National POLST Technology Guide

Executive Summary

Note: National POLST started describing “POLST” as “portable medical orders” in 2018, though most states continue to use an acronym.¹

Technology is transforming delivery of care. For POLST to be most beneficial and useful, the most recently completed POLST form (medical order) needs to immediately available when and where health care professionals need it to make treatment decisions.² Unfortunately, most EHRs (even those within the same health care system) and other technology systems are not interoperable, meaning they do not have the ability to easily transfer data if they have the ability to transfer data at all.³

Growing demands for care coordination, particularly in light of COVID-19, require considering how to securely integrate POLST into technology. Working with over 100 POLST program leaders, vendors, and experts in a number of fields (technology, security/privacy, EHRs, HIEs, registries, legal, patient communications, state and federal government and emergency personnel) National POLST undertook the creation of this guide to investigate both what was possible with current technology today and what we should focus on tomorrow.

The POLST process emphasizes eliciting, documenting and honoring patients’ preferences about the treatments they want to receive during a medical emergency or as they decline in health. After a discussion of the patient’s diagnosis, prognosis, treatment options and goals of care, the health care professional can complete a POLST form for the patient. The POLST form is not just for emergencies but also provides guidance to other facilities and hospitals as patients transition across the care continuum. POLST is a national movement encouraging consistency among the POLST process and form to support patients wanting to use POLST who travel among states, even if just across a border for treatment.

This guide shares state experiences and recommends standards to help ensure technological interoperability of POLST data nationwide, meaning how a POLST form can travel among technology systems throughout the country to be available when and where the patient or health care professional need it. Where possible, this guide provides best practice recommendation, however data are not yet available in many areas to make a definitive judgment. In those instances, current options were shared.

Technological interoperability is a huge undertaking with many possibilities, but many small steps support the overall vision. A standalone EHR, either in a single facility or in a large health care system, can serve as the single source of truth about current POLST forms for patients within its system. Registries and HIEs can expand institutional and geographic boundaries. Improving standard data sets and data exchanges are opportunities that may lead to bigger success and movement towards connecting disparate systems across all care settings.

¹ National POLST. (n.d.) Logo. www.polst.org/logo
At the end of the day, it will take trust (both at the level of POLST form completion and at the level of data exchange), the right workflow, and a standardized data set to achieve technological interoperability. POLST programs leaders, health information exchanges, electronic medical record vendors, policymakers, application vendors and other health care and industry leaders are encouraged to review and reference this guide when considering technology options to support POLST implementation efforts.

Thank you to our sponsors!
This project would not have been possible without the sponsors for our two working conferences. Our supporters are listed in order of funding support provided to this project:

- The John A. Hartford Foundation
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- Medcordance

Thank you to all participants!
This project also would not have been possible without the volunteered time of so many POLST program leaders, vendors, and experts in a number of fields (technology, security/privacy, EHRs, HIEs, registries, legal, patient communications, state and federal government, EMS). A full list of the participants is provided towards the end of this guide.
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A glossary is provided at the end of this guide. Three terms highlighted below specifically identify individuals responsible for the implementation of POLST forms and are referenced throughout the document.

- “EMS” refers to responders that are dispatched to a medical emergency to provide emergency medical care. EMS is comprised of emergency medical technicians (EMTs), advanced emergency medical technicians (AEMTs), paramedics, and other medical providers based on state categorization. EMS provides emergency and interfacility care using ground and air ambulances. While there are national standards for certification and training, most providers are also certified through their respective states, and authorized to practice through their agencies. EMS care delivery may vary drastically based on employer-specific criteria, local, and/or state regulatory and accrediting bodies.

While EMS are also health care professionals this guide calls them out specifically since they have unique needs when it comes to honoring a POLST form.

- “health care professionals” refers to any health care professional, provider or clinician involved in the POLST process acting within their scope of practice. This guide distinguishes those licensed health care professionals who have authority to sign POLST forms from other health care professionals, including nurses and social workers, who are typically part of the care team supporting POLST and may be involved in POLST conversations even though they lack authority to sign a POLST form.

- “participants” refers to those individuals who participated in the 2018 and/or 2019 National POLST Technology Conferences (a full list is provided at the end of this guide)
National POLST started describing “POLST” as “portable medical orders” in 2018, though most states continue to use an acronym.\(^4\)

Conceptually, POLST is an approach to advance care planning (ACP) for patients who are considered to be at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty.\(^5\) The POLST process emphasizes eliciting, documenting and honoring patients’ preferences about treatments they want to receive during a medical emergency or as their health declines. At the end of the process, a health care professional may document these treatment preferences in a portable medical order called a POLST form. POLST forms must be completed by health care professionals and signed by a licensed provider; a physician, advanced practice registered nurse or physician assistant in line with their scope of practice and state law.\(^6\)

While both POLST forms and advance directives are advance care planning tools, they serve different purposes. The POLST form complements advance directives in that it serves as a translational tool and it can promote continuity of care. Advance directives are legal documents that cannot be honored by EMS, instead advance directives require interpretation and discussion about how to apply the general patient wishes to the current emergency.\(^7\) Since POLST forms are medical orders, they can be honored by EMS.

A POLST form consists of a set of medical orders that applies to a specific population of patients and addresses a limited number of critical medical decisions. It was designed to support patients throughout the health care continuum as they transition between health care settings (i.e., acute care, sub-acute care, post-acute long-term care, home care, etc.). POLST forms communicate a limited number of critical medical decisions, namely the use of CPR and mechanical ventilation, to other health care professionals, including emergency personnel (EMS), when the patient lacks the capacity to speak for themselves. Not solely for emergencies, POLST forms also provide guidance to:

- hospitals for creating in-hospital resuscitation status and other treatment order sets;
- facilities for transfer care upon discharge; and
- other health care professionals. By providing goals of care statements, the POLST form assist other health care professionals coordinate treatments that align with the patient’s preferences.

POLST forms primarily serve three groups of stakeholders:

- **For patients, families, and caregivers:** it is a medical order communicating the patient’s treatment preferences to health care professionals, including EMS. It documents medical orders decided upon in collaboration with their health care professional and states individual treatment goals, providing a much-needed context for the types of care preferences the patient chooses. This can be helpful in assuring loved ones that the treatment decisions were carried out in line with the patient’s preferences, current health status, prognosis, and goals.

- **For health care professionals:** it is a medical order intended to communicate patient treatment preferences and goals to other health care professionals, helping ensure treatments provided are consistent with the patient’s stated preferences.

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\(^4\) National POLST. (n.d.) Logo. [www.polst.org/logo](https://www.polst.org/logo)


\(^6\) National POLST. (2020, June 30). *Signature Requirements for Valid POLST forms by State*. [https://polst.org/state-signature-requirements-pdf](https://polst.org/state-signature-requirements-pdf)

• For EMS: unlike advance directives, it provides immediately actionable orders in an easy-to-understand format regarding respiratory interventions prior to and including full resuscitative measures and transporting the patient to the hospital.

The success of POLST depends on five processes:

1. verification of the appropriateness of the patient’s status for a POLST form to prevent overuse or inappropriate use of the medical order;
2. personal, high-quality collaborative conversations between health care professionals and patients (or surrogates) about the patient’s goals of care considering their current diagnosis, prognosis, and treatment options (including risks and benefits of each);
3. accurate translation by the health care professional of those patient treatment preferences into medical orders on a POLST form;
4. the health care professional’s ability to know that a POLST exists for a patient and to easily locate the most current version of a patient’s POLST form when needed; and
5. the health care professional’s knowledge about how to correctly interpret and follow POLST form orders, thereby enabling them to honor patient treatment preferences.

Project Background

National POLST exists to create and support a shared vision that all states adopt POLST, resulting in greater national consistency of the process, improved patient care and greater patient control and direction over medical treatment when they cannot speak for themselves.8

By the time the National POLST Paradigm Task Force (Task Force), the precursor to National POLST, was created in 2004, six states already had POLST forms and programs. While sharing similar goals, they were using different forms, colors, and acronyms—already too much variation for effective reciprocity. Rather than agree on a single shared version for all programs to use, the founders created the Task Force to establish standards and encourage all state programs to develop their own forms using those standards. As a result, in 2017, there were:

• 47 versions of POLST forms
• 16 names for POLST programs (MOLST, POST, etc.)- a full list is available at www.polst.org/map
• 5 different colors for POLST forms
• 50 POLST programs, each with its own leadership and coalition

In 2017, Susan Hickman and Rebecca Critser published a review of all endorsed programs POLST forms. They compared those state POLST forms to the national POLST form requirements and found that, while the form requirements helped create substantive similarities among state forms, significant variation existed, leading to issues with reciprocity between states.9 The standards and reliability impacting standardization, repeatability and scalability were insufficient for achieving National POLST’s vision. Form variation undermines the vision and unnecessarily limits the value of POLST, creating unnecessary

9 National POLST is the expert and preeminent leader in advancing POLST, creating the standards for POLST implementation, including the process, forms, program recognition, guidance, and policies through consensus. All programs are invited to participate in National POLST; those that choose to are recognized as “active,” “endorsed” or “mature” on this map: www.polst.org/map.
administrative burdens and worries on the very patients POLST intends to help. National POLST is working to address this through its National POLST form project.\(^{11}\)

There is no point in investing in variability where it doesn’t need to exist. As more POLST programs start adopting technology—specifically registries—National POLST was concerned that variation in technology systems could similarly pose challenges to National POLST’s mission and vision.

Goals of this Guide

Technology allows for rapid and effective sharing of POLST forms \textit{within} and \textit{across} care settings, which is of particular importance for POLST as a portable medical order. Within the POLST framework, technology can improve POLST by:

- Improving access to POLST at the point of care, thereby improving health care professional ability to honor POLST form orders and reduce medical errors;\(^{12}\)
- Improving the process of completing a POLST by providing just-in-time education such as videos and graphics to aid in the conversation between the patient and health care professional;
- Reducing administrative burdens by automating data entry and, where appropriate, registry submission;
- Standardizing the processes health care professionals use to complete forms, including forcing functions that ensure required fields are completed and that forms are internally consistent;
- Enabling appropriate access by only allowing authorized users to complete and access forms and providing easy electronic access and sharing of the completed POLST form to patients and loved ones;
- Validating POLST form accuracy and integrity; and
- Providing additional document protections by storing electronic copies in more than one location.

The growing demands for care coordination require considering how POLST can be securely integrated into technology. The purpose of this guide is discussing how health care professionals can know that a POLST exists for a patient and to easily locate the most current version of a patient’s POLST form when needed. National POLST wants to encourage the effective and appropriate use of technology to support POLST, as well as capitalize on the efficiencies gained using a consistent and unified approach to technological interoperability.

This project examined the four areas of technology most likely to support National POLST’s goals:

1. \textbf{Interoperability and Data Exchanges}: architecture foundations that follow principles of trust, security, identity, portability, and accessibility; provides standards that are needed to ensure data can be pulled or pushed as needed for access in all care settings.
2. \textbf{Electronic Health Records (EHRs)}: how health care professionals can create the POLST orders, document the conversation, capture the history of previous conversations and orders, and retrieve orders for provision of care.

\(^{11}\) National POLST. (n.d.) \textit{National POLST Form: Portable Medical Order}. \url{https://polst.org/national-form}

3. **Registries:** centralized storage systems for POLST forms that permit POLST forms to be uploaded from and accessed by health facilities and health care professionals throughout the area of coverage.

4. **Mobile Technology:** what viable mobile technologies would support patients and health care professionals like EMS, helping facilitate access to and sharing of POLST forms/data outside health care facilities.

In examining each, this guide identifies technology-related priorities National POLST should be advocating for on a national level, as a precursor to developing a concrete strategy for nationwide policy. The goal is to have a nationwide framework and consistent approach to the electronic exchange of, and access to, POLST forms/data, which would help the electronic exchange of, and access to, POLST medical orders, which would help the electronic exchange of, and access to, POLST medical orders spread more quickly.

Consistency can improve the ability to research the impact of POLST and POLST electronic exchanges, helping align technology development (software, registries, applications, etc.) that supports POLST and National POLST’s fundamental values, helping ensure a robust POLST process, eliminating invalid POLST forms (forms that are missing required elements or have incompatible orders, and enabling immediate access to POLST forms everywhere -- ultimately improving the ability of the U.S. health care community to provide care consistent with patient wishes.

In creating this guide, participants considered current methodologies versus creating a potential new methodology to support the recommendations for integration of POLST and technology by developing recommendations that ensure the integrity of POLST, including supporting a nationwide transition from paper to digital POLST forms without creating unnecessary barriers or risk. This guide hopefully encourages POLST program participation in National POLST where leaders collaborate on policies, best practices and guidance that support POLST generally. Additionally, this guide hopefully eliminates the need for states to conduct their own analysis.

This guide shares experiences from states to date and recommends standards to help ensure POLST form technological interoperability of POLST data nationwide, meaning how a POLST form can travel among technology systems throughout the country to be available when the patient or health care professional needed it. Where possible, recommendations for best practices were identified, however data are not yet available in many areas to make a definitive judgment. In those instances, current options were shared.

**Relationship Between Patients and POLST Forms**

A significant part of the 2018 conference focused on the individual patient’s relationship to their POLST form, since this would inform to what extent technology should enable patient access to POLST forms.

**Supporting the POLST Form Process**

Participants agreed technology should support and produce tools that could be used to assist the patient-health care professional conversation and process behind completing a POLST form, not just provide a blank form for completion.

**POLST Form Ownership**

In general, data are owned by the person or organization who houses, captures, or documents them. For POLST, many organizations have access to the same data. The same data may be in several locations at
one time: patients have the original POLST forms; health care professionals have a copy of the form in the patient’s medical record, possibly and EHR, and registries and HIEs may also have the POLST form data.

Patients should always have autonomy and control over the treatment decisions captured on POLST forms (to the degree they have the capacity for such decisions).

**Patient Access to Their POLST Form**
Unlike advance directives, POLST forms are medical orders and there are limitations about what patients can do with them. Just as a medication prescription must be written in a standardized format with appropriate authorization so that health care professionals can safely and efficiently use them to inform the patient’s care, so too do POLST forms require a standardized format and authorization by an appropriate professional.

In addition to receiving a paper copy or the original form, patients should have the ability to securely view their current POLST form electronically, to share their form with their surrogate, loved ones, friends and other health care professionals, and to void their form themselves (not just request that it be voided). However, patients should not be:

- Able to obtain or download a blank version of a POLST form (however a watermarked sample would be acceptable for use as needed for patient, surrogate, loved ones or caregiver education). While the form would not be valid without an appropriate health care professional’s signature, this is not always clear to patients and the National POLST office has received many calls over the years about patients having completed a POLST and wanting to know next steps.
- Prompted to make treatment decisions. Only the health care professional should be selecting treatment options on the form based on the preferences expressed by the patient during their conversation; or
- Able to complete or modify their POLST form without including a health care professional in the process.

**Addressing Access Issues**
While this guide focuses on developing strategies relative to technology, it is important to recognize that many patients will have trouble accessing or engaging with technology. In order to avoid worsening existing inequities for such patients, alongside the development of technology-based solutions, it will be important to build and support alternative methods of reliably engaging such patients in the advance care planning process that do not rely upon such patients directly interfacing with technology. Such patients include:

- Those of advanced age or advanced serious illness, who may suffer from limited dexterity as well as from visual, hearing, or cognitive impairments that make it difficult or impossible for them to use technology;
- Those with limited English proficiency, who may not be able to effectively navigate English-only interfaces; and
- Those with disadvantageous social determinants of health – including limited economic means or limited literacy – who may be unable to acquire, access, or effectively engage with technology.
Recommendations Related to Patients

Integrating POLST into any technology should address the following:

- Educate how POLST relates to other ACP documents and the population of patients each document is most appropriate to serve;
- Increase patient's confidence in POLST by educating them how POLST forms are used during medical emergencies and their general application in care delivery;
- Promote patient access to their POLST form, giving patients a sense of ownership and empowerment over their health care;
- Promote transparency and trust by encouraging facilities and health care professionals to share who is accessing their POLST form and how it is being used; and
- Enable technology for patients that can access it to engage them in the POLST process while also developing engagement strategies for patients who do not have access to technology.

Cross-Setting Access to POLST Forms: The Interoperability Challenge

There is no single definition of interoperability. According to The Office of the National Coordinator for Health IT (ONC), the group responsible for advancing connectivity and interoperability of health information:

According to section 4003 of the 21st Century Cures Act, the term 'interoperability,' with respect to health information technology, means such health information technology that — "(A) enables the secure exchange of electronic health information with, and use of electronic health information from, other health information technology without special effort on the part of the user; ",(B) allows for complete access, exchange, and use of all electronically accessible health information for authorized use under applicable State or Federal law; and "(C) does not constitute information blocking as defined in section 3022(a)."

