting (ePCR) integration with optional web-based portal for upload; backup call center for EMS; bidirectional transmission available; health information exchange (HIE) integration where HIE is present	Web-based portal with optional EHR and HIE integration	Web-based portal and call center-based system, bidirectional transmission available, HIE integration complete, access also available via Emergency Department Information Exchange (EDIE)	Web-based portal with HIE integration with the West Virginia Health Information Network
Bidirectional EHR Integration	Yes	Yes	Yes	No
HIE Integration	Yes, where HIE is present (one pilot site)	Yes	Yes	Yes
Emergency Medical Service (EMS) Electronic Access	Yes	Yes	No	Yes
EMS Access via Call Center	Activated for one pilot site; discontinued in 2019	No	Yes	No

Source: Adapted and updated from Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment Documentation Access Through Health Information Exchange, Office of the National Coordinator for Health Information Technology, July 2018, <https://www.healthit.gov/topic/health-it-health-care-settings/long-term-and-post-acute-care>.

All clinicians who care for POLST-appropriate patients could benefit from access to POLST forms across care settings to understand what conversations have taken place regarding preferences for life-sustaining treatment, and to have access to that information in emergency situations.

In particular, timely access to POLST information would significantly benefit EMS field personnel, emergency department providers, hospital-based (inpatient) providers, and clinical staff in skilled nursing facilities (SNFs), to help them make critical decisions about treatment.

POLST Electronic Registry (eRegistry) Pilot Project Background

In October 2015, California Senate Bill 19 (Wolk) required the state's EMSA to establish a pilot project to operate a POLST electronic registry (eRegistry) with non-state funding. The pilot launched in September 2016 with financial support from the California Health Care Foundation (CHCF). Core implementation activities ran through December 2018. While the original timeline for the pilot was targeted at 20 months, initial implementation challenges associated with governance, technology integration, organizational readiness, and provider engagement necessitated an eight-month extension to the timeline.

EMSA, CHCF, and CCCC provided overall pilot leadership and oversight; CCCC also provided project management for the initiative.

The goal of the pilot was to test the feasibility, functionality, quality, and acceptability of a POLST eRegistry in order to inform and support the development of state-wide electronic access to POLST. These goals were to be tested in two types of environments:

- 1. A community where health information exchange (HIE) was actively used by health care provider organizations.** This would provide an understanding of challenges, successes, and lessons learned when health data exchange has an existing infrastructure within which POLST data can be integrated for a variety of health care organizations, including EMS, health systems, SNFs, and hospices. The City of San Diego, under the leadership of San Diego Health Connect (SDHC), an HIE organization, served as the community for this approach; SDHC contracted with Stella Technology as the technology vendor for this pilot site.
- 2. A community without an HIE infrastructure or culture, yet where strong interest and commitment to POLST and advance care planning was present, and where a variety of health care organizations understood the potential benefits of a registry.** Contra Costa County, under the

leadership of the Alameda-Contra Costa Medical Association (ACCMA), served as the community for this approach, and Vynca served as the technology vendor for this pilot site.

Additionally, an evaluation team from Oregon Health & Science University (OHSU) and the Public Health Institute (PHI) used quantitative and qualitative methods to assess outcomes and lessons of the pilot. Quantitative data were collected from pilot sites. Qualitative data included more than 200 key informant interviews with a wide variety of pilot participants, community stakeholders, and leaders of other POLST registries, as well as surveys and focus groups with registry users. This document is based on the final evaluation report provided to CHCF by the OHSU/PHI evaluation team.

Core Functionality Requirements

EMSA was tasked with creating guidelines for the pilot. The EMSA guidelines defined the pilot's operational structure, including the roles of pilot participants and the basic requirements for registry functionality. The pilot leadership team further defined core technical functionality requirements for POLST form input and retrieval, storage and processing, and security provisions. Throughout the pilot, revisions to these core functionality requirements were considered by the pilot leadership team in response to the practical realities of registry development in both communities.

Core Technical Functionality Requirements for Pilot Registries

Input and Retrieval

- ▶ Round-the-clock access to POLST forms in the registry through integration within EHR and via HIE portal, electronic patient care reporting (ePCR) (electronic records used by EMS personnel), and web-based registry portal.
- ▶ Ability to submit forms through integration within EHR and via HIE portal and the web-based registry portal.
- ▶ Ability to retrieve forms from EHR, HIE, and ePCR through integration with the registry, and via web-based portal.

- ▶ Use of single sign-on to minimize provider burden when accessing the registry through their EHR or other applications.
- ▶ Transfer of patient context or demographics if providers are already viewing a patient record in their EHR, HIE, or ePCR.

Storage and Processing

- ▶ Use of minimum set of patient-identifying demographic data elements in structured format.
- ▶ Availability of submitted forms and entered information for viewing by authorized users within 24 hours.
- ▶ Procedures in place to archive and display forms for users to be able to distinguish current from outdated forms.
- ▶ Procedures in place to protect the confidentiality of patient identifying data when stored electronically.
- ▶ Procedures in place to automatically verify that data fields of submitted electronic forms have been completed correctly and to detect errors (e.g., contain no inconsistencies or gaps).
- ▶ (Optional) Ability to reconcile forms against a standard statewide registry to ensure that forms of deceased patients do not remain active.

Security and Standards

- ▶ Secure EMS access from mobile platforms as well as a round-the-clock call center.
- ▶ Procedures in place for electronically authenticating the identity of authorized users.
- ▶ Ability to audit utilization (e.g., portal access, queries placed, forms retrieved).
- ▶ Ability to prevent simultaneous user account access from multiple locations.
- ▶ Compliance with technical standards to ensure proper configuration and security.

Structure of the Pilot Project — Two Environments

Each of the two pilot sites brought specific organizational, technical, and operational characteristics and challenges; together they enabled the pilot to gather a reasonable understanding of how POLST eRegistries may be implemented in different environments with different sets of stakeholders and assets.