The Healthcare Information and Management Systems Society (HIMSS) has a lengthy definition available that starts with "in healthcare, interoperability is the ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged."  

For this guide, interoperability focuses on the technology capability of different systems and software communicating POLST data in a secure way for authorized use.

Trust is THE Essential Element for Success

Trust is critical for POLST to succeed, both at the level of POLST form completion and at the level of data exchange.

A known issue today is the possibility of multiple conflicting POLST order sets. For example, if a patient has a POLST form completed at hospital A, hospital A keeps a copy in their EHR, and these are the POLST orders that will appear if the patient shows up with an emergency at hospital A. If the patient does not inform their health care professional at hospital B that they have a POLST form already and has a new

POLST form completed, potentially with different treatment options picked, then hospital B will have a POLST form in their EHR that differs from hospital A. If hospital A and B do not share data, it is possible each will believe they have the most recent version of the patient’s POLST form within their EHR and rely on that version of the POLST to provide treatment to the patient during an emergency. Technology can help solve this problem by building workflows and solutions to ensure the most recent version of a POLST form is located when it is needed.

Every health care professional treating a patient using a POLST form must trust that:

- they have the most current version of the patient’s POLST form;
- the form is valid, including that it was signed by an appropriate and legally authorized health care professional acting within their scope of practice;
- there was appropriate conversation with the patient or their surrogate prior to completing the POLST; and
- the form actually represents the patient’s treatment wishes.

Keeping the fidelity of the POLST form as it moves through the technology framework between systems helps build that trust. Two approaches were discussed.

First, having a primary source that receives preference above all others, called the “single source of truth. In other words, this is THE source that has the most recent version of the POLST form at any time and what other sources connect with to learn the most recent POLST orders for a patient. With this approach, one of the most important aspect of this work is identifying the single source of truth for POLST information. While a national registry could serve this role, participants did not feel a single national POLST registry was needed.

Instead, participants focused on the second approach of having a network of registries and HIEs that can query each other for POLST forms and can each then determine and provide the most recent POLST form. This would not have a “single source of truth”, but it would have a process for finding and identifying the “truth” (aka the most recent POLST form). They felt National POLST has a role in creating the data set and data structure related to POLST that all EHRs, registries and HIEs use to facilitate the interoperability and sharing of POLST form information across the country. Having either standardized code sets, data structures and rules for reconciliation are necessary so that POLST orders from different registries or HIEs can be easily accessed and made available at the point of care.

Taking the approach of focusing on a standardized dataset used by all sources to communicate POLST information further supports—rather than competes with—the success of registries in several states.

Clinical Document Architecture (CDA)
HL7’s Clinical Document Architecture (CDA) has been an international standard format for electronic exchange of healthcare documents for the past 20 years. CDA documents have been so successful for exchanging healthcare data because while conveying discrete, computer-interpretable data, they also can be viewed in any web browser using a standard style sheet. Currently, over a billion CDA documents are exchanged each year among US healthcare organizations and between healthcare organizations and patients. Most of these exchanged CDA documents are of the 13 types defined in the Consolidated Clinical Document Architecture (C-CDA) Implementation Guide (currently at version R2.1). These include, for example, Discharge Summaries and Continuity of Care Documents (CCD). There are also many other CDA documents that are compatible with C-CDA in that they share the same foundational pieces that make up C-CDA documents but may be in a different order or have different required fields or
constrained vocabulary choices. Examples of these C-CDA-compatible CDA documents include the International Patient Summary (IPS), the Personal Advance Care Plan (PACP), and the Emergency Medical Services Patient Care Report.

CDA documents are currently exchanged electronically either by sending the document as a secure email attachment (AKA “Direct” message), or through a query (e.g., IHE XCPD/XCA or FHIR). These Direct messages and queries each occur over a billion times a year as the result of CMS requirements under the “Meaningful Use” program that all EHRs are capable of doing this. When an EHR does a query across multiple networks and healthcare organizations looking for documents pertaining to a particular patient numerous CDA document might be discovered. Instead of sending all of them to the requestor, a list of documents and the document types are sent first. The types of documents are defined in the “IHE XDS Metadata classCode” value set (e.g., Reports, Summaries, Plans, etc.). The EHR user sees those classCode value set names and then has the option of requesting any of the individual documents if the CDA document holder is authorized to send them.

In order to distinguish POLST forms from other CDA documents so that they can be handled appropriately when discovered through network query, there needs to be a new CDA “Portable Medical Order” (AKA POLST) document template defined that is compatible with C-CDA R2.1, as well adding “Portable Medical Order Form” (LOINC code 93037-0) to the IHE XDS Metadata classCode” value set. This CDA POLST could contain both the image of the document (PDF or other scanned document image types such as .JPG or .PNG) along with discrete metadata. At a minimum, this metadata should include the following:

- **patient demographics** sufficient to uniquely identify the patient;
- date form was signed (not uploaded);
- document status (active, void, invalid, etc.);
- NPI and contact information, including Direct address, for ordering health care professional in case there are any questions regarding the order and potentially to notify them if the patient revokes the order; and
- Electronic endpoint to which to submit <what?> to notify them of revocations and/or new versions of the order.

Further discussion is needed about the value of additional elements, such as:

- a unique document identifier (e.g., a combination of a unique registry identifier (e.g., National Provider Identifier (NPI)) because the “registry” may sometimes be a health care organization) + registry’s document ID + version number.
- contact information of anyone that has downloaded the form so that they can be proactively notified of changes;
- context during which it was entered (e.g., inpatient/outpatient);
- links to the note documenting the discussion;
- links to other ACP documents; and
- any other known document discrete data, such as code status.

Once created, National POLST should explore the possibility of adding the CDA POLST document template data elements the United States Core Data for Interoperability (USCDI) standard and mapping them to Fast Healthcare Interoperability Resources (FHIR) to enable future functionality (for example, query by EMS to specifically find patient code status that leverage open APIs). And, if exists, exploring whether connecting registries to a Trusted Exchange Framework & Common Agreement (TEFCA) Qualified Health Information Network (QHIN) and sending POLST forms and metadata as CDA POLST documents and
“Portable Medical Order Form” (LOINC code 93037-0) classCode in response to queries. This would include determining if EHRs should be configured to query, recognize, automatically download, incorporate, and display CDA POLST documents as part of a query of a national, regional, or other network during various workflows:

- prior to scheduled visits
- at the time of registration or check-in for visits
- whenever a new POLST form is about to be created; and
- manually on demand.

While it would only take 6-12 months to create the new CDA “Portable Medical Order” (AKA POLST) document template standard and add “Portable Medical Order Form” to the IHE XDS Metadata classCode value set, it will take longer for EHRs and registries to be able to create and take full advantage of the CDA POLST. While they are similar to the C-CDA documents that EHRs currently generate, transfer, and consume a billion times a year, EHR vendors would still likely take another 1-2 years to accommodate these and deploy this capability to their customer base.

Health Information Exchanges (HIEs)
HIEs act as hub for patient data, connecting multiple data sources to ensure relevant patient information is accessible across all health care settings. HIEs may aggregate and store patient information for query when needed, or they may dynamically connect entities for data exchange just like a phone network. Electronic documents can either be pushed to and from the HIE using, for example, Direct secure messaging, or pulled using, for example, IHE XCPD/XCA or FHIR queries.

Using standardized mechanisms for POLST data exchange described previously (i.e., POLST-specific CDAs and CDAs on FHIR) is ideal. However, POLST information is already be consumed by some HIEs today, although the forms (or data elements) may not be universally stored in a discrete and accessible way which makes understanding their value difficult in the multiple settings where they may need to be retrieved. HIEs can play a critical role in ensuring POLST documents are accessible across care settings and, unlike some of the other technology approaches in this guide, this may be achievable regionally and statewide in the relatively short term.

Statewide HIEs, in particular, could provide a natural home for POLST documents without the need to create extensive additional registry infrastructure, or could be a safe home and hosting solution for a robust registry. Each HIE has different capabilities currently in place.

While many HIEs do not currently have the functionalities in place to sort between versions of POLST forms to provide the most recent version and archive previous forms for reference, because of the increased focus on HIEs and POLST; other HIEs are looking to include archiving capabilities in their service dictionary.¹⁵ According to The Strategic Health Information Exchange Collaborative (SHIEC) the national association for HIEs, more than 95 percent of the United States population includes coast to coast HIE coverage.¹⁶ Some HIEs maintain health care professional portals that permit documents to be accessed outside of an EHR environment altogether (e.g., pre-hospital), which could be a beneficial functionality for many independent health care professionals and nursing homes, among others.

¹⁵ Sharon Muscatell, personal communication, November 2, 2020.
¹⁶ Sharon Muscatell, personal communication, November 2, 2020. “This information was part of SHIEC’s 2019 Annual HIE Survey. Of the total member population, we had an 89% response rate.”
HIEs can take steps today to flag POLST forms as discrete document types. When they receive POLST forms the documents can be marked for appropriate storage and retrieval – even if they’re simply scans of POLST forms that are drawn out of EHRs, registries or even submitted directly to an HIE where that functionality exists. Some HIEs may be doing this already, although they also may be incorrectly storing POLST forms as “advance directives” instead of as actionable medical orders, which will require correction.\textsuperscript{17} Timely provider point of care access and rapid implementation is dependent on accurate collection, labeling and storage of the POLST form by HIEs. Flagging POLST forms as a discrete document type in an HIE can happen ahead of balloting a new POLST CDA through HL7\textsuperscript{18}.

HIEs may find that POLST forms are critically important documents necessary for care transitions that must be treated differently from other document types. POLST forms do not technically provide historic context but rather are considered an actionable medical order that should be made available, if necessary, without consent or “opt-in” as based on state regulations or other emergent circumstances. This critically important designation or category of transaction should be included as part of a HIEs “break the glass” policy.

**Leveraging POLST Registries in HIEs**

Registries, where available, should seek to become data sources for regional and statewide HIEs. Registries may provide POLST forms directly to HIEs for storage, or, more ideally, they may dynamically respond to query requests from the HIEs by health care professionals. The query-response relationship serves to ensure that registries and HIEs continue to act as the source of truth for current POLST data and allows for quality assurance activities regarding the specifics of POLST data use and outcomes.

Registries should leverage well-established RESTful Application Programming Interfaces (APIs) such as FHIR to respond to queries from HIEs in a structured format. Recommended responses can include the full POLST form or its discrete data elements when those are requested and available.

Where state regulations over HIEs are lacking, registries should be cautious when dealing with organizations that may call themselves an HIE. It is important for the registry to understand its role, particularly if the registry is considered a Covered Entity, in permitted and non-permitted data sharing. The Centers for Medicare and Medicaid Services (CMS) and states vary in defining an HIE. When selecting an HIE to contract with, registries should consider national and state data sharing regulations to ensure compliance is adhered to and data are not being misused. Finally, registries should also be cautious about potentially misaligned incentives that may exist when sharing registry data with other organizations, some of which may refer to themselves as HIEs.

**National POLST Form: Patient Demographic Metadata**

National POLST leads creation of standards for POLST implementation through consensus, including the process, forms, program recognition, guidance, and policies. In September 2019, National POLST released a National POLST Form, the product of almost two years of consensus building through interviews, feedback, compromise and iterative versions of the form and patient guides. To move towards

\textsuperscript{17} The Office of the National Coordinator for Health Information Technology. (2020, April 15). *Meeting Notes: Health Information Technology Advisory Committee (HITAC) COVID-19 Pandemic Response Hearing.*


\textsuperscript{18} HL7, or Health Level 7, “refers to a set of international standards for transfer of clinical and administrative data between software applications used by various healthcare providers.” Health Level 7 (2020, June 1). In *Wikipedia.*

consistency in POLST across the country, the National POLST Form—including the patient demographic section—should serve as the standard form for any standardized dataset created.

Patient demographic information is critical for matching patients with their forms, and it is presented as the first section on the National POLST Form. Successful POLST use requires health care professionals and EMS be able to accurately match the patient to their POLST form immediately at the point of care. The more patient information available when matching the patient and their POLST form, the better the chances are of an accurate match. It is challenging to balance the desire for highly reliable matching with the administrative burden of capturing the necessary patient demographic given the limited amount of space in order to satisfy the request to keep POLST orders on one page.\textsuperscript{19}

As part of National POLST’s role in creating a National POLST form\textsuperscript{20}, 2018 conference participants in this technology project weighed in on what patient demographic information was necessary for technology platforms to accurately match patients with their forms:

- **Patient Name.** There was universal agreement that the full legal name was one of the most critical elements to successful patient matching. Participants agreed including space for a middle name or initial and suffixes would be helpful.
- **Date of Birth.** There was universal agreement that this data element was one of the most critical components of patient matching.
- **Gender.** Most felt gender was not required but would potentially be useful for patient matching. Participants advised using checkboxes of a selection to choose from as opposed to a free-form text block that could be typed into in order to ensure consistent data fields and help with accurate matching. For example, the National POLST Form offers male, female and X as options.
- **Social Security Numbers (SSN).** Participants agreed this was a widely adopted identifier for patients, and that space for it should be included on the National POLST form but that it should not be a required data element due to privacy concerns. Additionally, there was concern that requiring an SSN might discourage the use of the form by patients who receive care in the U.S. and do not have an SSN.
- **Addresses.** Participants agreed addresses were not particularly helpful to match patients because of the inconsistent data. Data inconsistency is due to the mobility of patients, and the fact that there is inconsistency in the address types captured in EHRs health care systems and facilities use (e.g., definition of legal address, where the patient actually lives, where the patient receives mail, as opposed to previous address, permanent address, and current address—all of which may be different).

These participant recommendations are reflected in the National POLST Form. More recently most EHRs/MPIs are now including cell phone number as demographic data with increased weight for matching because, when they exist, they tend to be for an individual person and follow them wherever they may move to. Adding a cell phone number will be considered for the National POLST Form in the future.

**A Quick Note About Federal Movement Towards Interoperability: The Cures Act**

Among other initiatives, in 2016, Congress passed the 21\textsuperscript{st} Century Cures Act to support interoperability and the access, exchange and use of electronic health information. Effective June 30, 2020, the Office of the National Coordinator for Health Information Technology (ONC) finalized rules implementing certain


\textsuperscript{20} National POLST. (2019, September). *National POLST Form*. https://polst.org/national-form
provisions of the 21st Century Cures Act that supports improved sharing of health care information within and among EHRs and between health care professionals and patients.21

Connected Healthcare and Health Data:
Priority Target Areas in the Cures Act

**Figure 1.** The Office of the National Coordinator for Health Information Technology graphic describing priority target areas in the Cures Act.22

As these rules are implemented, the ability to securely share POLST data among systems and with patients should be improved.

**More Than Just the Right Technology is Needed**

Interoperability is not just a technology concern: it is also a patient safety and legislative one. Siloed patient information can lead to unreliable version control and contradictions, possibly leading to providing treatments not aligned with patient preferences.

Many state laws make seamless movement of ACP documentation difficult by having laws mandating specific language for advance directives or POLST forms. For example, the American Bar Association attempted to make a “bare bones” health care power of attorney document that would comply with the legal requirements for identifying a surrogate (or proxy or health care power of attorney) in all states. They were unable to do so because “five states have laws so inflexible and cumbersome that the bare bones power will not work: Indiana, New Hampshire, Ohio, Texas, and Wisconsin.”23 Indeed, no national advance directive is possible “in New Hampshire, Ohio, Texas, or Wisconsin unless it includes a detailed

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mandatory disclosure statement, unique to each of the states, attached to the form.”

Unless the document or data elements of the document are valid in each state, interoperability will remain a challenge.

National POLST is attempting to address interoperability of the POLST form in a few ways, including:

1. Developing and encouraging the adoption of the National POLST Form;
2. Establishing endorsement requirements for POLST forms and encouraging states to develop forms complying with those requirements;
3. If states are using legislation to implement their POLST program, encouraging reciprocity with other state forms as part of the legislation.

Finally, culture change is necessary. A full technology solution is not just having the right technical solutions but also creating effective workflow processes, addressing legal and regulatory issues (including privacy and security concerns), engaging the community and health care professionals, using trusted platforms, and finding sustainable funding sources. Within each section of this guide, there is a discussion about these issues. National POLST and state programs are working to help shift the culture of ACP through continual public and health care professional education about appropriate POLST use.

Recommendations Related to Interoperability

- The National POLST Form should require the full patient’s legal name, including a middle name or initial, date of birth, and gender (M, F, X). It should not require SSN but provide a space to include it. Because of data inconsistency, use of address as a demographic identifier should be discouraged on POLST forms. As noted above, National POLST should consider adding space for a cell phone number as an identifier in future iterations of the National POLST Form.
- National POLST should promote demographic information on the National POLST form as the data set standard for all POLST forms and in interoperability standards for POLST orders.
- Create an HL7 CDA Portable Medical Order (POLST) document template standard Implementation Guide based on the National POLST Form and map it to a FHIR document.
- Work with EHR and Registry vendors as well as major HIEs to promote the use of the Portable Medical Order (POLST) CDA and to include the Portable Medical Order Form (LOINC code 93037-0) in their recognized IHE XDS Metadata classCode value set.
- Collaborate with the ONC to incorporate the HL7 CDA Portable Medical Order data elements into the US Core Data for Interoperability (USCDI) and their Interoperability Standards Advisory work.

How EHRs, Registries and HIEs Can Support Interoperability

EHRs, registries and HIEs can expand the geographic area where a POLST form can be completed, and where the most recently completed POLST form may be electronically available to health care professionals, including EMS. Including POLST forms appropriately in an EHR, such as an ACP tab or in the

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banner bar, can quickly inform health care professionals of patient treatment preferences during an emergency, helping mitigate or eliminate unwanted treatment.

Potentially, the easiest approach to integrating POLST with technology, and leveraging work that has already been done within large technology organizations such as Epic and Cerner, is within EHRs. EHRs provide opportunities to make POLST form data more widely available than paper POLST forms are today. However, a standalone EHR, either in a single facility or in a large health care system, can only be the single source of truth for POLST forms within its system. Once the patient leaves the area or accesses care in another health care setting that doesn’t have access to that EHR, they must rely on keeping their paper POLST form with them at all times. A registry or HIE can expand that geographic scope and should consider bidirectional connectivity with the health care ecosystem; “bidirectional connectivity” meaning data flows into and out of connected systems.

This section shares current approaches for integrating POLST within EHRs, creating a POLST registry and then connecting the two so that the registry (ideally pulling from other EHRs) can serve as the source of truth for a larger geographic area.

**Electronic Health Records (EHRs)**

While many people use the terms “electronic medical record” or EMR and “electronic health record” or EHR interchangeably, the differences between them are significant. Whereas EMRs are limited, essentially digital versions of paper medical charts containing medical treatment and history of patients in a single practice, EHRs are designed to collect and compile patient information from multiple health care professionals involved in the patient’s care. This guide uses EHR because it more appropriately represents the purpose of integrating POLST with technology: to “easily share medical information among stakeholders and to have a patient’s information follow them through the various modalities of care engaged by that individual.”

While EHRs can simply store POLST forms, the real power of EHRs relate to improvements in quality of, and access to, POLST information made possible by: (1) electronic form completion (ePOLST); (2) clinical decision supports (CDS); and metrics.

There are three ways POLST forms can be integrated into EHRs:

1. **EHRs can scan and store a POLST form as a PDF.** While electronically stored, this is not an “ePOLST” because it was not completed online. This is not the best practice since it is possible, through human error, for the POLST form to be saved to the wrong part of the EHR or wrong medical record. It also limits the ability for the components of the POLST form to be captured as discreet data and integrate functionally with all other aspects of the EHR.
2. **EHRs can receive an electronic version of the POLST form in a structured format within the Clinical Data Architecture (CDA) standard, which certified EHRs are required to be able to send and receive, or what may be more common, is a link in the EHR to a centralized, web-based registry or HIE.**

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3. A POLST form may be electronically completed within an EHR (ePOLST) leveraging the logic, data validation, and error reconciliation that is important to establishing the authenticity and accuracy of the form’s responses. This ePOLST is distinguished from number 1 above because it is created within the EHR technology as discreet data elements and relieves the health care professional’s need to scan, upload and store a file.

ePOLST refers solely to a digital version of a POLST form that resulted from form completion with computer software, not a digital file that is the result of a scanned paper form. In some instances, however, it also refers to a technology process that includes:

1. supporting patient decisions by providing education about POLST and includes the ability to print supportive materials and/or embeds educational videos as part of the ePOLST completion process;
2. supporting the POLST process by walking the health care professional through the steps of the POLST process, beginning with questions relevant to the POLST conversation;
3. allowing the patient’s preferences for end-of-life treatment to be recorded within the EHR;
4. helping ensure the conversation and decisions result in a digital POLST form (most likely in PDF format) that is saved to the patient’s record and is printable so that a copy may be provided to the patient immediately; and
5. helping ensure that secure transmission of the digital form to other appropriate health care organizations or POLST registry is facilitated.

**Seamless Workflow**

Many of the benefits below speak more to the system overall but they will not be achieved unless the system makes it easy for health care professionals to use the specific area within the EHR where ACP documents are housed and complete appropriate documentation in the EHR itself.

It is not enough to have the POLST form and data in the EHR: the EHR architecture and workflow must support POLST form data entry, seamlessly coordinate with health care professional workflows, allow for meaningful conversations, and be easily and immediately accessible. There should be a specific area within the EHR where ACP documents are housed that can be easily accessible and there must be separate locations for advance directives and POLST forms as they are not the same.31

The paper workflow should not be reproduced: technology is a different medium and new workflow processes should be carefully considered. Health care professional ease of workflow throughout the POLST process cannot be underestimated. The workflow for ePOLST completion must be easier than completing a paper form for health care professionals completing, reviewing, and using POLST forms (all these individuals have different workflow processes). Too many bells, whistles and repetition decrease health care professional use and adoption of ePOLST.

For example, health care professionals caring for POLST-appropriate patients benefit from access to ACP conversation notes to understand what conversations have taken place regarding treatment preferences and to have access to that information in emergency situations.32 While the specific area within the EHR where ACP documents are housed have sections dedicated to tracking conversation notes, some health care professionals consider it a burden to put ACP notes in the specific area within the EHR where ACP documents are housed, preferring instead to write the entirety of the conversations during a patient encounter—rarely just about POLST—in the progress notes for that encounter. Some may then go into

the specific area within the EHR where ACP documents are housed and refer to the date of the encounter, but this then requires future health care professionals to click into that separate part of the EHR and then find the encounter (if they even know it exists).

Workflows should include documented processes for:

- Identifying POLST appropriate patients (patients who would be appropriate to initiate a conversation about POLST);
- Determining whether a valid and accurate POLST form has already been completed for the patient (accurate meaning it matches the patient’s preferences) and reviewing to confirm preferences are still accurate;
- Identifying previous conversations about POLST that may not have been finalized;
- Completing ePOLST;
- Printing ePOLST for patient (consider that printers are generally not in patient’s rooms where POLSTs are completed);
- Any other technology integration: submission to a registry or HIE (or opt-out options) and helping patient obtain electronic access to their POLST form; and
- Patient ability to view, and ideally share, their POLST forms on the patient portal.

Benefits of EHR Integration

There are many benefits for integrating the POLST process and form completion within EHR technology:

<table>
<thead>
<tr>
<th>Known Paper Process Issues</th>
<th>POLST-EHR Integration Improvements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential error in scanning/placing scanned copy into wrong section of EHR – health care professional then unable to locate. This is generally caused by human processing (scanned to wrong patient chart or wrong document type, etc.).</td>
<td>Automated consistent location for POLST form (and conversation notes) within EHR. Available in a single click from the banner bar eliminates health care professional search time.³³ (HIM teams need to be educated to archive previous versions.)</td>
</tr>
<tr>
<td>Paper-based education materials need to be ordered and distributed.</td>
<td>Education materials can be easily accessed and/or printed from ePOLST screen or shared through the patient portal.</td>
</tr>
<tr>
<td>Approximately 18% of POLST forms have errors that invalidate them as a whole, such as missing patient demographics, health care professional signature or date, or incompatible order sets.³⁴</td>
<td>System can auto-complete form fields for patient information, pulling it from EHR, complemented by ePOLST form logic that prohibits invalid responses from being recorded. (Though this can also be a barrier or liability if systems are not automatically updated.)</td>
</tr>
<tr>
<td>Potential illegibility of document, e.g., handwriting; being too dark or light to read (especially if faxed); having medical record label placed in an area that restricts view of POLST form content.</td>
<td>POLST form is legible.</td>
</tr>
<tr>
<td>Convenience of completing POLST as part of health care professional workflow without the need to transition to some other application.</td>
<td></td>
</tr>
</tbody>
</table>


³⁴ For example, a POLST form ordering CPR and comfort-focused treatments is an incompatible order set that invalidates any POLST form in the US.
**Improved Patient Care**

Clinical decision support (CDS) helps inform decisions about a patient’s care by providing timely information, usually at the point of care, and can help improve patient outcomes and lead to higher-quality health care. CDS tools and systems help health care teams by handling some routine tasks, warning of potential problems, or providing suggestions for the health care team and patient to consider.

Through background logic, EHRs can provide many forms of CDS around POLST including:

- identifying appropriate patients and reminding health care professionals to discuss POLST with them;
- reminding health care professionals to review POLST form orders during patient encounters; at admission and discharge processes and during other health care appointments;
- ensuring each section of the POLST form is reviewed, even if not completed;
- alerting health care professionals anytime an order incompatible with the current POLST form orders is entered; and
- alerting within the EHR workflow to support desired processes.

For example, the University of California- Los Angeles (UCLA) adopted New York University’s hospital admission implementation strategy using the “surprise question”: would you be surprised if the patient died in the next six months? This hard stop requires a health care professional’s intervention. If “no” is selected, the ordering health care professional is shown an advance directive, POLST or goals of care note in the EHR and asked if ACP is needed. Additionally, the EHR summary discharge template includes a reminder for the health care professional to consider completing a POLST if a patient has a do not resuscitate (DNR) order but no POLST in place.

Additionally, UCLA implemented the following within their EHR system for patients 65 years or older:

1. If the patient does not have an advance directive or POLST in the EHR, the health care professional sees this as a discrepancy with best practices, called a Health Maintenance gap, and the patient sees the lack of document as a reminder in the patient portal. UCLA is working to merge this with “Care Gaps” to help primary care health care professionals complete preventive care measures.
2. If the patient has an advance directive or POLST older than 5 years in the EHR, it also appears as a Health Maintenance gap to the health care professional and reminder to the patient that it should be reviewed to confirm it is still accurate. The document remains valid in the system, regardless of review, unless voided or updated.

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41 Neil Wenger, personal communication, June 15, 2020. Per Dr. Wenger, the system uses the date the document was scanned in to determine 5 years, with the assumption that thaw was the time it was likely reviewed. “For example, if the patient brought in an advance directive signed in 2004 and presents it as a valid advance directive in 2015, it is scanned into the EHR in 2015 and marked as needing review in 2020.”
CDS becomes challenging, however, if some of the datum is in disparate systems or not intuitive to use. Additionally, many health care professionals complain of “alert fatigue” and start ignoring pop-ups, which eliminates the value of some alerts.

Another example of CDS are rules and alerts that can be built into the EHR architecture to identify conflicts between POLST resuscitation status, treatment preferences and potentially to recognize potential misalignment with advance directives (when they are available electronically). It is important ACP documents align so health care professionals are confident about a patient’s treatment preferences and goals of care. This is especially important in the few states that have legislation directing health care professionals that the most recently signed document controls. This would allow an updated advance directive to void a POLST form. If ACP documents are aligned in preferences, conflict can be minimized and POLST can still be used as guidance.

It may also be possible to set up encounter notification services for health care professionals to receive notifications of situations that should trigger a review of the patient’s POLST form, including when their patient is hospitalized at any hospital or admitted to an alternative care setting such as a long-term care, skilled, or assisted living facility or any emergency department encounters, especially those that may result in potential readmissions.

Depending on the EHR, it is possible to improve the patient-health care professional communication and exchange of information. For example, most EHRs have patient portals that can be used by patients to notify their health care professional they want to change or modify their POLST or that they have voided it. These portals can be used to engage patients in other ACP activities such as answering goal directed questions and capturing advance directives to ensure alignment with the POLST.

There can be opportunities for health care professionals and patients to access educational materials such as videos or handouts to be available with a single click from the ePOLST screen within the EHR, often referred to as “just in time” education. For example, when the ePOLST is on the cardiopulmonary resuscitation (CPR)/DNR section of the EHR, there may be a video about CPR the health care professional can click on to educate the patient with, available in a single click.

Finally, health care professionals may also find they can improve patient care with increased access to historical information such as previous POLST form orders, revision dates, changes in the responses and decisions found on the form, and the entity that was involved with each revision.

Administrative Workflow Improvements
Administrative time can be reduced, and errors eliminated by having the EHR autocomplete the patient demographic and health care professional information sections and automatically adding signature dates. Completing POLST forms within the EHR standardizes the location of POLST forms, increasing health care professionals’ ability to quickly locate forms during an emergency. Having the form immediately available, rather than waiting for a paper form to be scanned into the EHR, eliminates the crucial and potentially dangerous delay of honoring POLST form orders due to their lack of availability.

Backup policies can be helpful in addressing system downtimes, unanticipated emergencies, and other technology related issues in populating automated fields.

Quality Improvement

ePOLST can eliminate errors found in paper POLST forms by preventing incompatible combinations of orders, requiring certain fields be completed, and prohibiting signatures on POLST forms until all information is completed.

ePOLST may allow for several new metrics to be collected, as well as streamlining the review of current metrics, including:

1. How often health care professionals override alerts about orders they are submitting that conflict with POLST form orders;
2. How often educational materials were accessed as part of the conversation and, possibly, how much time was spent reviewing them (though time may not be a good indicator unless the level of patient understanding, or the number of times revisions may have occurred is taken into consideration);
3. Who is involved with POLST form completion and how much time was spent on the process;
4. Who is initiating POLST conversations;
5. Who is signing POLST forms and who is not signing them but likely should be;
6. How often POLST form orders are reviewed with patients and other related quality monitoring approaches; and
7. Ability to track operational efficiency and conduct quality assurance (QA) activities, including audit tracking, reports of ePOLST utilization, and identification of the department(s) or individual(s) who would benefit from more support or education.

Supporting Reimbursement

ePOLST provides a framework and materials for an ACP conversation (as well as an audit trail) that can support billing for ACP time.

EHR Signature Options

see telehealth section on Signatures

Accommodating Paper POLST

Paper workflows are still necessary because the ePOLST workflow may not work for all health care professionals and patients may bring in current paper POLST forms they completed with other health care professionals. Therefore, systems need to ensure a proper workflow for entering paper forms into the specific area within the EHR where ACP documents are housed. According to the California Health Care Foundation “scanned paper forms were often inconsistently stored or labeled (e.g., bundled together with other ACP documents), requiring careful analysis to address these issues during the early stages of readiness assessment and planning.”

A defined process should be developed for all paper POLST forms to be sent to HIM staff for (a) validation of POLST forms (i.e., presence of required elements such as patient name/demographics, signatures, dates) and (b) placement in the right area of the EHR, to support consistency of process and to make the documents easier to find. Additionally, this helps ensure the patient dashboard and banner have accurate information reflecting the most recently completed POLST form.

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EHR Design Elements

EHR builds generally vary depending on the EHR vendor and what degree of build sophistication the specific organization has in the build, the design process, funding and other external factors (i.e., whether or not there is a web based POLST registry). Ultimately, the design for POLST integration should support health care professional workflow, which is challenging considering the space limitations of the dashboards and patient banners. At a minimum, builds should include:

- The EHR dashboard should include POLST status (yes/no), code status, access to ACP activity (other ACP documents and conversations).
- The patient banner should have the POLST displayed as its own discrete data element in the banner so that one can easily see if a POLST exists (easily seen yes or no) and can hover over it to get more info. Ideally, it should live next to the code status in the banner.

![Figure 2. Sample banner in an EHR showing patient has a POLST](image)

If an EHR is connected to a POLST registry, the EHR would ideally automatically and instantly transmit a POLST form to the registry or HIE once finalized (this may require additional programing). While not available in some places today, as standards for exchange and APIs become more readily available, the potential benefit of POLST integration in EHRs and should be considered wherever a registry or HIE exists.

Recommendations Related to EHRs

EHR vendors should be encouraged to develop an ACP summary that includes POLST form orders, as separate and distinct from advance directives.

National POLST should consider updating its policy and guidance for EHR vendors to reflect the standards and protocols for ePOLST as outlined here, including:

- Ensuring ePOLST is standard in all ACP workflows;
- Providing advice and guidance on what POLST education should be included in both health care professionals and patient-facing portals using quick education or reference text to help both groups understand the difference between POLST and advance directives (e.g., [this chart](https://example.com/chart) or [this chart](https://example.com/chart));
- Advocating for standardized processes/policies for storing ACP documents and conversations.\(^4\) This includes ensuring that POLST forms are not identified or labeled as “advance directives” in the EHR; and
- Advocating for using the standardized data set for POLST forms to facilitate bidirectional technology with the source of truth for POLST forms.