San Diego

Led by San Diego Health Connect (SDHC), the San Diego pilot provided insight into how electronic exchange of POLST can be integrated into an HIE environment, and how HIE participants may incorporate POLST form submission and access to their preexisting HIE-related workflows. This community's technology infrastructure and longstanding culture of HIE between hospitals, health systems, EMS, and other provider types within the community were well aligned with the goal of testing POLST eRegistry implementation. Key assets included:

- ▶ SDHC's core HIE functionality and federated architecture, in which health care data reside with each participant organization (e.g., a health system), all participant organizations submit specified data elements to SDHC, and SDHC's query/response methods enable users to access these data from other organizations.
- ▶ Experience with community collaboration efforts, which during the pilot included leading an ongoing POLST workgroup of health systems and other stakeholders to discuss POLST eRegistry strategies, activities, progress, and obstacles.
- ▶ Experience implementing SAFR (search, alert, file, reconcile) functionality, which integrates EMS systems with HIE organizations to enable EMS personnel in the field to access and securely share a patient's vital medical information electronically.

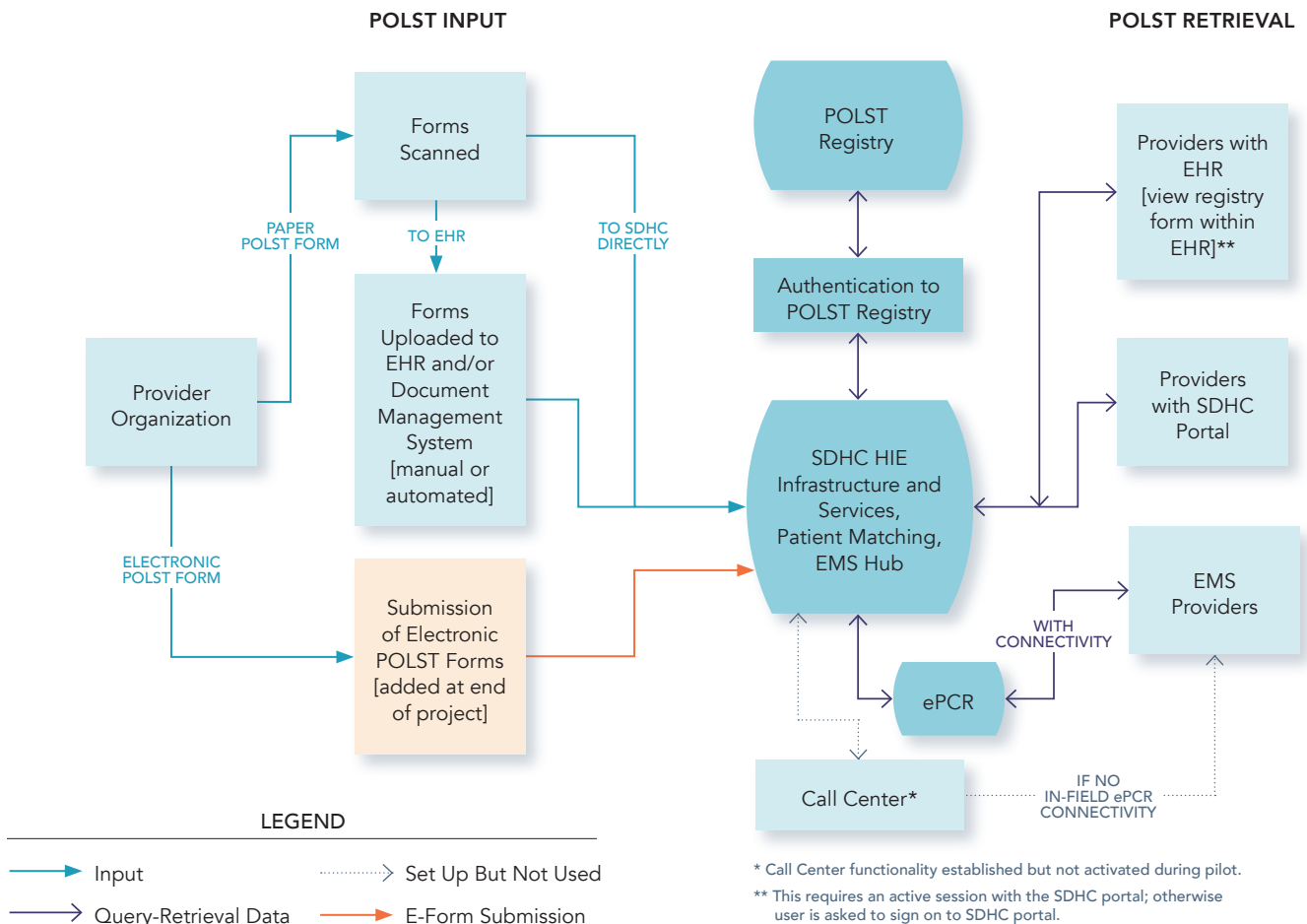
SDHC's participants (organizations that are members of the HIE) include broad representation of health care settings. While not all were involved in populating SDHC's registry, 34 organizations had access to forms in the registry, including eight health systems, one EMS agency, 15 Federally Qualified Health Centers, one hospice, and

one medical group serving 11 SNFs, along with various other local and regional organizations. SDHC's most active participants in the pilot registry efforts included Sharp HealthCare, University of California San Diego, Rady Children's Hospital, Integrated Health Alliance and their affiliated SNFs, and City EMS.

Two principal mechanisms were used for local providers to access the registry, depending on whether their organizations were participants in and actively transmitting data to the HIE. HIE participant organizations could have direct integration with the HIE and access to the registry through their standard HIE access mechanisms. Users in nonparticipant organizations could have access to the registry through a web-based portal. City EMS users had access through the direct integration of their ePCR with the HIE, and a backup call center had access to the registry through a web portal (although this functionality was ultimately determined by this site to be unnecessary).

Because SDHC had not been involved in receiving and processing POLST forms from HIE participants prior to the pilot, an immediate need was to better understand each participant organization's policies and practices regarding POLST document management. This knowledge informed the approaches used for each institution. At the outset of the pilot, the planned process for HIE participants to upload POLST forms to the registry was to scan paper POLST forms into their organization's document management system and automatically transmit those scanned forms electronically, via HL-7 message feed, to the registry (in addition to maintaining a copy of the form in the participant organization's EHR). This planned process had to be adjusted during the pilot given a number of technical barriers described under "Pilot Outcomes" below. Organizations without direct integration and with no automated feed were to use a manual process for uploading scanned forms through a web portal.

Figure 1. SDHC High-Level Flow View



Contra Costa County

The Contra Costa County pilot was led by Alameda-Contra Costa Medical Association (ACCMA), a professional association of physicians in Alameda and Contra Costa Counties that works to improve public health, health care quality, and patients' access to care. ACCMA had served as that region's local POLST coalition (promoting POLST education and implementation activities) and has led other community initiatives related to improving advance care planning. This pilot site provided the opportunity to understand POLST registry implementation in a setting with strong advocacy and collaboration among the physician community but lacking an HIE infrastructure, community-wide information exchange governance practices, or a common technology platform to house a POLST registry. The technology vendor for this site, Vynca, provided the registry platform with several distinct mechanisms of access to the registry depending on the provider type and its EHR system:

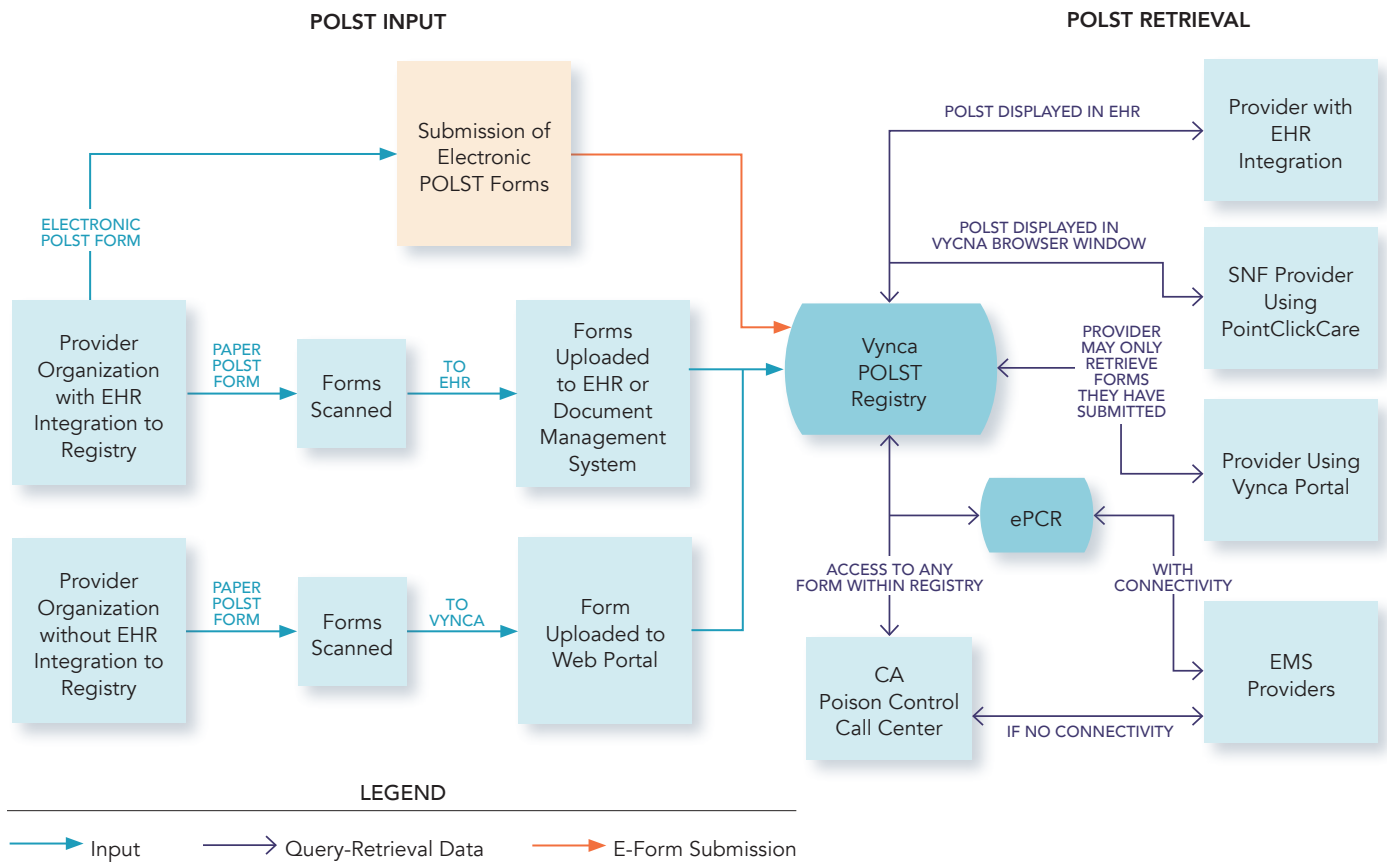
- ▶ Health system users had access to the registry through integration with the Epic EHR system; Vynca/Epic integration functionality pre-dated the pilot. Cerner EHR integration would have also been pursued if a health system using Cerner had engaged in the pilot, but this did not occur. EHR integration enabled POLST form submission to and retrieval from Vynca's registry.
- ▶ Skilled nursing facilities (SNFs) had access to the registry through integration with PointClickCare (PCC), an EHR system used by approximately 70% of SNFs in Contra Costa County, which enabled POLST form submission and retrieval. Vynca/PCC integration took place much later in the pilot than originally anticipated due to changes to PCC's approach to all third-party platforms.
- ▶ SNFs without PCC integration, and other providers in Contra Costa that were not integrated through other EHRs, had the opportunity to use a web-based portal to manually upload scanned paper POLST forms to the registry. Users of this service were only able to view forms that they or their designated staff submitted; the ability to access the full registry required EHR integration.

- ▶ Contra Costa County EMS personnel could retrieve forms from the registry through the electronic patient care reporting (ePCR) software of its ambulance provider, American Medical Response, via a query process. If internet connectivity to the registry was not possible in the field, EMS personnel could contact a backup call center, managed by California Poison Control, with search and view access to the registry.

Vynca's platform does not differentiate between the mechanisms or formats by which forms can be submitted to the registry as long as they are received from a previously validated source. Authentication of EHR users was achieved through direct integration to provide single sign-on, whereas individual web-based portal users registered through an identity verification process.