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Registries and Health Information Exchanges

A POLST registry is a centralized digital storage location that houses POLST forms and provides a way to access the POLST forms either directly through the registry and/or through interfaced locations such as an EHR or HIE, in order to make them available to health care professionals across care settings when they are needed. A registry or HIE should preferably be able to:

- Distinguish between valid forms and invalid forms, rather than simply storing forms.
- Recognize the key elements of the document and return discrete data from it, such as demographic information or medical orders.
- Generate a printable form.
- Stores and provides access to an individual’s archived and current POLST forms.
- Facilitate accurate patient matching. Preference is using established HIE matching.
- Generate a unique patient identifier and a unique per-document identifier.

“This approach may require additional technical, legislation and regulatory solutions to advance.”

A registry can be built fairly easily, however making that registry truly accessible for bidirectional document retrieval across care settings is harder to achieve. HIEs are currently available and cover over 95 percent of the United States population. Standing up additional technical solutions in an HIE is also not difficult as evidenced by the recent 2020 COVID-19 data collected through SHIEC members.

While this guide attempts to consolidate lessons learned from all sources, any program interested in a registry or participation with an HIE should review these other reports:

- Pathways to POLST Registry Development: Lessons Learned
- California’s POLST Electronic Registry Pilot: Lessons for All States
- Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment (POLST) Documentation Access through Health Information Exchange (HIE)

Value of a POLST Registry

As opposed to storing POLST forms in an EHR, registries can be the single source of truth for electronic POLST forms in the geographic area they serve. When POLSTs are only stored in an EHR, a patient may have multiple POLST forms if they receive care in multiple health care settings, which exposes an issue of a single person having multiple POLST forms and the potential that the health care professional does not have access to the most recently completed form. When those forms contain different orders, the patient’s care is subject to change depending on the health care setting. POLST forms can potentially be listed in a patient’s electronic record in order of date uploaded, rather than date completed/signed, which doesn’t always lead to the most recent form being listed first. The opportunity for treatment to be

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47 Sharon Muscatell, personal communication, November 2, 2020. “[SHIEC] conducted a survey in late February [2020] for ONC and the CDC about COVID data and how rapidly the HIEs could standup other technical solutions. Again, we had a tremendous response and while 66% of the HIEs already had capability in place, another 14% said they could be ready to provide information within a matter of days.”

48 This project was supported by The Retirement Research Foundation and the Archstone Foundation. Zive, Dana and Terri Schmidt. (2012, October, at 31). POLST Registry Development: Lessons Learned. National POLST. https://polst.org/registry-development-pathways-pdf


mis-aligned or miscommunicated arises when the POLST form that is on file within the healthcare setting is a different version than a form housed within the registry. The form may be outdated and, therefore, inconsistent with what the patient currently wants. Having a “single source of truth” in digital form such as a registry provides, access to the most current version of a patient’s POLST form regardless of the setting or circumstance for which the patient requires or receives care.

The use of POLST registries can reduce complexity and implementation costs for health systems and may help to improve the quality of available information across care settings. This is facilitated by the registries ability to educate and ensure health systems and other agencies know of their availability and the purpose for using a POLST registry.

A core value for using a registry or, possibly HIE, is centralization. Being a sole source for the patient’s current POLST version is an example that demonstrates the ability of a registry or HIE to provide a numbered, validated POLST form thus reducing the potential for inconsistencies in communicating and executing the patient’s medical treatment plan. Careful consideration should be taken when partnering with an HIE for distribution of POLST data as there are different legal parameters and state protections that come with using a private entity.

Registries and some HIEs are expensive. While several states have started registries, the return on investment is an elusive argument based on the relatively little research conducted on the impact of POLST registries on care patterns and adherence to patient goals. Conversationally, it is easy to appreciate the value of a registry or HIE as the single source of truth and extrapolate that to how it could play out during an emergency: a patient doesn’t have their form, but EMS is able to find it quickly through the registry. This type of argument has been successful for a number of states including West Virginia51, California52, and Louisiana.

A clear value of a POLST registry or HIE is the ability to support research, quality assurance and health care professional education and outreach, and developing protocols and policies for all care settings especially emergency department and EMS to understand how to guide patients through medical encounters or emergencies all of which are invaluable to the POLST movement. The data provided by Oregon’s and West Virginia’s registries have been included in numerous research articles, many of which are provided in the OPR annual reports and website.53

Registry Set Up
There is no single or easy answer for how to set up a POLST registry and data are not yet available to judge one system as better than another. This section provides information about the current state of registries, demonstrating the variety in approach states have taken. Attachment 1, the Registry Matrix, provides tables about a variety of issues related to POLST registries from states that have started the process and responded to the survey.

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**Funding**

In doing diligence for a potential registry, in 2012 Maryland reported “the implementation cost of a registry linked to the statewide HIE was about $252K-$500K annually to maintain.”54 The report suggested, once funding was secured, it would take about a year to develop.55 As of July 2020, Maryland had not implemented an active registry.56 This table provides additional detail to the implementation costs information provided in the Registry Matrix:

<table>
<thead>
<tr>
<th>State</th>
<th>Source of Registry Implementation Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>California’s POLST eRegistry Pilot was established by legislation passed in 2015, which required non-state funding for the pilot. The California Health Care Foundation (CHCF) funded the initial implementation and pilot testing in two communities. When the pilot ended, those two registries continued without CHCF grant support. Two additional independent regional registries also launched during the pilot period.</td>
</tr>
<tr>
<td>Colorado</td>
<td>A Statewide System for Advance Health Care Directives was signed into law on May 16, 2019. An appropriation of $993,147 for the 2019-20 state fiscal year was earmarked for the health department. Breakdown as follows: $32,100 for personnel services (assumed additional 0.5 FTE), $211,047 for operating expenses and $750,000 for purchase of information technology services.</td>
</tr>
<tr>
<td>Idaho</td>
<td>Cost of implementation &amp; maintenance was absorbed by the Secretary of State’s office.</td>
</tr>
<tr>
<td>New York</td>
<td>“The original eMOLST program began in 2008 with seed money from a health information technology Health Care Efficiency and Affordability Law (HEAL) grant secured by the Rochester Regional Health Information Organization.”57 HEAL NY Phase 5, “Advancing Interoperability and Community-wide EHR Adoption in New York State”, grant funding enabled the eMOLST program to become operational. Current funding for eMOLST is from Excellus BlueCross BlueShield, a not-for-profit health insurer in upstate New York.58</td>
</tr>
<tr>
<td>Oregon</td>
<td>The Oregon POLST Registry (OPR) was funded by legislation passed in 2009 and is part of the Oregon Health Authority, though housed at Oregon Health &amp; Science University.</td>
</tr>
<tr>
<td>South Carolina</td>
<td>Grant funding from BlueCross BlueShield for initial startup costs.</td>
</tr>
<tr>
<td>West Virginia</td>
<td>In 2010, West Virginia received a $7.8 million federal grant from the State Health Information Exchange Cooperative Agreement Program and created the West Virginia Health Information (WVHIN), which included the West Virginia eDirective Registry that health care professionals 24/7 access to advance directives and POST forms.59</td>
</tr>
</tbody>
</table>

Table 2. Sources of Registry Implementation Funding


56 Paul Ballard, personal communication, July 1, 2020.


Although state funding may be helpful for implementation, additional sources of funding should be considered for ongoing activities. While Oregon POLST officials stated, “they believe POLST registries should be state funded and administered,” West Virginia officials reported challenges when its registry, funded by the state from 2009-2017, did not receive state funding in 2018.60 Oregon currently receives funding from federal Health Information Technology for Economic and Clinical Health Act (HITECH) and CMS in addition to the Oregon legislature.

Similar to EHRs and HIEs, registry development and implementation can be expensive, but it is only part of the overall cost. Factors that impact cost include connections to HIEs, technology, integration activities, staff, testing, roll-out, marketing, education, and outreach. Continuous community and health care professional education and training is necessary and must be included in the budget.61 Consider Washington’s experience with their registry: “with no internal mechanism for promotion or marketing, the registry had little public visibility, and outreach to health care professionals promoting registration was also difficult. Soon after implementation, the 2010 Legislature reduced the registry’s budget by 60%, eliminating funding for the already limited educational and promotional efforts.”62

In approximating appropriate full time equivalent (FTE) staff for a state registry, the OPR Director suggests considering type of registry, services offered, state population and form volume. Oregon’s Registry receives about 50-60k forms each year and about 70% of those are hand-written, requiring more manual data entry and FTE than a registry allowing ePOLSTs only. Additionally, Oregon’s main form of communication with registrants is mail, a cost that could be reduced with an online patient POLST portal. With a population of about 4.1 million, the OPR has 6-7 FTE at all times for registry operations such as:

- Quality data reports
- Form validation and data entry
- 40K letters mailed annually to registrants
- Fielding emails and calls from registrants/clinics
- Program and technology oversight and development
- Data stewardship for state to accommodate all POLST data requests to the public (The person who is responsible for keeping the data, ensuring data quality, providing registry reports, and providing data for research or continuous quality improvement (CQI) requests.)

Finally, HITECH and HIMSS funding could be an option.

Registry Ownership and Administration
Similar to registry funding states have taken different approaches to registry ownership and administration, captured in the Registry Matrix (Attachment 1). The Government Accountability Office (GAO) evaluated state approaches to registries in its 2019 report Advance Care Planning: Selected States’ Efforts to Educate and Address Access Challenges.63 The 14 states with active registries varied on

ownership and administration. Some were administered through state agencies or by contracting with an outside organization.64

Registry Purpose
A registry can either be set up as a backup to paper POLST forms or as a primary source for POLST form orders. If the former, EMS rely on the paper POLST form and can use a registry (or HIE if POLST is part of its platform) to confirm orders for any reason such as a question about the paper form content or the paper form is not available, and information provided suggests one exists. If the registry or HIE is the primary source for POLST form orders, EMS protocols should include accessing the registry to obtain the POLST form orders, even if a paper POLST form exists.

Data does not yet exist to know which approach may have more value but as discussed in the Mobility section of this guide, it is critical that EMS protocols support the approach taken.

Health Care Professional Registry Access
Depending on the state registry implementation and approach, today's registries are accessed either electronically or by calling a 24/7/365 registry line to get POLST form information. The initial focus should be on EMS, emergency departments, long-term and post-acute care adoption of the registry, since these health care professionals must make decisions about care quickly.65 Registry access must be easy for them.

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<table>
<thead>
<tr>
<th>POLST Registry Access Approach</th>
<th>Benefits</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web-Portal Access</td>
<td>• Requires only an internet connection&lt;br&gt;• Potentially requires less IT resources/investment that would be needed to integrate distinct data systems&lt;br&gt;• Accessible wherever the patient is, and not dependent on EHRs</td>
<td>• Requires an internet connection (may be a challenge in rural areas)&lt;br&gt;• May require an additional login if the systems are not integrated as single sign on&lt;br&gt;• Use of a separate system may require more time and effort to integrate into user workflow</td>
</tr>
<tr>
<td>ePCR/EHR Integration</td>
<td>• Ease of integration for communities that have one or two dominant EMS electronic patient care reporting (ePCR) or health system EHR vendors</td>
<td>• Requires coordination and funding to establish registry connections from registry to each ePCR, EHR or HIE&lt;br&gt;• May require point-to-point integration with each ePCR or EHR</td>
</tr>
<tr>
<td>HIE Integration</td>
<td>• Minimizes interfaces and connections for communities with stable and operational HIE organization</td>
<td>• Dependent upon maturity of the HIE organization&lt;br&gt;• Requires EMS ePCR and EHR vendors to have capabilities and functionality required to integrate with HIE organization&lt;br&gt;• Requires community providers to access HIE for POLST information rather than their own EHR or exchange platforms specific to their EHR</td>
</tr>
</tbody>
</table>

Table 3. Electronic Health Care Professional Access to POLST Registries: Characteristics of Different Approaches

It is important to recognize that different roles will require different access (preparer vs viewer) and having multiple access avenues is helpful.

“Push” notifications, proactively informing EMS of the presence of a POLST form in the registry, were preferred by California pilot participants over manual queries. For a query approach to be successful, California’s experience suggests that a registry must first achieve a critical mass of POLST forms for a given geographic area, such as the EMS agency’s catchment area, before the approach is available. Otherwise, as Washington found, EMS may be frustrated by frequently unsuccessful searches and stop using the system altogether.

California’s pilot found that connectivity capabilities and how long it took for EMS to access a POLST form for a patient on the scene from a registry influenced whether and how POLST forms were consulted.

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during an emergency.\textsuperscript{70} If the technology infrastructure for information exchange with EMS is not robust, consider approaches that can be tailored to the needs of each locality. Low tech approaches should be considered, such as medical alert bracelets, barcodes, dedicated call centers, access via smartphones (see also the chapter on Technology Focused on Mobility).\textsuperscript{71}

**Necessary Registry or HIE Features for Success: Technological Functionality Supporting Interoperability**

Ideally, registries should offer the following additional functionality.

**EMS Access**

Providing EMS 24/7 access to POLST form data likely may require an operator. However, queries could be completed from the ePCR system, potentially via QHIN. This initially would be an XCPD/XCA query for the CDA POLST document, though it eventually could return specific FHIR resource data such as code status (within the Consent resource).

**Patient Access**

The challenge is how to authenticate a patient wanting access to the registry POLST form. It could be accomplished through a chain of trust where an authenticated health care professional or support staff logs into the registry and enters an email address or phone number of the patient. With that health care professional or staff person as witness, the patient responds to that text or email and establishes their login credentials. Alternatively, the health care professional or staff could generate a code from the registry and provide it to the patient to enter online when setting up their credentials. Vendors are discouraged from offering patients a way to enter their signature using a smartphone as there is currently no way to authenticate it.

Authenticated patients should be able to extend their access to caregivers, loved ones and friends. Patients would be able to void their POLST online, with an automatic notification of this event to the health care professional who signed the POLST and to anyone else who viewed or downloaded the original form or was extended access to view the form (caregivers, etc.). Ideally, the voiding process would (a) warn the patient that they will no longer have a POLST on file and that they will receive the standard of care in the event of a medical emergency; (b) record, notify and send the reason that the form was voided to the signing health care professional so follow up can be made with the patient.

**Multiple POLST Form Formats**

The registry would need to manage the various ways POLST forms are presented: image files of scanned paper forms, electronically completed POLST forms, and faxes of paper forms. For all, discrete data should be used for validating forms for internal consistency; this may be challenging for out-of-state forms. Encouraging the adoption of the National POLST form would help this process.

For scanned paper forms, a person may need to manually transcribe and/or validate the form.


For electronically completed forms, the POLST form can be entered in multiple ways:

1. Using the EHR’s tools to upload discrete data elements, which would require a national standard for the data elements such as the United States Core Data for Interoperability (USCDI). These POLST forms would be sent from the EHR to the registry or HIE as a CDA POLST document using Direct Messaging.
2. Single sign-on with shared user and patient context from EHR to a web browser with the registry’s or HIE’s URL, either exposing within a window within the EHR or in a separate window.
3. SMART-on-FHIR app within the EHR when in a patient record that pre-populates patient demographic fields and then uploads the final data to both the EHR and the registry.
4. (not recommended) Manual login to the registry’s website, which is a workflow burden/barrier and increases the risk of patient matching errors.

**Form Voiding**

Recognizing that POLST orders may need to be updated frequently based on changing health status, prognosis, and goals near the end of life, a Void Request status of a POLST CDA document also needs to be created. Past versions of POLST forms should be clearly labeled to avoid inappropriate use (e.g., marked “VOID” and archived to limit access to only the rare cases in which there is a need to reference an outdated form). The need to access archived forms in a registry differs from the need to access them in EHRs when past history may be instructive for the health care professional having a conversation with the patient.

Each registry or HIE needs to be able to upload new POLST forms received from EHRs and remove invalid forms. They need to be able to void inactive POLST forms: forms either voided by the patient or by the patient’s health care professional or forms voided and replaced by a newer POLST. This must happen regardless of whether internal or external to that registry or HIE, which means they must be able to receive requests from health organizations external to the registry or HIE to void a POLST. Finally, each registry and HIE need to implement some mechanism for providers to submit void requests.

A registry should ensure there are well-communicated processes and policies in place to avoid automatically voiding a document purely based on the received request. Registries need to be able to create a process that includes a worklist or file of void requests, manual reviews, and a mechanism to easily retrieve and review voided forms to make it easy to review the requests and process the voids.

A corollary is that in order to increase trust, the request needs to clearly identify the patient, the document ID, the requestor, the role of the requestor (primary health care professional, administrator, etc.), contact information including Direct address of the requestor, and reason for the void (duplicate, updated form, etc.). Including a newer document as an attachment would be a best practice.