The most actively engaged participant in the Contra Costa pilot was Sutter Health, which had been in discussion with Vynca prior to the pilot about Vynca's full suite of advance care planning tools. While the geography of this pilot site was Contra Costa County, Sutter Health contracted with Vynca for an enterprise-wide deployment that extended across all of Sutter's hospitals and clinics in Northern California. Additional active participants included five SNFs; Contra Costa EMS and its provider, American Medical Response; and community providers including two additional SNFs, a community clinic, two hospices, and individual physicians who registered to submit POLST forms to Vynca's registry through the web-based portal.

Figure 2. Contra Costa County High-Level Flow View



Pilot Outcomes

Both pilot communities implemented their respective eRegistry solutions — enabling POLST form submission, storage, and retrieval based on the capabilities and needs of different organizations — despite numerous challenges. Original eRegistry design specifications were revised during implementation in response to the realities of document practices and workflows across the different provider types and care settings.

Overall, both pilot sites were unable to engage as many participants in the registries as they originally aimed to, due to a variety of factors explored in this report. While the limited participation meant the registries did not achieve community-wide penetration and use during the pilot period, each pilot community was able to engage different types of organizations (e.g., health systems, SNFs, EMS, and others), which facilitated learning about the unique barriers in different settings.

In both sites, POLST form submission was primarily performed by scanning paper forms, as opposed to electronic form completion and submission. This was in part related to the design of the pilot, which did not require electronic form completion capability. However, Sutter Health did elect to include Vynca’s electronic form completion capability in its enterprise-wide rollout; data from January 2019 showed that in that month, about 8% of Sutter’s POLST forms submitted to the Vynca registry were electronically completed. Late in the pilot, SDHC also worked with Stella Technologies to build electronic form functionality into the SDHC registry; by the end of the pilot, that functionality was undergoing testing and initial rollout.

Over time, both registries are anticipated to encourage increased use of electronic form completion, given its advantages in reducing incomplete forms or forms with conflicting orders by using real-time decision support and alerts.

Importantly, use of the POLST eRegistries continued after the pilot project (and grant funding) ended. Organizations in both communities recognized the value of access to POLST across care settings, and showed continued commitment to ensuring adherence to patient wishes.

eRegistry Use

Health system engagement was key to populating the registries during the pilot. While many individual providers and other organization types (SNFs and hospices, for example) regularly produce POLST forms, the sheer volume of forms created in hospital and health system settings and their robust integration of EHRs in patient care make them the necessary centerpiece of any POLST eRegistry effort. In SDHC's registry, 98% of the forms submitted came from health systems; in Vynca's registry, 99% were from health systems. Following are details from the two communities.

During the pilot, 30,378 unique POLST forms were submitted to San Diego Health Connect's registry, and 216,836 forms were submitted to Vynca's registry across Northern California, including the Contra Costa County pilot site.

San Diego

Over 15 months (January 2018 to March 2019), 30,378 unique POLST forms were submitted to SDHC's registry, including initial backloads and ongoing submissions. Sharp HealthCare was the highest-volume submitter with 27,394 unique forms, followed by University of California, San Diego Health with 2,377, the Integrated Healthcare Association (a medical group serving SNFs) with 478, and Rady Children's Hospital of San Diego with 129. The number of POLST form retrievals ranged from 113 to 620 across those sites (a total of 1,281 retrievals). The most form retrievals (1,700) came from City EMS, where the preexisting SAFR (search, alert, file, and reconcile) technology, which enables bidirectional information exchange between City EMS and SDHC, was modified to add POLST forms to the information automatically queried and retrieved for EMS personnel. This "push" technology — which alerted EMS personnel when a

POLST form was available in the registry for their patient — enabled them to access critical POLST information in the context of their existing workflow.

Contra Costa County

The Vynca registry went far beyond the pilot site of Contra Costa County, given Vynca's enterprise-wide contract with Sutter Health. Across Northern California, more than 130,000 POLST forms from Sutter were backloaded in February 2018; ongoing Sutter form submissions and other community participation in the county brought the total to 216,836 forms as of January 2019. In addition, 1,208 POLST forms were uploaded into the Vynca registry through the web portal from September 2017 through March 2019, both by SNFs (before their PointClickCare integration took place late in the pilot) and by other individual providers and organizations. After PointClickCare integration, 31 additional forms were uploaded from four SNFs in the county.

After initial form backloads, Sutter submitted an average of about 2,800 forms per month to the Vynca registry, and three San Diego health systems submitted about 1,400 forms per month to the SDHC registry, for a combined total of 4,200 form submissions per month for these two new regional registries. For comparison, the Oregon POLST Registry had 4,200–5,500 forms submissions per month statewide in 2018.⁴

POLST Document Quality, Practices, and Workflow

Across both sites, the pilot demonstrated the importance of understanding and addressing the quality and consistency of organizations' POLST practices before trying to integrate with a registry, to ensure that the information captured in the registry is complete and accurate. This includes attention to processes for:

- ▶ Identifying which patients are POLST-appropriate.
- ▶ Determining whether an accurate POLST form has already been completed.
- ▶ Facilitating a high-quality conversation about the patient's health condition and preferences for medical treatment, and completing a POLST form when desired.

- ▶ Identifying and addressing incomplete forms (e.g., missing signatures) or those with conflicting orders, as these forms are invalid.

Practices and workflows for managing POLST forms varied considerably within and across the different provider types. For example, each organization typically had its own internal process for scanning forms for electronic storage within its health records, as well as for electronic retrieval and archiving. Larger health systems with a range of patient encounter types (ambulatory office visits, hospital discharges, intakes, and registration) were especially challenged by variation in the location of POLST forms. Scanned paper forms were often inconsistently stored or labeled (e.g., bundled together with other advance care planning documents), requiring careful analysis to address these issues during the early stages of readiness assessment and planning.

Overall, pilot experience demonstrated the critical necessity of understanding existing workflows for various users and ensuring that the registry would cause minimal disruption to those workflows. If the registry required end users to use processes outside their usual workflows or to go through multiple steps, adoption was slower and more limited compared to settings with full EHR integration or where system prompts made it easy for users to input or retrieve forms.

Document Management Systems and POLST

Many health care organizations use document management systems that function alongside the main EHR. They store images such as x-rays and CT scans as well as paper forms like POLST.

San Diego's original registry design planned for automatic transmission of scanned forms from document management systems, via an HL-7 message feed, to the registry. In practice, however, customized solutions were needed based on document format (e.g., PDF versus TIFF or JPG), health system storage practices (e.g., varying location of documents within the EHR), and versions of the document management system in use by different health systems.

SDHC ultimately worked with the document management system vendor to establish a direct outbound feed of POLST forms from two participant health systems; this should ease the process of onboarding additional users to the SDHC registry in the future.

Outcomes Specific to Type of Care Setting

While many of the implementation enablers or barriers were specific to particular organizations or technology systems, some common findings were associated with the three main types of participant care settings — health systems, skilled nursing facilities, and emergency medical services.

Health Systems

- ▶ Because of their size and complexity — and the number of people impacted by changes in workflow or processes — health systems that successfully engaged with the registries provided the structure, support, and accountability of a dedicated project team as well as leadership support and resources. These capabilities enabled systems to push through barriers.
- ▶ Multisite health systems tend to approach any information technology (IT) project, including POLST eRegistry participation, with a systemwide strategy. For example, Sutter Health pursued a systemwide implementation across Northern California rather than implementing only at their one hospital in Contra Costa County during the pilot. Systemwide strategies impact the time and resources needed for implementation and are essential for health systems that stretch across the catchment areas of multiple regional registry efforts.
- ▶ Health system success relied on providers' and staff members' commitment to populating and using the registry as a "single source of truth," preventing duplication of effort in uploading or retrieving forms from multiple platforms and ensuring the registry holds the most current POLST forms. Trust in the mechanisms for version control was essential for user confidence in the registry.

Skilled Nursing Facilities

- ▶ Integrating SNFs into POLST eRegistries is essential, given the critical health status of many SNF patients, but significant challenges exist. In the pilot communities, SNFs demonstrated highly variable use of EHRs, many operating with a

combination of paper and electronic recordkeeping. In some SNFs, providers charted in their own health system's EHR and did not have access to the SNF's EHR, limiting the ability to move provider-dependent paper-based processes to electronic systems. These challenges mean POLST is susceptible to being maintained as a paper-only record in SNFs, challenging efforts to automate transmission of POLST forms to a centralized registry.

- ▶ In California, SNFs are required to document all patients' preferences regarding CPR. While POLST addresses more than just CPR, some SNFs may conflate documenting CPR preferences with POLST completion, and may make POLST form completion a routine part of the patient admission process. The pilot revealed a need to better understand how SNFs are using POLST forms in patient care, and how SNFs are communicating about patients' POLST information with hospitals as patients transition between these care settings. Considerations warranting attention include the following:
 - Ensuring POLST is only discussed with patients who are POLST-appropriate (people with advanced serious illness or frailty who are considered to be at risk for a life-threatening event) and that it is presented as optional, not a required admission form.
 - Securing POLST forms that may have already been created in other settings (such as during a hospitalization preceding the SNF admission) rather than creating new POLST forms. This requires clear information exchange workflows between these organizations.
 - Implementing reliable processes for primary SNF staff (nurses and nurse aides) to facilitate: timely POLST conversations between providers and patients, provider review of POLST forms that may have been populated by other staff, confirmation of the form's accuracy, and obtaining the provider signature.
- ▶ Pilot organizations observed that many SNFs are resource constrained, lacking localized technical expertise or project support to implement change

processes or new technology platforms. These constraints pointed to the need for a dedicated, coordinated effort by community stakeholders to ensure appropriate integration of SNFs into POLST registry efforts.

Emergency Medical Services

- ▶ EMS field personnel are primary end users of POLST eRegistries. The pilot demonstrated the importance of integrating POLST form retrieval into existing EMS workflows. For example, "push" notifications that were embedded in existing EMS ePCR systems — proactively informing users of the presence of a POLST form in the eRegistry — were preferred over manual search processes.
- ▶ Where query functionality was implemented rather than push notification, usefulness was limited by the low volume of forms from that specific geography. A registry needs to achieve a critical mass of POLST forms from a given geography (such as the EMS agency's catchment area) before it is made available for searches by EMS teams to help avoid the frustration of frequently unsuccessful searches.
- ▶ How and when EMS personnel could access forms from an eRegistry influenced whether and how POLST forms were consulted during an emergency. The pilot demonstrated some technical and operational considerations for EMS in this regard, including:
 - Whether connectivity issues impacted EMS personnel access to ePCR information outside of the ambulance when treating a patient
 - How long it took for paramedics to access records for a specific patient while on scene, versus during transport to the hospital
- ▶ The pilot experience pointed to the need to consider approaches for EMS access to POLST eRegistries that look different than for other care settings. If the infrastructure for information exchange with local EMS agencies is less robust, alternate approaches to full ePCR integration may be warranted, such as access via smartphone, medical alert bracelets/barcodes and associated phone applications, or dedicated call centers for EMS.

Lessons Learned

The pilot demonstrated many challenges and considerations for a statewide eRegistry rollout and long-term sustainability. Lessons learned in both regions produced insights and ideas for entities interested in pursuing POLST eRegistries. They fall into five main areas — some overlapping in practice — that are discussed below:

- ▶ Organizational readiness and commitment
- ▶ Community engagement / stakeholder and participant education
- ▶ Workflow considerations
- ▶ POLST document practices
- ▶ Technology features and functions

Organizational Readiness and Commitment

Ensure high-quality POLST implementation before starting an eRegistry project. This requires health care organizations to have robust POLST programs that ensure POLST is being implemented appropriately — as an optional process for people with advanced serious illness or frailty that is centered around high-quality conversations between providers and patients (or their legal decisionmakers) — and that the organizations' POLST forms are valid: complete patient information, signed, and containing consistent orders.

Optimize organizational readiness. In the pilot, the challenges encountered and the level of effort required for organizations to implement connections to the registries were greater than anticipated, especially in settings that did not already have a POLST-related effort underway. To assist other organizations preparing for a POLST eRegistry, the pilot partners team developed a [Readiness Assessment Tool](#) to identify some of the needed preconditions and capabilities and to help organizations anticipate and address barriers.