Since registries may need additional information to comply with a void request, they must be able to reply to the void request asking for more information, a refusal with reason, or an acknowledgment of the void. Most requestors are not going to want to see acknowledgements that the POLST was voided, so these responses ideally should have some standard structure in order to facilitate automation on both the requestor and registry ends. With a Direct message (including an attachment of the replacement CDA POLST document that is going to replace the to-be-voided POLST) it is recommended that a CDA POLST document Void Request status should also be created, which can act as both the request and response. This is a simple solution because all CDA documents are human readable with just an HTML style sheet and EHRs are used to making CDA documents received from Direct messages visible. This makes it usable for manual processing initially and automated processing when trust is established. Finally, it makes sense...
to also map this CDA POLST document Void Request status to a FHIR document status so that it can be similarly used in the future.

**Patient Voiding POLST Forms Through Registry**

An unresolved debate included whether patients could contact a registry for the purpose of voiding their POLST form. Because the form is a medical order, some participants felt it would be more appropriate for a patient or their surrogate to contact their health care professional when a request to void a POLST form is made. A request to the patient’s health care professional would serve a dual purpose. It would give the professional an opportunity to evaluate why a request to void the POLST form was initiated and would also require the health care professional to submit a void notice to the registry if that ultimately is confirmed through the conversation. This process facilitates keeping the health care professional knowledgeable while maintaining the patient’s ability to participate in their health care decision. This potentially helps ensure the POLST form is voided in the EHR and the registry. Details about the workflow were not discussed.

Others felt it was unrealistic for a technology vendor or an HIE to act as the arbiter of whether the person calling to void a POLST form is authorized to do so.

This is a state-by-state decision. Oregon allows patients to call the registry and void their own form and the registry then advises the patient to contact their health care professional to inform them, so the form is deleted from any medical record the health care professional has. This process puts the onus on the patient, leaving open the possibility that the patient’s POLST may be voided in the registry but still exist in an EHR. Putting the onus on the patient contradicts a primary benefit espoused by POLST: unlike advance directives, health care professionals have the administrative responsibility for placing the POLST form in the EHR and registry when it is created and removing it when it has been voided.

**Auditing, Reporting Functionality and Quality Measurement**

In order to assure patient identities are secure, an audit log should be established. This is especially necessary for registries that receive paper POLST documents. Audit logs can be useful for tracking:

- Utilization statistics and patterns
- Frequency of changes which may identify workflow or educational issues
- Documentation patterns between death records and POLST to see how the two compare in accuracy, completion compliance rates and whether or not a POLST was included as part of the patient’s health care plan.

The OPR reports that approximately twenty percent of POLST forms are incomplete in some way. To track workflow patterns and outcomes, implementation of audit logs or other standardized tracking methodology will help identify both model performances as well as gaps that offer performance improvement opportunities.

Examples of CQI metrics that registries, health care systems, and professionals might implement for improving POLST utilization include:

- Number of complete and incomplete POLST submissions
- Average age of patient or resident and gender breakdown
- Number of documented CPR and medical orders
- Percent of POLST form errors
Role Based Security
Role-based security should include guidance for describing the level of access EMS and health care professionals have when completing, accessing, editing, voiding, and reading a POLST form. Examples may include:

- Health care professionals with authority to complete or sign a POLST form: read/write access
- Health care professionals with permission to read and/or discuss a POLST: read access
- Defined EMS: read only access
- Care managers: can submit recommended changes to health care professional with authority to complete or sign a POLST form; edit to update form information that is not part of medical order (e.g., page 2 of the National POLST Form)
- Clarification for health information management: to edit metadata (document filed to wrong patient, etc.) but that permission must exclude editing content

Fault Tolerance
Registries, like other health care professional settings, should have a process in for a disaster recovery plan and business continuity plan in place to mitigate an EHR disaster recovery and back up potential for a malware attack.

Other Necessary Registry Features for Success
Beyond technology, registry success requires a good partnership with the POLST program, facilitated workflows, policies for assuring health care professionals submit completed POLST forms to the registry in a specified timeframe, and have the initial capacity for implementing a registry through the identification of critical volume of POLST form submissions.

Education & Good Partnership with POLST Program
Marketing and awareness of the registry and health care professional education is critical for registry success. In asking the OPR Director how states can improve adoption, the answer was “education, education, education!” Lack of funding for education and marketing was one of the reasons listed above for the failure of Washington’s POLST registry.

National POLST encourages all POLST programs to include representatives from all stakeholders in POLST implementation, including health care professional champions, patient advocates, faith-based leaders, EMS champions, HIEs etc. Programs manage education and quality assurance in their state. Strong engagement between registry leadership and state POLST program leaders is necessary for implementing a high-quality POLST program.

Registries accepting POLST forms should be partners with National POLST and POLST programs in providing patient education about POLST. Any time a POLST form is submitted to a registry, a notification to the patient should be sent confirming that their form has been received by the registry and is available to health care professionals.

In addition, information should be provided to the patient and health care professionals reiterating and reinforcing what POLST is, what it means during care delivery, and what the role of the registry is. As an example, the "What Your POLST Form Means" patient guide created by National POLST could be provided.72

Workflow
As with EHRs, it is not enough to have the POLST form and data in the registry: the registry architecture and workflow must support POLST form data entry, seamlessly coordinate with EHR workflows, and make POLST forms easily and immediately accessible to the variety of stakeholders accessing the registry. Beyond having a workflow for registry staff itself, it is critical to understand the existing workflows for various users to ensure that the registry will cause minimal disruption. California’s registry pilot experience showed that “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.”

Mandating Submission of POLST Forms to Registries
A critical element is a legislative or regulatory requirement for health care professionals to submit completed POLST forms to the registry. This promotes consistent care delivery, as opposed to only storing POLST forms in EHRs or HIEs, by reducing the incidence of multiple, inconsistent orders for a single person. This can be a contentious requirement.

In 2009, both Oregon and Washington passed laws establishing registries to house POLST forms; Oregon used an opt-out model while Washington used opt-in. Oregon’s registry is highly successful, providing extensive data which has been used in numerous research articles. Washington’s registry was not as successful and ultimately failed, in part, due to their opt-in model. As Dr. Bruce Smith, MD, co-chair of the Washington POLST Task Force and member of the Washington End of Life Consensus Coalition, observed “As an ‘opt in’ program, the [Washington] registry required a significant commitment to participate on the part of both patients and health care professionals….To be successful, I think a registry program should be automatic (‘opt-out’) to insure broad participation...” Judy Thomas, CEO, Coalition for Compassionate Care of California, agreed: “when structuring a registry, develop a system that is integrated into the existing health care delivery system and doesn’t rely on patients to opt-in.”

Delaware does not currently have a mandate that health care professionals must submit completed forms to their registry but may consider changing in the future if they cannot get the registry started in some other fashion.

High Level of POLST Use
Several reports have concluded there must already exist a “robust database of completed POLST forms” for a registry to be successful. Washington acknowledges the limited number of POLST forms in their

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registry was part of its’ failure\textsuperscript{79}, agreeing with ONC’s conclusion that “if there are not enough POLST forms in the registry, emergency care health care professionals will discontinue accessing the registry when they repeatedly cannot locate any POLST information during emergency patient care.”\textsuperscript{80} Coordination between registries, health care professionals, EMS and HIEs may help alleviate this issue as interoperability continues to unfold.

**Should POLST Registries Include Advance Directives?**

Of the 14 states the GAO looked at, 8 states had registries for only advance directives and 3 states had a combined POLST and advance directive registry.\textsuperscript{81}

![Map showing state advance care planning registries](https://polst.org/registry-development-pathways-pdf)

**Figure 2.** State Advance Care Planning Registries, November 2018\textsuperscript{82}

An acknowledged issue with advance directives is that they are unavailable when health care professionals need them. Patients don’t necessarily consider providing copies to their health care professionals and both health care professionals and systems are not consistently asking for a copy.


Including advance directives into a POLST registry may increase the ability for health care professionals to locate a patient’s wishes more readily when the patient is unable to communicate.

Because advance directives and POLST forms DO NOT provide the same critical information\(^3\), it is important that registries keep the forms separated and ensures EMS, other health care professionals and HIEs have immediate access to POLST forms.

**Recommendations Related to Registries and HIEs**

Currently, POLST registries are developed and supported at the state level and participants did not see any reason to change this or invest in a nationwide registry. National POLST is committed to supporting states that have already invested in developing registries and recognizes states have different needs (everything from population and demographic to the presence of an HIE and the EMS structure will affect how a POLST registry is developed and maintained). It is recommended that every state with a registry have a legislative or regulatory requirement directing health care professionals to submit completed POLST forms to the registry.

**Bidirectional Benefits: EHR Integration with a Registry**

EHR integration with a registry and/or HIE provides the opportunity for:

- An automated real time transmission of a completed POLST form from the EHR to the registry or HIE (may require additional programming workflow);
- Completion of an ePOLST in the registry or HIE using a HL7 connection; and
- Pulling the most current POLST form, or form orders, from the registry or HIE and automatically populating the EHR without any manual interaction (may require additional programming workflow).

Without technological integration, facilities in geographies where registries exist should develop workflows that include manual interaction with a registry using a phone call or log in methodology to determine the most current POLST form orders (assuming that POLST forms are submitted to the registry after completion, which is a challenge in places where such submission is not legally mandated or where systems or workflows don’t support automatic registry submission). Not all EHR systems with the ability to create and store ePOLSTs have bidirectional access to a centralized registry of HIE: if a registry exists in their region and the EHR does not have this functionality, the system needs the same manual workflow process of checking the registry for the most recently completed POLST.

POLST registries without any EHR connection or support have still demonstrated value while serving as a standalone entity. To achieve technological interoperability, however, it is important to ensure stakeholders have EHRs ready and capable to connect with a registry.\(^4\) In addition to what was previously provided, a registry:

- should be able to interpret what the document contains and be capable of returning discrete data from it. In addition to providing systems and users with an entire POLST form, it should also be able to selectively provide information from the form’s CPR/DNR question, as a single response;

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• must not just store forms but analyze form content in order to validate user or system errors;
• must be capable of storing multiple versions of a form once created, dated, and signed by a licensed health care professional. Forms should be considered immutable; changes are not made – new versions are created. The registry must provide access to all versions; and
must facilitate patient matching including storing unlimited health system medical record number (MRNs) to facilitate matching, preferably leveraging HIE capability.

With each encounter, either in-person or another communication method, the EHR needs to be able to automatically query and prominently display the existence of a POLST form and possibly the code status. Viewing the full form should be a simple click, and ideally include a note capturing the discussion. This is critical for both acute and post-acute care settings, especially ERs and other ambulatory locations. Health care professionals could even determine every encounter to trigger an alert, however opt-out options should not be permitted for EMS or health care settings including the emergency department (ED), or critical care units.

EHRs should be able to recognize exact duplicates (e.g., the same document ID) and potential duplicates (same patient but different document IDs). Exact duplicates will occur if registry documents have been downloaded and incorporated into other EHRs and may be discovered during a query. The EHR and HIE should treat each version as a single document and potential duplicates should trigger a reconciliation process and notification to void the older duplicate(s) if need on the same patient.

EHRs and HIEs should be able to automatically identify conflicts between the code status on the POLST form and the code status within the EHR. Users should be alerted any discrepancies and have the ability to reconcile differences. Organizations should be able to routinely complete timed batch (bulk-queries) for forms/statuses in order to accommodate the next day’s scheduled patients. This can be built as part of the quality improvement efforts to identify high-risk patients without a POLST.

Uploading POLST forms from the EHR to registries or HIEs should be seamless using an automated patient identification process. Ideally, the following could be included in an upload:
• Discrete data collection using EHR tools;
• Discrete data identified through the use of an online form built into the EHR;
• Scanned POLST forms; and
• Metadata and linked forms/notes.

Uploads could leverage C-CDA POLST documents and Direct messages because:
1. Scanned forms should be sent to the registry or HIE as a C-CDA POLST Direct message document containing the minimum data set (described above).
2. ePOLST forms captured by the EHR may use native functionality (Orders, Questionnaires, Forms, etc.) or a SMART-on-FHIR app. The ePOLST could be transformed into a C-CDA POLST document and potentially sent to the registry or HIE in a bidirectional process as in the case of a SMAR-on-FHIR attachment. (Note similar functionality already exists in many EHRs for referral orders containing discrete data and which generate a C-CDA document as a Direct message attachment).
3. Each registry or HIE needs to be able to incorporate new POLST forms received as a Direct message containing C-CDA POLSTs as an attachment.

Health care professionals should have the ability to be notified of changes, voids and/or superseding, of their patient’s POLST forms.
Standardized Data Sets & Terminology
Standardized data sets should be used to facilitate bidirectional technology with the source of truth for POLST forms. This means the EHR and, for example the state POLST registry or an HIE, are able to seamlessly exchange POLST form orders, ensuring the patient’s POLST form orders in the registry of HIE is always the most current and provides health care professionals the ability to view the most current POLST form at all times (the only exception is if the patient receives a paper from or has a POLST completed at a facility not connected to the registry of HIE).

With respect to terminology, the specific area within the EHR where ACP documents are housed information should consistently match language used for POLST education. For example, if the state uses “POLST”, then that is the term that should be used, not “orders for life-sustaining treatment.” Consistency in terminology increases intuitive adoption.

A Note About Integration with Skilled Nursing Facilities
Skilled nursing facilities (SNFs) house many patients who are POLST appropriate and, therefore, integrating POLST registries or HIEs with SNFs is ideal. Currently, this is a significant challenge as SNFs have highly variable use of EHRs and are therefore mainly paper-based, meaning that automated transmission of POLST forms is unlikely.\(^8^5\)

Technology Focused on Mobility

This section focuses on the challenges and solutions of POLST mobility, which we defined as: “the accuracy, portability, and accessibility of POLST data throughout the continuum of care, with an emphasis on EMS settings and patient facing apps.” The key obstacles to POLST mobility are connectivity and efficiency. Our recommendation to overcoming these obstacles is that each jurisdiction should implement a hybrid approach to POLST query and recovery from the menu of options listed below. Further, we strongly recommend that no matter what technology each jurisdiction uses, providers must be trained to recognize and use that technology.

The out of hospital environment poses unique challenges to patient care, and the complexity of addressing any issue related to EMS is complicated by a number of factors including provider certification level, provider education, the diversity of settings in which EMS operates and the austerity of some of those settings, and the jurisdiction-level oversight and protocols by which every EMS agency operates. Further, the workflow of an EMS team responding to a patient in peri-arrest or cardiac arrest is significantly different from that of an in-hospital team – we have included those differences in our analysis of each mobile technology. Our recommendations are not an attempt to remediate any of these issues, but rather account for them in our offering of potential solutions that agencies may choose from when developing or refining their approach to serving patients who use POLST.

Challenges in the Out of Hospital Environment
The information that drives the patient care decision-making process outside of medical facilities is unique from other care settings. Within seconds, EMS must elect to begin or deescalate patient resuscitation. These decisions are often made with less information and with fewer personnel present than in a hospital emergency department or floor unit – in the hospital setting, staff have the advantage

of searching for available records and orders, while EMS personnel may or may not have access to a hardcopy of patient care documentation. Fewer personnel on scene also means that any providers dedicated to looking for records or documentation are not providing direct care, and in particularly resource-lean environments, this can mean critical interventions are delayed or not performed at all.

Because resuscitation must begin promptly for the greatest chance of success – defined as a living patient with few to no deficits resulting from the cardiac arrest or peri-arrest – EMS personnel almost universally begin care without registering their patient or inputting any patient data into their computer system. EMS personnel also may not receive much information prior to arriving on-scene; Radio dispatches are limited to protect private health information, and Computer Aided Dispatch information can only reflect what the 911 call-taker/dispatcher has been able to gather from the caller. Gathering information from the highly stressful and emotional moments surrounding a respiratory arrest, cardiac arrest, or other end-of-life care scenario can be challenging.

**Analog Solutions**

**Paper POLST**

The paper POLST form is the original solution for conveying and facilitating a patient’s care goals in the form of a portable medical order. Some patients may still benefit from keeping a copy of their physical POLST form in their home or with their immediately available records; Patients in long term care settings, in hospitals, or in more remote (lower connectivity) environments, may not need or have convenient access to higher tech solutions – and higher tech solutions may serve as an additional barrier in these settings. Additionally, physical copies of portable medical orders or advanced directives remain part of EMS education and workflow – completely removing them as a tool is inadvisable.

**Medical Alert Jewelry**

Another tried and true method of alerting EMS personnel to special medical needs is wearable jewelry. The American Medical Association (AMA) endorsed the use of medical alert bracelets in the early 1960’s – predating the United States’ modern Emergency Medical Service system. In effect, medical alert jewelry has always been a part of EMS workflow, and should remain an option for alerting medical personnel to medical orders or advanced directives.

There are regulatory exceptions in some states preventing EMS from equating any wearable to a DNR order – for example, in Virginia there is only one authorized dealer of DNR bracelets. If a non-endorsed DNR bracelet is found, EMS must locate the DNR order or POLST form before acting on it. If those requirements are met, however, some states do allow the wearable to serve as the durable DNR. Due to regulation challenges and the practical restrictions of size, a medical alert bracelet on its own may not be a viable solution and a hybrid approach that encodes digital information allowing EMS to locate the POLST form may be beneficial.

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Medical alert jewelry may serve as a substrate for two other technologies as part of a hybrid analog/digital approach: QR codes\textsuperscript{87} and RFID\textsuperscript{88}. QR codes that either encode information telling EMS personnel where a POLST form is located (wallet, refrigerator door, nightstand) or takes the providers via URL directly to an up to date POLST order could be a very effective piece of a hybrid mobile technology solution. RFID codes are another possible solution, but to date, no agency has used the technology because it requires additional equipment to read and medical alert bracelets are often made of stainless steel which blocks RFID signals.

**Wallet Cards**

Wallet cards are not endorsed by the American Medical Association, but they are used as an approach for providing a low-tech alert option for medical providers about the existence of POLST orders. The card may be a miniature or condensed POLST form, or it may have information (such as a unique POLST Registry identification number or web address) that enables providers to access the POLST orders for that individual via data query or phone call. Anecdotally, patients have said they like having something smaller than the form to carry on their person, and some states like Pennsylvania provide miniature POLST forms.

![Figure 3: Example of POLST wallet card.](image)

However, the utility of wallet cards is inconsistent across the care continuum as EMS protocols vary by region and scenario. EMS participants agreed that while wallet cards would probably be more useful in the emergency department, hospital, or nursing home for less time-sensitive decisions like feeding tubes, they are not as useful for EMS because of how disruptive it is to resuscitation workflow in the field (requiring a patient to be rolled in the middle of CPR, for example.)

\textsuperscript{87} A QR code is a type of matrix barcode consisting of an array of black and white squares, typically used for storing URLs or other information for reading by the camera on a smartphone. These can help identify the patient, match them to the digital location of their POLST form or provide the current POLST form.

\textsuperscript{88} Radio-frequency identification (RFID) uses electromagnetic fields to automatically identify, and track tags attached to objects, such as jewelry.
Additionally, the location of certain emergencies provides contextual clues that EMS may rely on to make treatment decisions; EMS personnel will be more likely to search or ask for documentation in a nursing home than for a patient who suffered a crisis in public while running errands alone. Specifically, in the context of a significant medical emergency in a public place, EMS may not look for identification until after the initial stages of the resuscitation are well underway and the patient is in the ambulance. This is part of the routine workflow of significant medical emergencies, where the patient’s identity does not inform the treatment protocol, and where undressing or searching a patient may not serve the patient’s dignity. Patient identification cards also may or may not be easy or practical to locate in a timely manner and may not be on the person at all.

If using an ID for POLST, the best practice is to place it in a clearly visible pocket of the wallet next to the patient’s state identification card (e.g., driver’s license). In localities where wallet cards are widely adopted, it is recommended that EMS health care professionals are educated and trained to look for the cards.

As with any solution, a wallet card or other similar product should be presented with appropriate expectations; the scope of expectations needs to be clear in order support the utility of the wallet card. Simple DNR cards are sold on the internet with the implied or explicit promise that it will be honored everywhere. Because this type of misinformation exists, POLST educators, EMS, and the public would benefit from additional education that reinforces a better explanation of what a wallet card provides.

**State Identification Cards**

National POLST does not recommend using state-issued identification cards such as drivers’ licenses to indicate POLST status because they are not easily changed to reflect voided or updated orders.

**Stickers**

Stickers are another low-tech solution. The Oregon POLST Registry adopted stickers as part of their hybrid solution already and has identified the strengths and weaknesses with real world data. OPR sends a letter, a magnet, and a set of stickers to every patient so that the patient has documentation that their POLST form is in the registry. The magnet and stickers bear the patient’s unique Oregon POLST identifier number which are used by Emergency Communications Center staff to look up the patient’s POLST orders and relay those orders to EMS. They recommend that one of the stickers be placed on their copy of the POLST form, one be given to the patient’s primary care health care professional, and the third placed on something the patient would carry with them, like a wallet or day planner. Patients are advised to place the magnet on their refrigerator since in Oregon EMS are trained to look for the POLST magnet.89

Nursing homes have also used stickers to indicate which patients have POLST forms; generally, the stickers are placed on the back of the patient’s name tag pinned to their clothes.

Stickers have significant durability issues, and can easily get torn, crinkled, or lost and then have no value, especially those that require scanning an imprinted code. Other stickers which provide an easily human-readable ID number may be more durable. Like the wallet card and bracelet, any of these types of stickers would require EMS to cross reference the provided information with an active registry.

Emergency Call Centers
Emergency call centers across the United States use two different technologies for gathering information and dispatching calls: cards and computer prompts. The computer programs that assist call-takers are essentially digital cards that mirror their analog counterparts. They act as scripts or talking points to ensure all the appropriate questions are asked and the information is relayed to the dispatched emergency responders.

The content of the cards / prompts is not standardized. Multiple companies offer these products, but individual jurisdictions may modify them to suit their own needs. The standards that have been created around Emergency Medical Dispatch (EMD) appear to be concerned only with dispatcher competencies, dispatch times, and similar measures of overall system performance. It is strongly recommended that emergency dispatch centers adopt a POLST specific question to facilitate a more efficient response.

Digital Solutions

Electronic Patient Care Reports (ePCR)
EPCR systems are used by EMS to document patient records. Part of the data collected by EMS for these reports include patient demographics (name, date of birth, social security number,) which can be used to query a POLST data exchange. Using an industry standard, such as the HL7 FHIR standard for healthcare data exchange, an embeddable POLST module could be developed for use in any ePCR system, regardless of vendor.

Several challenges must be addressed before integrating this type of solution. Vendor regulatory requirements must be reviewed and met so that an appropriately robust integration is feasible nationwide. A standard for patient identification for POLST query must reach consensus – this is a potentially high-risk data query, and a mistake in patient identification can lead to erroneous resuscitation decisions.

Poor connectivity is also a reality for many EMS agencies and must be considered before implementing an ePCR module. Query responders, such as a POLST data exchange or POLST registry, must optimize outgoing data for EMS users. Data payloads can be optimized in two ways: (1) sending the POLST data elements prior to sending the POLST document. (2) reducing the image resolution (often measured in dots per inch or DPI) of the POLST document such that it is still legible, and its file size is reduced. Reducing a POLST document stored at 300 DPI to 70 DPI can decrease its size from 7MB down to 500KB and its transport time from 4 minutes to 3 seconds on a 256 Kbps connection.

Registry data must use existing NEMSIS elements for “advanced directives” to ensure the data elements are consistent with existing national EMS standards. The transmission of the image is desirable at some point for attachment to the EMS record – presumably once the ambulance reaches its base station, a hospital, or an area with better connectivity.

Asynchronous Registry
For cases where no Internet access is available, an asynchronous registry can continue to serve POLST data without interruption. An asynchronous registry is a snapshot of all patients in a service area that gets synchronized when the device is returned from the field. For example, an EMS agency would list the zip codes covered by their service in the POLST module. The POLST module would then download a copy of all patient records from a POLST data exchange and keep that as its local registry. The device is then used in the field, and, when returned the POLST module would then synchronize its local copy of patients with
the POLST data exchange. Ideally this synchronization should happen on a scheduled basis, such as daily or at shift changes.

**Recommendations for POLST Mobility**

- EMS Providers must be familiar with and train with POLST products they will encounter ahead of time.
- Drivers’ licenses and State IDs should **NOT** have POLST status on them.
- EMS workflow should be considered when implementing changes to POLST use in a region – providers should not be encouraged to engage with POLST in a way that impedes their workflow.
- Physical POLST forms and adjuncts such as Medical Alert Jewelry should continue to be available, especially in low-connectivity areas or for patients who do not have connectivity.
- Adjuncts with durability issues should not be used in a standalone way.
- Emergency Call Centers should train their call-takers to ask specifically about POLST forms if applicable to the call type.
- Electronic POLST data should be optimized for poor connectivity.
- Construct Asynchronous Registries for areas with poor known little / no connectivity.

**Patient-Facing Apps for POLST**

As health care professionals who create POLST forms move from paper-based to digital capture, other health care professionals, patients, caregivers, and loved ones have asked for digital access to POLST forms as well. Currently, patients must obtain a paper copy of their form after their health care professional completes it. That paper version may be shared via fax, scan, or copy machine to many health care professionals, caregivers, and loved ones. While many patients and health care professionals appreciate the tactile nature of a paper form, applications that connect patients to their paper or digital POLST form and allow the patient to share their form have three advantages over paper. (1) paper forms are easily lost or destroyed by accident. (2) digital forms can be shared as web links (URLs, QR codes, etc.) instead of copies, which eliminates cases where a health care professional, family member, or caregiver has an outdated version of a patient’s POLST form. POLST form pictures can also be shared, and they will not have the same credibility as a form from the primary source. (3) patients can review audit logs of access to their form. These logs contain information such as who accessed it, where, when, and how, as well as historical information such as the dates when the POLST form was created and updated.

Although apps provide benefits, it is vital that health care professionals and patients know that EMS professionals are unlikely to access a patient’s phone to see a POLST during an emergency unless they are specifically told it is there and how to access it.

**Facilitating Patient Sharing**

National POLST and POLST programs encourage patients to share their POLST form with friends and loved ones so they (1) know about the patient’s POLST form and can inform EMS about their existence and (2) can help support the patient’s choices if there are questions and the patient is unable to communicate. With paper, the patients must copy, take a picture, or scan the form to share with friends and loved ones while mobile technology provides patients a way to quickly share the current version of their POLST. Mobile apps also present an opportunity to easily provide more context to loved ones and friends for the existence and choices the POLST orders offer. As described below the patient may use the app to show loved ones and friends any educational components included in the app itself if that is offered - apps

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90 See also [https://polst.org/patient-guide-after-pdf](https://polst.org/patient-guide-after-pdf)
could be designed to consider loved ones and friends of patients as another audience for which they
specifically include educational components.

**Improved Patient Engagement**

Digital access to POLST offers opportunities to increase patient engagement, education, and awareness of
POLST and its purposes. For example, resources should be easily accessible in patient-facing apps that link
to guides made by National POLST and POLST programs. Topics should include detailed explanations of
the POLST form, layperson explanations of POLST, various treatment options covered by the form, and
the appropriate use of a POLST form by patient demographic and diagnosis. Apps can also make POLST
resources more accessible by translating the form and its resources into the user’s native language (using
the official translations of National POLST where available) and supporting screen readers for the visually
impaired.

Other opportunities for patient engagement include reminders, data, and examples to support
understanding. The app could schedule regular reminders for users to review their POLST form during
their annual visit or other appropriate medical appointments. Written or videoed stories can be used as
an educational tool to explain a range of choices made on POLST orders. Because POLST choices are very
personal, stories are helpful to explain that multiple factors can affect the decisions captured on a POLST
form and that these decisions may or may not change over time.

**Incorporating POLST in Patient-Facing Apps**

POLST conversations are nuanced and require skilled facilitation by appropriately trained staff; they
should not be reduced to a logic formula. Apps that capture POLST orders must preserve the personalized
conversation between a patient and their health care professional, allowing discussion of the specific
patient’s goals of care, medical condition, prognosis, and the benefits and burdens of potential treatment
options. It is critical that patient-facing apps incorporate and protect the fundamental elements of POLST:

- Verification of the appropriateness of the patient’s status for a POLST form to prevent
  inappropriate or overuse of the medical order.
- Personal, high-quality conversations between health care professionals and patients (or
  surrogates) about the patient’s goals of care considering their current diagnosis, prognosis, and
  treatment options (including risks and benefits of each)\(^91\).
- Accurate translation by the health care professional of those patient treatment preferences into
  medical orders on a POLST form.
- Health care professionals’ ability to know that a POLST exists for a patient, and to easily locate a
  patient’s POLST form when needed.
- Health care professionals’ knowledge about how to correctly interpret and follow POLST form
  orders, thereby enabling them to honor patient treatment preferences.

Apps that access and present POLST documents need to take care that POLST is kept distinct from other
ACP documentation like advance directives. If multiple ACP forms are available for a patient, it is
important that the app provides resources that educates the patient on each of the different forms and
when possible checks for consistency in goals of care across the collection of ACP documents.

POLST forms must be credible for EMS and other health care professionals to act on them. A patient’s
POLST form must come from a verifiable source such as a registry, HIE, or EHR. Done correctly, digital

\(^91\) See [https://polst.org/appropriate-use-pdf](https://polst.org/appropriate-use-pdf) (see #3)
approaches to providing POLST forms can improve the credibility of the document as compared to the paper version.

Because the current standard is to capture POLST on paper, valid paper forms submitted by patients into an app could be accepted with the clear understanding that they may be subject to a review and verification process – checking them for completion, validation, and correctness. Correctness requires that the form is filled out properly and has all the required components, including signatures and dates. Authorization requires verifying the identities of both the patient and the signing physician. It is inappropriate for apps (or any system) to allow patients to upload their POLST with an expectation that the form will be made immediately available to all health care professionals and EMS, however the timeframe for the verification process and availability of documentation must be explicit.

The person responsible for the validation process described above depends on the domain expertise of the organization that authors the app as well as the relationships brokered between that organization and POLST exchanges and registries. The authorization process would likely differ by scenario and setting, some organizations may prefer managing it internally whereas others may outsource to a registry or POLST exchange. Additionally, there may be a vertical system where payors could detect that a patient has uploaded a POLST form to the app and then arrange for a health care appointment to confirm the POLST is accurate and valid. Apps must explicitly indicate that POLST forms completed independently by patients will not be valid.

Alternatively, an app could be designed to not perform any verification but merely accept a digital version of the uploaded form for the patient’s convenience, in which case, this digital format is nothing more than another copy of the original paper POLST. If shared with others, the app should be regarded in the same way as a paper form. It is assumed to be valid but does not necessarily guarantee it.

Whatever format a POLST app takes, the purpose and features must be clear so that they can be used by patients, loved ones, and health care professionals appropriately.

Recommendations for Patient-Facing Apps
- POLST Apps must be credible with healthcare professionals and EMS professionals.
- POLST Apps should not replace high quality conversations between providers and patients.
- Apps must explicitly state that forms filled out without a provider are not valid.
- Apps must have audit logs for patients and providers to review.
- Apps must be easy to use and facilitate sharing with loved ones, care takers, and healthcare providers.

Other Technologies and Similar Approaches

Participants discussed a number of technologies and approaches to interoperability that POLST programs might want to model. Two that immediately came to mind are blockchain and the prescription drug monitoring program (PDMP).

Blockchain
Participants recommended that blockchain not be an area of focus for National POLST at the moment. Blockchain may eventually be a solution but the technology is evolving and still immature. Participants recognized blockchain could:
• streamline the process, reducing the manpower of certification;
• preserve history, which is helpful (but we already have that capability); and
• establish authentication.

While some aspects of blockchain make sense, the chain of custody with protected health information contained on a POLST form is problematic. As a medical order set, the origin of data is an essential component of for authentication, which is not strong in this model.

Prescription Drug Monitoring Program (PDMP)
Participants identified similarities between a PDMP and the technology goals of National POLST but had the following concerns about potentially integrating POLST with PDMP:

1. There is currently a monopoly (49 states use the same vendor).
2. It would require legislative action for POLST forms/data to be submitted.
3. There is potentially a problem in patient matching.

While access was previously extremely limited; HIEs have considered firewalled patient portals. Although concerns were raised about firewalls limiting health care professional and patient access to POLST information, information blocking is now legislatively addressed and therefore limitations should be resolved. When developing internal policies, entities should include the request for POLST as part of the complete longitudinal medical record.

POLST & Telehealth

Electronic Signatures
POLST forms require health care professional signatures and almost all POLST forms also require the patient’s signature. Paper forms are easy with “wet” signatures, meaning pen to paper. State law varies about what comprises an electronic or digital signature and in what circumstances they can be used. It is important to understand that these are not interchangeable terms and refer to completely different mechanisms for electronically recording a signature.

• Electronic signature (eSignature) describes a broad category of methods for signing a document.
• Digital signature (also called a certificate-based digital signature) is a type of eSignature that uses specific technical implementation, such as the public key infrastructure (PKI) protocol, to verify/authenticate a signature.

With a digital signature, every signer is issued a digital identification in the form of a certificate from a trusted service provider.92 “When signing the document, the signer’s identity is re-validated, and the signature is cryptographically bound to the document using PKI technology.”93 This process makes digital signatures ideal for private transactions.94

For states without any electronic/remote signature option, the POLST form must be printed (even if completed electronically) and both the health care professional and patient sign it before the form is scanned back into the EHR.