Establish and support a project champion/lead. It is critical to provide designated leaders with adequate time to manage the process of connecting to the eRegistry,

engage other stakeholders, and address problems as they arise. The POLST eRegistry champion/lead need not be a physician; in some settings, administrators, social workers, or medical records staff may be more appropriate and effective eRegistry champions.

Involve decisionmakers up front. Initial engagement of health systems should generally include a clinical champion, health system administrator, and the IT/medical records group, to ensure broad understanding, buy-in, and prioritization of the project as well as to clarify technical requirements and necessary preconditions to implementation.

Prepare for staff turnover. Turnover of staff within registry organizers and among champions at participant organizations happens; mitigating the disruption that turnover has on project activities and goals should be prioritized. Because much of the work of POLST eRegistry development is change management that depends on individuals, strong relationships between partnering organizations is essential to weathering staff changes.

Community Engagement / Stakeholder and Participant Education

Engage stakeholders in the eRegistry's targeted community early. To establish POLST eRegistry efforts as a shared priority, organizations need lead time to build budget and staff support. Promote awareness and buy-in among all organization types and stakeholders that are key to populating or retrieving forms. Early engagement helps those organizations understand how POLST eRegistry efforts fit into and may support their existing priorities.

Create standard processes and provide ample education. Any change process requires extensive education and participant engagement over time. Standard processes for input and retrieval must be supported by ongoing training and education of providers and staff.

Consider financial incentives to encourage participation. Funds were not available to encourage health care organizations to participate in the pilot, other than providing the technology for free during the pilot period.

This proved to be a deterrent for some organizations. Where possible, those leading eRegistry efforts may want to consider the role that financial support or incentives could play in promoting engagement.

Prepopulate POLST registries to a critical mass. Ensure that a sufficient volume of forms has been loaded to the registry in advance of going live and giving access to EMS, emergency departments, and others that require access to POLST forms. User adoption will suffer if searches frequently lead to no results.

Workflow Considerations

Ensure that processes will work for all user types — even those without EHR/eRegistry integration. Make submitting and retrieving forms as easy as possible for as many different provider types and settings as possible. This may mean providing a number of different ways that users can submit forms, including older processes (like fax or manual uploads) that seem antithetical to the long-term goals of automation but which may be necessary in the near-term. Ease of use needs to be appropriately balanced with sound data security practices; this balance can be difficult. Challenges with engaging participants in the pilot underscored the importance of easy access to inputting and retrieving POLST forms, even for those without EHR/eRegistry integration. Providers and organizations that had to incorporate several additional workflow steps proved difficult to engage or maintain as participants. If users experience frustration with using the eRegistry, they may quickly give up.

Where possible, avoid the burden of manual processes. In some cases, manual processes for tasks such as uploading forms may be necessary, either as an interim step while technical integration is being developed or on an ongoing basis due to technical limitations. However, organizations' motivation to participate in eRegistry efforts are likely to be much higher if automated, behind-the-scenes processes are in place.

POLST Document Practices

Assess how file format and documentation management system capabilities impact integration. Even with preexisting HIE functionality at the San Diego site,

activation of a feed for POLST forms was not straightforward because of variations in POLST file format and document management policies and practices among HIE participants.

Establish POLST form quality-assessment processes. The pilot shed light on preexisting POLST form quality problems, including incomplete forms (e.g., missing signatures) and those with conflicting orders that rendered them invalid. POLST form quality remained a concern throughout the pilot. Moving forward, eRegistry organizations and their participants should clearly identify their respective roles and processes for addressing these quality issues.

Ensure reliable, accurate documentation of signature date for version control. In some cases, forms that were uploaded to the registry in batches through automated feeds displayed the date of upload rather than the physician signature date; this made it difficult to identify the most recent form if a patient had multiple forms in the registry. Form submission workflows need to include careful attention to this data element.

Technology Features and Functions

Prepare a test environment. Providing a test environment with sample forms allows participants to gain comfort with the eRegistry and helps identify any workflow issues that can be addressed by tweaks to the technology before rollout.

Implement single sign-on (SSO) where possible. SSO between the EHR or HIE systems and the POLST eRegistry reduces the burden of having to log in with different usernames and passwords for authentication on these different systems. In addition to user authentication credentials, the SSO process includes the passage of patient identity information between the initiating application to the receiving application, further reducing user burden by taking away the need to manually search for a patient within the eRegistry.

Recognize and address the limits of optical character recognition (OCR). One pilot site had intended to use OCR technology to capture specific fields from scanned paper POLST forms. Although the OCR functionality

worked effectively in a test environment, during implementation the low quality of scanned forms prevented the use of OCR. Problems included holes punched on paper forms over key fields, labels placed over text, incomplete forms, low resolution or reduced-scale scans, and illegible handwriting. As a result, users uploading scanned forms had to manually enter required patient-identifying data. In addition to the burden on users, this required the registry to manage a manual exception queue for forms to be examined by staff to assess accuracy and completion before submission to the registry.

Where EHR integration is lacking, consider eFax options. In the interest of engaging as many providers and organizations in the eRegistry as possible, consider online fax (eFax) submission as one option for form submission, rather than manual methods for uploading scanned forms into a web portal.

“Push” POLST forms rather than relying solely on queries. Electronic alert notifications within the ePCR, EHR, or HIE system indicating that a POLST form exists in the registry allows for quick access and relieves providers or paramedics of the burden of manually searching for a form. In HIE settings, efforts should be made to link to a POLST eRegistry within the EHR banner of HIE participants to eliminate the need for users to check for forms in both the EHR and the HIE.

Three Potential Models

Although the pilot did not definitively demonstrate the feasibility of a single California POLST eRegistry, it did point to possibilities for future approaches. The pilot project evaluators identified three potential models with summarized pros, cons, and overall feasibility, as shown in the table on page 16.