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Signer authentication is vital, especially when the process is remote. Vendors have various approaches for obtaining signatures remotely on POLST forms, but it is important to confirm the approach complies with applicable state law and HIPAA:

- Capturing signatures by allowing the user to sign the document using their finger on a mobile device or the mouse on their computer / laptop. Eventually users (health care professionals, patients) will have the ability to create and store their signature as part of their user profile for updating future POLST forms so that, for example, a POLST can be used in real time by all parties during a telehealth conversation.
- Using a HIPAA compliant process that uses a one-time use link allowing patients and surrogates to e-sign the POLST form. Links are sent via text or email and signatures are then automatically uploaded into their dashboard which communicates to the EHR. As described by the developer: “The one-time use link is possible by using a unique validation record in their database. Only an authenticated user with-in to their system who has the role allowing such a feature is permitted to generate this validation record and a one-time use link. As soon as the page is loaded by the end user with the one-time use link the validation record is flagged as being used and is no longer valid for re-use. The authentication for the above operation is safeguarded in their system behind an Azure Active Directory user account the health care professional needs to sign-in with as well as two-factor authentication from the Microsoft Authenticator app that either uses biometric security (iPhone Face ID or fingerprint scan) or one time use code the authenticator application regenerates every 30 seconds. When the end user digitally signs the POLST form with their finger on the iPad they capture the XY coordinates of the touch interaction on an HTML5 canvas and saving the operation as an image file with the other information inputted as well as a time stamp and IP address. All data in transit occurs over an encrypted TLS 1.2 connection.”

COVID-19 suddenly thrust this topic onto the centerstage with the increase of telehealth visits. Without a remote signature option, there is significant lag time and effort required to obtain the requisite patient and health care professional signatures and ensure both have a final copy:

- The health care professional completes the POLST form after a telehealth conversation about POLST;
- The health care professional signs the POLST and sends two copies to the patient to sign.
- Patient returns one copy to the health care professional for to add to their records.

There are better solutions. National POLST heard of several facilities around the US using DocuSign, a product already used for consents and other forms. DocuSign has a HIPAA compliant product—available at an extra charge—that meets all the necessary regulatory criteria for authenticating and transacting a health care professional order. Capital Caring shared their DocuSign experience with VA POST as follows:

Capital Caring Health explored several different products in response to the United States Government declaration that the COVID-19 Pandemic constituted a National Emergency. This Federal proclamation authorized modifications to workplace practices and necessitated remote work operations. We recognized that electronic signature capabilities were needed to bridge the gap that moving towards telehealth services created. Organizationally, our pre-eminent priority is to ensure patients and families maintain access to the documents and forms that enable their end of life goals to be known and honored.

Towards that end, our organization sought an electronic signature option that was user friendly, secure, HIPAA compliant, and cost effective. We reviewed this from the organizational build team perspective, staff functionality, and from the standpoint of the patient’s ease of use. Our research found that the DocuSign product meets some of the most stringent global security standards and uses the strongest data encryption technologies available. In addition, it complies with the U.S. ESIGN Act, and the Uniform Electronic Transactions Act which has been adopted in 47 states and grants legal validity to electronic contracts. Given the flow of patients in our geography between Virginia, Maryland, and the District of Columbia, we also confirmed with each jurisdiction’s Attorney General and their respective Department of Health that electronic signatures were valid and would be accepted the EMS system.

We found DocuSign offered the capabilities we were seeking and have been using it effectively for remote completion of various organizational Consent forms and medical orders to include the DDNR and POLST forms utilized within our tri-state region. In addition, Capital Caring Health has developed an internal process for dual authentication of the patient or surrogate signature: Once the forms have been signed by all required parties a final copy is automatically generated via email to the patient or surrogate and our HIM department places a copy in the patient’s electronic medical record. We also offer a printed copy of the completed document if the patient or surrogate lacks printing capabilities. The use of DocuSign and this confirmatory process has enabled a relatively seamless transition to remote operations and allowed medical orders to be completed more efficiently and expediently.96

This is just one example of HIPAA compliant electronic signature capability. There are several other vendors that have developed apps and are even National Committee for Quality Assurance (NCQA) certified. Technology is constantly changing and that registries and HIEs have the opportunity to secure accredited or certified electronic signature products that would meet authentication requirements.

Beyond finding a tool for signatures, however, is the validity of an electronic signature itself on a POLST form. Although historically advance care plans, advance directives and POLST forms alike, have required wet signatures, “the definition of writing and signature have been so transformed in so many spheres of business, health, and personal life that insisting on a wet signature is becoming archaic.”97 Specifically within health care, “electronic signatures are increasingly common in clinical setting for HIPAA notifications, prescribing drugs, and recording advance care planning conversations.”98

Though explicit permission is preferred, even if the law is ambiguous, it makes good clinical sense to accept electronically signed POLST forms. Health care professionals have an obligation under common law and constitutional principles to honor the patient’s clearly expressed treatment preferences: health care professionals are at risk if they ignore clearly expressed preferences, no matter how they are conveyed, unless there are concerns about ethical appropriateness or there are reasonable questions about their validity.99 Therefore, even if a POLST form were invalid under state law because it was signed

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electronically, rather than with wet signatures, it still conveys a patient’s expressed treatment preferences and other laws compel health care professionals to honor the document.

Recommendations Related to Telehealth

National POLST should support state efforts to recognize digital signatures on POLST forms as valid and expanding ACP codes to telemedicine.
Glossary and Acronyms

**advance care planning (ACP)** refers to a person-centered, ongoing process of communication that facilitates individuals’ understanding, reflection and conversations of their goals, values, and preferences for future health treatment decisions. ACP includes documenting discussions health care treatment decisions in medical records, advance directives and POLST forms.

**advance directive** refers to any legal document in which a person specifies what actions should be taken for their health if they are no longer able to make decisions for themselves and/or may authorize a surrogate for when the person loses their decision-making capacity. This term encompasses living wills, power of attorney for health care, personal directives, health care directives, durable powers of attorney for health care, medical powers of attorney, and health care proxies.

**covered entities** are subject to HIPAA and include health plans, health care providers and clearinghouses. The business associates of these individuals and organizations also must comply with HIPAA.


**emergency medical services (EMS) personnel** are responders that are dispatched to a medical emergency to provide medical or emergent care. EMS is comprised of emergency medical technicians (EMTs), advanced emergency medical technicians (AEMTs), paramedics, and other medical providers based on state categorization. EMS provides emergency and interfacility care using ground and air ambulances. While there are national standards for certification and training, most providers are also certified through their respective states, and authorized to practice through their agencies. The care emergency responders are permitted to provide, even with specific certifications may vary drastically based on local, state, or other regulations; especially during a declared national emergency such as a hurricane or pandemic.

**ePOLST** refers solely to a digital version of a POLST form. It is not a digital file that is the result of a scanned paper form and is not a digital file that resulted from form completion with computer software. Instead, it refers to a technology process that includes:

1. supporting patient decisions by providing education about POLST and includes the ability to print supportive materials and/or embeds educational videos as part of the ePOLST completion process;
2. supporting the POLST process by walking the health care professional through the steps of the POLST process, beginning with questions relevant to the POLST conversation;
3. allowing the patient’s preferences for end-of-life treatment to be recorded within the EHR;
4. Helping ensure the conversation and decisions result in a digital POLST form (most likely in PDF format) that is saved to the patient’s record and is printable so that a copy may be provided to the patient immediately; and
5. Helping ensure that secure transmission of the digital form to other appropriate health care organizations or POLST registry is facilitated.

**health care professional** means any health care professional, provider or clinician involved in the POLST process acting with their scope of practice. This guidance is trying to separate those licensed health care professionals who have authority to sign POLST forms and those who may be involved in the conversation (other health care health care professionals, including nurses and social workers, are typically part of the care team that supports POLST, even though they have no authority to sign POLST forms).
**health information exchange (HIE)** a system that allows health care professionals and patients to appropriately access and securely share a patient’s medical information electronically either locally, regionally or nationally.

**invalid POLST form** a POLST form that is missing required information or contains incompatible orders.

**opt-out** process whereby a patient can choose not to have their POLST form submitted to a registry.

**POLST form** is a portable medical order set designed to document and implement a clinical process across care settings for a patient with serious life-limiting medical conditions, which may include advanced frailty, and who voluntarily participates in the process which includes shared, informed decision-making, reflecting the patient’s goals of care and values.

**POLST** the ideal process of eliciting, completing, documenting, and honoring a POLST form. This includes appropriate conversations and completion of the form, as well as use of the form across care settings in honoring patient treatment preferences. It is the ideal that National POLST promotes and what all POLST programs are strongly encouraged to implement.

**National POLST** the nonprofit entity that standardizes the core requirements for POLST and works to ensure that individuals with serious advanced illness or frailty not only have access to POLST forms but to professionals who understand the value of POLST and are trained to have meaningful goals of care conversations to elicit, document and honor patient treatment preferences properly through a POLST form. National POLST creates and educates on those standards, as well as reviews POLST programs for compliance with those standards.

**registry** a centralized digital storage location that houses POLST forms, or the location of the POLST forms in distributed locations such as EHRs, in order to make them available to health care professionals when they are needed, across care settings.

**surrogate** is a substitute health-care decision-maker. For consistency, the term “surrogate” is used in this document to describe the person who consents or refuses to consent to some or all medical treatments on behalf of the patient who lacks decision-making capacity. We include the following in this definition:

1. an agent under a health care power of attorney, health care proxy, or a health care agent (the term varies by state);
2. a guardian or conservator of the person with health care decision-making powers, a court-appointed surrogate;
3. a surrogate recognized under state law;
4. any other similarly authorized decision-maker, regardless of the terminology used in a particular state; and
5. in the absence of anyone legally appointed, the individual identified by the facility to make decisions on behalf of the incapacitated patient.

Even when the patient appoints the surrogate, questions can still arise as to the extent of the surrogate’s authority. For more information about surrogates, please review our Legislative Guide or Surrogate information document.

**technological interoperability** the ability for a POLST form or data to travel among disparate systems across all care settings throughout the country to be available when and where the patient or health care professional needed it.
Project Participants
Thank you to our sponsors, supporters, and project participants.

Sponsors & Supporters
(sponsors are listed in order of funding support provided to this project)
The John A. Hartford Foundation
Vynca
California Health Care Foundation
Coalition to Transform Advanced Care
The Gordon & Betty Moore Foundation
Healthdoers.org (no longer in existence)
The David and Lura Lovell Foundation
COHRO
Medcordance

Conference & Technology Guide Participants
This project included national and state leaders, registries, electronic health record vendors, lawyers, health information exchanges, patients, mobile technology vendors, privacy and security experts, and others. All participants contributed their time to this project without compensation: National POLST greatly appreciates their support!

<table>
<thead>
<tr>
<th>Name</th>
<th>18</th>
<th>19</th>
<th>Guide</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rachel Abbey MPH</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>Office of the National Coordinator for Health IT (ONC-HIT)</td>
</tr>
<tr>
<td>Allen Abshire</td>
<td>•</td>
<td></td>
<td></td>
<td>Louisiana Health Care Quality Forum</td>
</tr>
<tr>
<td>Kelly Aldrich DNP, MS, RN-BC</td>
<td>•</td>
<td></td>
<td></td>
<td>Center for Medical Interoperability</td>
</tr>
<tr>
<td>Dave Anderson</td>
<td>•</td>
<td></td>
<td></td>
<td>Patient Alerts</td>
</tr>
<tr>
<td>Stephanie Anderson DNP, RN</td>
<td>•</td>
<td></td>
<td></td>
<td>Respecting Choices</td>
</tr>
<tr>
<td>Emelia Altschul MBA</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>Vynca</td>
</tr>
<tr>
<td>Paul Ballard JD</td>
<td>•</td>
<td></td>
<td></td>
<td>Maryland MOLST</td>
</tr>
<tr>
<td>David Barile MD</td>
<td>•</td>
<td></td>
<td></td>
<td>New Jersey Goals of Care</td>
</tr>
<tr>
<td><strong>Rick Bassett</strong> RN, MSN</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>Idaho POST Registry</td>
</tr>
<tr>
<td>Kathy Blanton RN, BSN</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>Sutter Health</td>
</tr>
<tr>
<td>Dawn Bonder JD</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>Cedar Bridge Group</td>
</tr>
<tr>
<td><strong>Keagen Brown</strong> MBA, CALA, CPHIMS</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>Seasons Hospice and Palliative Care</td>
</tr>
<tr>
<td>Howard Capon, MPH, NRP</td>
<td></td>
<td>•</td>
<td></td>
<td>National POLST EMS Advisor</td>
</tr>
<tr>
<td>Joseph Carr</td>
<td>•</td>
<td></td>
<td></td>
<td>New Jersey Hospital Association</td>
</tr>
<tr>
<td>Eric Chaney, MS, MBA, NREMT</td>
<td>•</td>
<td></td>
<td>•</td>
<td>EMS Specialist, Office of EMS, National Highway Traffic Safety Administration</td>
</tr>
<tr>
<td>Elizabeth A Char, MD, FACEP, FAAEM</td>
<td>•</td>
<td></td>
<td>•</td>
<td>Hawaii POLST, EMS Medical Director</td>
</tr>
<tr>
<td>Scott Code MBA, MS</td>
<td>•</td>
<td></td>
<td></td>
<td>Leading Age</td>
</tr>
<tr>
<td>Suelin Chen PhD</td>
<td>•</td>
<td></td>
<td></td>
<td>Cake</td>
</tr>
<tr>
<td><strong>Robert (Rim) Cothren</strong> PhD</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>Coalition for Compassionate Care of California</td>
</tr>
<tr>
<td>Abby Dotson PhD</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>Oregon POLST Registry</td>
</tr>
<tr>
<td>Sue Emmer JD</td>
<td>•</td>
<td></td>
<td></td>
<td>National POLST</td>
</tr>
<tr>
<td><strong>Aaron Fanta</strong></td>
<td>•</td>
<td></td>
<td></td>
<td>Huron Consulting</td>
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2021.04.21
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<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Jonathon Feit MBA</td>
<td>Beyond Lucid Technologies</td>
</tr>
<tr>
<td>Susie Flores</td>
<td>Care Directives</td>
</tr>
<tr>
<td>Amy Frye-Anderson MSN</td>
<td>Hospital Corporation of America</td>
</tr>
<tr>
<td>Danielle Funk MS</td>
<td>West Virginia Center for End-of-Life Care</td>
</tr>
<tr>
<td>Larry Garber MD</td>
<td>Massachusetts eHealth Institute and Reliant Medical Group</td>
</tr>
<tr>
<td>Ashley Geisel MBA</td>
<td>CORHIO</td>
</tr>
<tr>
<td>Matthew Gonzales MD</td>
<td>Providence St. Joseph Health</td>
</tr>
<tr>
<td>Matt Hoffman</td>
<td>Utah Registry</td>
</tr>
<tr>
<td>Sean Hubber</td>
<td>Epic</td>
</tr>
<tr>
<td>J. Sam Hurley MPH, EMPS, NRP</td>
<td>Maine EMS</td>
</tr>
<tr>
<td>Justin Keller MPH, JD</td>
<td>Collective Medical Technologies</td>
</tr>
<tr>
<td>Matt Kestenbaum MD</td>
<td>VA POLST</td>
</tr>
<tr>
<td>Jeannette Kojiane MPH</td>
<td>Kokua Mau (Hawaii POLST)</td>
</tr>
<tr>
<td>Doug Kunz MS</td>
<td>Stella Technology</td>
</tr>
<tr>
<td>Doug F. Kupas, MD, EMT-P</td>
<td>Commonwealth EMS Director, Pennsylvania Department of Health, Bureau of Emergency Medical Services</td>
</tr>
<tr>
<td>Jessica Little MS</td>
<td>Network for Regional Healthcare Improvement</td>
</tr>
<tr>
<td>Anthony (Tony) Loffredo MD</td>
<td>Cedars-Sinai Health System</td>
</tr>
<tr>
<td>Hannah Luette-Stahlman MPA</td>
<td>Cerner</td>
</tr>
<tr>
<td>Gina Malak</td>
<td>Medcordance</td>
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<tr>
<td>Paul Marola</td>
<td>CORHIO</td>
</tr>
<tr>
<td>Nancy McGee MS MBA</td>
<td>National Committee for Quality Assurance</td>
</tr>
<tr>
<td>Kate Meyers MPP</td>
<td>California Health Care Foundation</td>
</tr>
<tr>
<td>Marc Minkler, BS, NRP</td>
<td>Maine EMS</td>
</tr>
<tr>
<td>Ferdinando (Fred) L. Mirarchi DO</td>
<td>MIDEO</td>
</tr>
<tr>
<td>Maria D. Moen</td>
<td>ADVault/MyDirectives</td>
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<tr>
<td>Mike Mote</td>
<td>Health Current</td>
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<tr>
<td>Sharon Muscatell, RN</td>
<td>The Strategic Health Information Exchange Collaborative (SHIEC)</td>
</tr>
<tr>
<td>Brent Myers MD MPH</td>
<td>ESO</td>
</tr>
<tr>
<td>Katie Orem MPH</td>
<td>Excellus BlueCross BlueShield, New York eMOLST</td>
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<tr>
<td>Chelsey Patten MA, DBe</td>
<td>Illinois POLST</td>
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<tr>
<td>Carlo Reyes MD, JD</td>
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<td>Brian Richmond MBA</td>
<td>Louisiana Health Care Quality Forum</td>
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<tr>
<td>Joe Rotella MD, MBA</td>
<td>American Academy of Hospice and Palliative</td>
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<tr>
<td>Sandra Severson MBA/MHA</td>
<td>AzPOLST (Arizona POLST)</td>
</tr>
<tr>
<td>Gregory Smalter</td>
<td>Bross Group</td>
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<tr>
<td>Lauge Sokol-Hessner MD</td>
<td>Institute for Healthcare Improvement, and Beth Israel Deaconess Medical Center, both in Boston, MA</td>
</tr>
<tr>
<td>Brandy Taylor-Ayriss</td>
<td>Accessfm</td>
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<td>Kat Thomas</td>
<td>Epic</td>
</tr>
<tr>
<td>Kelly Thompson</td>
<td>National POLST Technology Committee Member</td>
</tr>
<tr>
<td>Barry Torman</td>
<td>StickyJ Medical ID</td>
</tr>
</tbody>
</table>
Methodology & Project Timeline