Table 2. Potential Models and Pros, Cons, and Overall Feasibility

	SINGLE STATEWIDE REGISTRY	REGIONAL/LOCAL REGISTRIES	HYBRID SYSTEM
Description	A single statewide registry would replace regional registries and be a unified repository and operation for POLST forms. This could be run through a third-party vendor, by the state, or by another organization type (health care, university, nonprofit, etc.).	All current registries would continue to operate with no change. Registries would have the option to expand, or new registries could be established to cover areas without registries. Individual health care systems, health plans, and/or other local organizations would be responsible for funding.	All current registries would continue to operate and expand under guidelines set in place by a single overseeing entity. A universal data set structure would unify registries into a single repository or into a reference architecture that enables interoperability between different systems.
Pros	Would allow patients to travel throughout the state and still have their medical wishes honored without concern that the POLST form would be lost. Statewide system would allow for more cohesive data and better access for outcomes studies and research.	May provide a scalable cost model based on the number of organizations participating. Current registries could continue without disruption or change in workflow. State-level oversight may remain at the level of creating, and requiring the endorsement of, standards for registries to adhere to. Individual health care organizations could have complete control of their own data and the requirements for their own organization's workflow.	Theoretically may offer the benefits of the single statewide registry option without eliminating the presence of established regional registries. Current registries would continue with minor disruption or change in workflow. Both individual health care systems and an overseeing organization could fund eRegistry components. May provide the opportunity for patients' forms to be available across a broader region based on interconnectivity of registries. A standards-based data set structure would allow for more cohesive data outcomes studies. Individual health care organizations could still have control of their own data and workflow while contributing data to a broader network.
Cons	Would need considerable funding that may include multiple sources. Implementation and rapid momentum to scale would be difficult since many organizations would have to connect directly to the registry. Established, local registries would need to feed this model and would likely close down. Form access or bidirectionality would need to be unified for multiple health care types and systems. Would need to determine data ownership structure. Would need to sustain extremely high volume of forms/data. Would need to establish a lead organization accountable for the initiative.	Patients traveling away from their region may not have their medical wishes honored unless local registries establish interoperability with each other. Adoption may be low, especially for smaller clinics, SNFs, hospices due to potential local costs and lack of support (operational and technical). Ability to do any type of systems effectiveness or outcomes research, auditing, and standardization would be difficult.	Redundant mechanisms may mean more duplication in costs, workflow, and POLST forms in the registry. Adoption may be lower, especially for smaller clinics, SNFs, and hospices due to costs.
Feasibility	Although this approach would have the greatest opportunity to impact patient care statewide and to achieve economies of scale in implementation costs, extensive coordination would be needed to fund and execute a unified approach.	Highly feasible in the near-term since it builds on the current reality of regional registries throughout California, while allowing additional regions to build solutions that work for their environments.	Implementation and operations would take careful planning, and considerable time may need to be spent in determining oversight entity and funding.

Recommendations for States Seeking a POLST eRegistry

The goal of the pilot was to test the development and implementation of POLST eRegistries to inform the establishment of statewide electronic access. Although the pilot was conducted in California, the following recommendations for the development, implementation, and sustainability of a statewide POLST eRegistry apply to all states.

State and Regional Infrastructure

- ▶ **Assess the state's technology infrastructure capacity.** Conduct an environmental scan to determine if the infrastructure can support full interoperability for the exchange of data between care settings. Assess emerging technologies with potential to automate eRegistry functionality and integration with existing health information technology solutions and workflows.
- ▶ **Assess the organizational infrastructure to house a statewide registry.** Explore policy mechanisms that establish the governance framework in areas of data exchange, security and privacy, ownership, and promotion of standards in electronic POLST form completion. Work with health care professional organizations and patient advocacy groups to develop guidelines for registry-based POLST management practices.
- ▶ **Identify funding sources for sustainability.** Assess future funding sources to invest in both eRegistry development and the integrity of the underlying POLST program (education, training, marketing). Health plans and risk-bearing health care entities would be most likely to see the value in investing in a statewide registry.
- ▶ **Invest in POLST education, training, monitoring, evaluation, and standardized guidelines.** All of these are critical for strengthening the quality and sustainability of a registry.

Community Resources

- ▶ **Engage with and understand the community.** The development and implementation of a registry must be founded on a comprehensive understanding of patient flow patterns, the care systems that patients use, and where POLST forms have been created and used within the community.
- ▶ **Convene community stakeholders dedicated to solving a shared problem.** Bring together health systems, emergency services, hospitals, long-term care facilities, hospices, and community physicians to discuss the development, implementation, and targeted outcomes of an eRegistry.
- ▶ **Evaluate implementation readiness.** Assess organizations' leadership, strategy, technology, and content management practices in order to understand the degree of customization that will be required during implementation. Readiness will be affected by organizations' cultures, technology infrastructures, resource availability, and workforce capacity.
- ▶ **Work effectively with health systems.** These organizational systems of care tend to view technology adoption at the enterprise level, rather than at the geographic level, and each system has its own unique culture. Implementation timelines must align with the systems' established internal practices for conducting IT-related due diligence.
- ▶ **Promote POLST education across the community.** Implement grassroots outreach and a marketing campaign to promote POLST, identify champions to advocate for high-quality POLST use within organizations, and develop a training infrastructure that engages participants in continuous education.
- ▶ **Present a business case.** Enable providers, payers, and other stakeholders to see the value of community-wide participation. The introduction of continual research capabilities with a registry will help demonstrate its ongoing value for patients and health care systems.

Prioritization of User Needs

- ▶ **Promote the development of user-centered products.** eRegistry products and procedures should integrate POLST workflows seamlessly with existing EHR and HIE functions.
- ▶ **Adopt best practice guidelines.** Best practices for eRegistries include automated bidirectional integration, standards for POLST document workflow management, continuous quality improvement metrics, and outcomes research.
- ▶ **Introduce quality audits of scanned paper forms before submission to the registry.** These should be accompanied by an educational feedback loop to target deficiencies in POLST form completion.
- ▶ **Provide ongoing user support.** Provide education, training, and continuous communication on POLST eRegistry use. Include nonphysician staff, such as nurses and social workers, as well as retrieval training for those with a greater need to access POLST forms (e.g., EMS and ED personnel). Install user support services to assist with registration, training, and troubleshooting, including contingency procedures in the event of system downtime.
- ▶ **Invest in supporting organizations through change management activities.** Technology adoption and implementation rely more on the human-dependent aspects of change than the technological ones. For full implementation to be effective, support organizations in the work of identifying and implementing needed workflow redesign.