In creating this guide, National POLST undertook the following activities:

1. Surveyed POLST Programs about their current use of technology and future plans related to integrating POLST with technology
2. Invited POLST program leaders, vendors, and experts in a number of fields (technology, security/privacy, electronic health records (EHRs), health information exchanges (HIEs), registries, legal, patient communications, state and federal government) to two working conferences where attendees discussed the merits of current approaches and considered what was possible and appropriate. Though participants were divided into groups based on technology, each discussed similar topics such as security, risk, patient, and provider workflows, etc.
3. Conducted a literature review on current approaches to registries (POLST and advance directives) and other technologies.
4. Worked with 13 experts to provide final edits on the content.

This is the timeline for select activities:

- **January 2017**: started the National POLST Technology Consensus Project, identifying the purpose and intent of this guide and methodology.
- **January 2017-September 2018**:
  - Created agenda and outline for guide
  - Identified participants
  - Hosted webinars in preparation for conference
- **October 2018**: Held first working conference. Based on their expertise and interest, participants were divided into four working groups (EHRs, HIEs, Registries and Mobile Technology). Each group had approximately 15 people, at least 2 discussion leaders and 1 notetaker. For a day and a half these groups independently discussed pre-arranged topics and questions related to legal & security compliance, consumer needs, professional user needs and technology design. Discussion leaders, notetakers and the National POLST Executive Director stayed another day to discuss areas of agreement and recommendations to start the initial draft.
• **November 2018-September 2019**: participants met periodically with their groups and National POLST worked on a first draft of the guide.

• **October 2019**: a second working conference was held for a day to address questions and issues from the first drafts of the guide.

• **November 2019-July 2020**: participants met periodically with their groups and provided feedback on second and third drafts of the guide.

• **August 2020**: entire guide reviewed by selected experts

• **September 2020-February 2021**: final edits completed

• **March 2021**: guide released

• **April 2021-October 2021**: webinar series “POLST & Technology: Navigating Your Options”
  - **April 13, 2021**: POLST: an overview of National POLST’s Technology Guide Project
  - **May 18, 2021**: When Someone Dials 911: How EMS Uses POLST Orders
  - **June 15, 2021**: Interoperability: Sharing POLST Orders Electronically Across All Systems
  - **September 14, 2021**: POLST Registries: Considerations for States
  - **October 12, 2021**: EHRs: How to Advocate for POLST Inclusion in Patient Workflows
References

https://www.federalregister.gov/d/2020-07419


Sharon Muscatell, personal communication, November 2, 2020.


The Office of the National Coordinator for Health Information Technology. (2020, April 15). *Meeting Notes: Health Information Technology Advisory Committee (HITAC) COVID-19 Pandemic Response Hearing*.


Appendix: Registry Information

A survey was emailed to all states listed on the National POLST Registry Map (2020) as actively working on, piloting or has a registry. The tables below address the common questions received by POLST Programs.

### Registry Ownership & Costs

<table>
<thead>
<tr>
<th>State (Start Date)</th>
<th>Owner, Administrator Information</th>
<th>Where Registry is Housed</th>
<th>Implementation Costs</th>
<th>Annual Costs</th>
<th>Current Staffing</th>
</tr>
</thead>
<tbody>
<tr>
<td>CO (in development)</td>
<td>Colorado Dept. of Public Health &amp; Environment</td>
<td>TBD</td>
<td>A Statewide System for Advance Health Care Directives was signed into law on May 16, 2019. An appropriation of $993,147 for the 2019-20 state fiscal year was earmarked for the health department. Breakdown as follows: $32,100 for personnel services (assumed additional 0.5 FTE), $211,047 for operating expenses and $750,000 for purchase of information technology services.</td>
<td>unknown</td>
<td>Developing</td>
</tr>
<tr>
<td>DE (2018)</td>
<td>Delaware Health Information Network</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LA (2010)</td>
<td>Louisiana Health Care Quality Forum</td>
<td>Amazon’s AWS Cloud</td>
<td>$400 - $450K Includes initial spend to get registry implemented, staffing, and development of education/training materials</td>
<td>$100-125K (includes subscription fees &amp; staffing)</td>
<td>Approximately: 1 FTE: HIT staff 1 FTE training &amp; education</td>
</tr>
<tr>
<td>ID (2007)</td>
<td>Transitioning from ID Secretary of State’s office to ID Dept. of Health &amp; Welfare</td>
<td>n/a</td>
<td>Unknown. Cost of implementation &amp; maintenance was absorbed by Sec’y of State’s office. No funds earmarked. Formal evaluation of costs being done during transition.</td>
<td>unknown</td>
<td>None. Workload incorporated into existing roles.</td>
</tr>
<tr>
<td>MA (2020)</td>
<td>In development by state officials</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State</td>
<td>Sponsor/Provider</td>
<td>Project Details</td>
<td>Initial Costs</td>
<td>Yearly Costs</td>
<td>FTE</td>
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<tr>
<td>-------</td>
<td>-----------------</td>
<td>-----------------</td>
<td>---------------</td>
<td>--------------</td>
<td>-----</td>
</tr>
<tr>
<td>NV (unknown)</td>
<td>Secretary of State</td>
<td>Unknown (line item in NV state budget)</td>
<td>$250K (2009)</td>
<td>$370-$500K (year 10)</td>
<td>6.5 FTE</td>
</tr>
<tr>
<td>OR (2009)</td>
<td>Oregon Health Authority; Oregon Health &amp; Science University (OHSU)</td>
<td>OHSU servers</td>
<td>$187,000</td>
<td>20% of initial costs</td>
<td>1.5 FTE: .5 FTE: Project Manager (1) .5 FTE: Human Services Program Specialists (2)</td>
</tr>
<tr>
<td>PA (2019)</td>
<td>PA Department of Human Services, Office of Medical Assistance, PA eHealth Program</td>
<td>IBM Watson Health (System Vendor)</td>
<td>$600K for staff (admin, planning, legislation, technology via Vynca)</td>
<td>$45K</td>
<td>.5 FTE for program manager</td>
</tr>
<tr>
<td>SC (2020)</td>
<td>SC Coalition for the Care of the Seriously Ill (CSI)</td>
<td>My Life Choices</td>
<td>$244,140: $60,000 startup cost for custom application; $150,000 in salaries/wages/fringes (2 full time employees and 1 student worker) for minimum effective number of employees; $11,640 monthly secure server hosting charges for the Registry; $2,500 in secure faxing services for forms submitted to the Registry; $15,000 in postage for registry related letter mass mailings; $5,000 in supply printing for mass mailings</td>
<td>$184,140: $150,000 in salaries/wages/fringes (2 full time employees and 1 student worker) for minimum effective number of employees; $11,640 monthly secure server hosting charges for the Registry; $2,500 in secure faxing services for forms submitted to the Registry; $15,000 in postage for registry related letter mass mailings; $5,000 in supply printing for mass mailings</td>
<td>1 FTE for program manager; 1 FTE for database manager .5 FTE for volunteers</td>
</tr>
<tr>
<td>UT (2020)</td>
<td>Utah Health Information Network (UHIN)</td>
<td>eHIE</td>
<td>Total cost for ongoing maintenance is still being determined. UHIN has incorporated this scope into existing registry work like immunization and death certificates. A CMS 90/10 grant was also obtained for $837,155 to help support the registry build and education to post-acute facilities for completion of POLST for their residents and upload to the registry.</td>
<td>No new hires; using existing UHIN employees &amp; volunteers.</td>
<td></td>
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<tr>
<td>State</td>
<td>Documentation Completion</td>
<td>Mandated Submission to Registry</td>
<td>Method of Access to Registry</td>
<td>HIE Integration</td>
<td>Bidirectional EHR Integration</td>
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<td>-------</td>
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<td>-----------------------------</td>
<td>----------------</td>
<td>-------------------------------</td>
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<tr>
<td>CA</td>
<td>Paper form upload</td>
<td>No</td>
<td>EHR and ePCR with optional web-based portal for upload.</td>
<td>Yes, where HIE is present.</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Electronic form completion</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Electronic fax submission</td>
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</tr>
<tr>
<td></td>
<td>(available for some organizations)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Other:</strong> Can alert providers of existence of POLST upon transition of care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CO</td>
<td>TBD; likely paper form and requirement for Electronic Affidavit when provider signatures are required (MOST; CPR directive)</td>
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<td>DE</td>
<td>Paper form Electronic form completion</td>
<td>No</td>
<td>Web-based portal</td>
<td>No</td>
<td>Yes</td>
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<tr>
<td>LA</td>
<td>Paper form upload Electronic form completion</td>
<td>No</td>
<td>EHR and web-based portal</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td></td>
<td><strong>Other:</strong> Contains documentation supporting POLST Form (e.g., conversation notes, medical condition)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>ID</td>
<td>Paper form upload</td>
<td>Web-based portal or by phone through Sec’y of State’s office (M-F 9-5).</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
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<td>MA</td>
<td>Paper form upload Electronic form completion</td>
<td>Web-based portal</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>NV</td>
<td>Paper form upload Fax</td>
<td>Web-based portal</td>
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<td></td>
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<tr>
<td></td>
<td><strong>Other:</strong> Entities must sign up to have access. This repository stores directives, POLST and guardianship information.</td>
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<td></td>
<td></td>
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<td>NY</td>
<td>Electronic Paper form upload</td>
<td>Electronic form completion</td>
<td>Electronic fax</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Electronic form completion</td>
<td>No</td>
<td>Web-based portal</td>
<td>No</td>
<td>No</td>
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<tr>
<td></td>
<td>Electronic fax</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>OR</td>
<td>Paper form upload Mailed Electronic form completion Electronic fax</td>
<td>Yes</td>
<td>Web-based portal and call center-based system. Access also available via Emergency Dept Info Exchange (EDIE)</td>
<td>No (previously yes, but ended in 2018)</td>
<td>Yes</td>
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<tr>
<td>PA</td>
<td>Electronic</td>
<td>EHR and web-based portal</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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<td>Electronic form completion</td>
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<td>Electronic fax</td>
<td></td>
<td></td>
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<td></td>
<td>Mailed in forms</td>
<td></td>
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<tr>
<td>SC</td>
<td>Paper form upload Electronic form completion</td>
<td>No</td>
<td>Web-based portal</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td><strong>Other:</strong> Has ability to contain documentation supporting POLST Form (e.g., conversation notes, medical condition)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UT</td>
<td>Paper form upload Electronic form completion Electronic fax Mailed in forms</td>
<td>No</td>
<td>EHR ePCR Web-based portal</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td><strong>Other:</strong> Medical condition noted on the POLST form, but no conversation notes uploaded. Working on capacity to contain supporting documentation.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>WV</td>
<td>Paper form upload Electronic fax submission Mailed in forms</td>
<td>No</td>
<td>EHR, Web-based portal, call center, faxed requests, mailed requests, and secure, encrypted email requests</td>
<td>Yes, with the WV Health Information Network</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td><strong>Other:</strong> EMS access; 24/7 provider access; contains advance directives and medical orders; can contain documentation of non-health care advance directives; can contain registry specific internal documents and notes; contains internal record of changes to the patient record and patient’s files; contains internal record of history of patient files being accessed; based on a multi-level quality improvement system; contains death records reported to the state; can be accessible to treating health care providers not within WV</td>
<td></td>
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</tr>
</tbody>
</table>
### Additional Registry Information

This information was also requested from respondents, here are the data reported from the 3 states that responded:

<table>
<thead>
<tr>
<th>Key technology backbone elements or infrastructure to support the registry. (i.e., SQL servers, etc.):</th>
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</tr>
</thead>
<tbody>
<tr>
<td>The technology infrastructure is managed by Vynca and is deployed on Amazon Web Services (AWS).</td>
<td>Data hosting with Local Data Solutions, SQL, Azure, Microsoft Access, SharePoint</td>
</tr>
<tr>
<td>Key technology components include:</td>
<td>Is there a high availability plan in place?</td>
</tr>
<tr>
<td>• Amazon Virtual Private Cloud (VPC)</td>
<td>Yes; we are currently in process with Local Data Solutions to build a custom application to improve the longevity and functionality of our Registry. Also, our Registry’s data is available through the WV Health Information Network (WVHIN) to improve the availability of the data to treating health professionals. Once Local Data Solutions finishes the upgrade, patients will be able to access their file in the Registry to check for latest document being stored.</td>
</tr>
<tr>
<td>• Amazon S3 - document storage</td>
<td>Is there a high availability plan in place?</td>
</tr>
<tr>
<td>• Amazon RDS - relational database for application and analytics</td>
<td>Yes.</td>
</tr>
<tr>
<td>• Docker/Kubernetes - auto-scaling application containerization</td>
<td>Is there a disaster recovery plan in place?</td>
</tr>
<tr>
<td>• Amazon Cloudfront - content delivery network (CDN)</td>
<td>1. Internally at the WVCCOLC/WV e-Directive Registry, no data is stored on our local drives. All the data is hosted off-site through LDS. In addition, WVU has numerous encryptions and plans in case a security breach happens at the University level; although, this wouldn’t impact us since all the data is stored off-site.</td>
</tr>
<tr>
<td>• Mirth Connect - FHIR/HL7 data exchange and ingestion</td>
<td>2. LDS’ disaster recovery plan includes data protection services to prevent the loss of SharePoint Online data, routine data backups every 12 hours with the backup retaining for 14 days, 2-factor deletion system with a 90-day grace period to prevent accidental deletion of important patient records, 14-day grace period after 2-factor deletion of data to allow us the opportunity to restore “permanently” deleted information, ability to restore the entire SharePoint library (documents, files, history, etc.) to a previous version in the event of disasters (unwanted deletions, overwritten data, corrupted files, malware infection) which will undo all of the actions that occurred on the data in the 30-day period prior to the recovery, resiliency and recoverability options built into SharePoint Online through Microsoft, and a complete backup internal copy located on secure LDS servers in the Azure cloud storage.</td>
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**Is there a high availability plan in place?**

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3. WVHIN is part of CRISP (the Chesapeake Regional Information System for our Patients). As the governing body of WVHIN, all of CRISP’s protective measures are applied to WVHIN. CRISP has the HITRUST Certification and HIE certification, follows the guidelines of the Maryland Department of Health (CRISP’s origin is in Maryland), conducts an annual review and audit, performs a bubble plan every quarter, and runs an annual disaster plan test on all the data shared with and available through CRISP/WVHIN.

**Key network security requirements used to ensure this registry is securely hosted and maintained:**

Password protected database; 2-factor daily security authorization to the network (SharePoint); full data encryption through LDS; multi-factor authentication for all users; content stored as encrypted blobs in the blob store; SQL server database for the content database; encrypted keys to access each encrypted file; securely stored encrypted keys located separately in the content database; no hint of the decryption process of the keys stored in the content database; physical separation between the blob store, the content database, the key store, and the map; security measures to prevent access to the Registry’s data without gaining access to all keys, blob store files, content database, and the map.

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