Conclusion: What's at Stake

Providers and patients have the power to improve advanced illness care by talking about and documenting patient preferences through POLST. But some seriously ill or frail patients will not get the care they want unless this information is reliably available when and where medical crises occur. For this to happen, health care entities must enable efficient communication of patient desires to the providers who need immediate access to them.

Widespread electronic exchange of POLST — ideally statewide — offers the most promising solution, but as this pilot project found, technical and other barriers may confound accessibility in a variety of ways. The findings and resulting recommendations provide some clarity and guidance to help states and health care organizations overcome the challenges that impact end-of-life care for so many.

Appendix: Other Models

Oregon POLST Registry Operations and Logistics

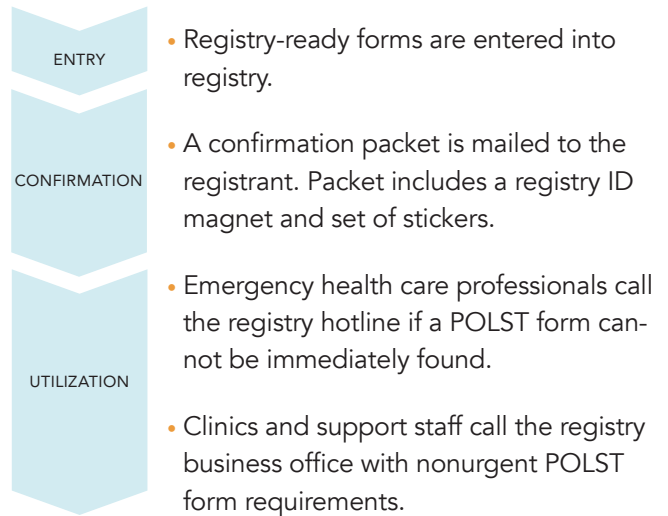
In 2007, the Oregon legislature passed Senate Bill 329, establishing the Oregon Health Fund Board, which was chartered with developing a comprehensive plan to ensure access to health care for Oregonians, contain health care costs, and address issues of quality in health care. In 2009, the legislature passed House Bill 2009 as part of Oregon’s health care reform efforts, enabling Oregon to launch the nation’s first 24-hour electronic POLST registry on December 3, 2009. The law creating the registry does not require a patient to have a POLST form. However, when a patient does elect to complete or revise a POLST form, the signing health care professional must submit the form to the registry unless the patient opts out of the registry.

Methods for health care providers or health information management systems to submit POLST forms to the Oregon POLST Registry (OPR) include fax, mail, secure File Transfer Protocol, and ePOLST direct submission.

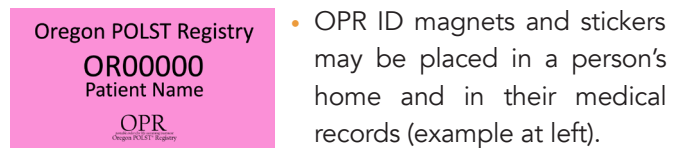
The registry’s data entry team uses the following steps for form entry:

- ▶ **Validation:** Initial verification that all required elements are present on the form
- ▶ **Entry:** Patient matching, demographic entry, and recording of medical orders into the database
- ▶ **Activation:** Last check to verify patient, assess form validity, and check for entry errors before the form goes live in the registry

The overall process includes these steps:



Registry ID magnets and stickers:



- OPR ID magnets and stickers may be placed in a person’s home and in their medical records (example at left).
- The magnet and stickers are used to alert emergency medical professionals and other health care professionals that the patient has a POLST form on file with the registry.
- POLST registry magnets and stickers do not replace the original POLST form.

Incomplete forms:

- Forms that have missing or illegible information, preventing them from being entered in the registry, are faxed back for clarification. These forms are considered Not Registry-Ready, or NRR. For example, this portion of a POLST form shows an illegible signature and a missing date.

E <small>Must Print Sign & Date</small>	ATTESTATION OF MD / DO / NP / PA / ND (REQUIRED)		
	By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's current medical condition and preferences.		
	Print Signing MD / DO / NP / PA / ND Name: required	Signer Phone Number:	Signer License Number: (optional)
MD / DO / NP / PA / ND Signature: required	Date: required	*Signed* means a physical signature, electronic signature or verbal order documented per standard medical practice. Refer to OAR 333-270-0030	
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED SUBMIT COPY OF BOTH SIDES OF FORM TO REGISTRY IF PATIENT DID NOT OPT OUT IN SECTION D			

Other reasons for health care providers or health information management systems to notify the OPR:

- A form is updated or a new form is received
- A POLST form is revoked or voided
- A patient is known to be deceased

Nonurgent access to a patient's POLST form is available for health care professionals via fax; in these cases, POLST orders cannot be relayed over the phone.

Health care providers can obtain a copy of a registered POLST by calling the OPR business office and faxing documentation confirming the patient is in that provider's care. Once documentation is received, forms on file are faxed to the provider within one business day.

Continuous Quality Improvement

The OPR partners with the Oregon POLST Program to carry out CQI measures. The registry is responsible for creating a number of reports that can be used for process improvement:

- Annual reports: OPR annual report (all operations metrics); individual institution metrics reports (confidential — for education only); signer metrics reports (confidential — for education only)
- Monthly reports: OPR monthly data report (all operations metrics); high-volume submitters data reports (confidential — for education only)
- Ad hoc: Data reports for research requests; quality audits (confidential — for education only)

Endnotes

1. "Program Designations," National POLST Paradigm, <https://polst.org/programs-in-your-state/>.
2. Dana M. Zive et al., "Changes Over Time in the Oregon Physician Orders for Life-Sustaining Treatment Registry: A Study of Two Decedent Cohorts," *Journal of Palliative Medicine* 22, no. 5 (May 7, 2019): 500–7, doi:10.1089/jpm.2018.0446.
3. Erik K. Fromme et al., "Association Between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and In-Hospital Death in Oregon," *Journal of the Amer. Geriatrics Society* 62, no. 7 (July 2014): 1246–51, doi:10.1111/jgs.12889.
4. *2018 Oregon POLST Registry Annual Report*, Oregon POLST Registry, n.d., <http://www.orpolstregistry.org/oregon-polst-registry/reports/>.