



December 31, 2020

General Assembly
Capitol Building
Springfield, IL 62706

Dear Members of the General Assembly:

Thank you for the opportunity to present a study of the feasibility of a statewide registry of advance directives and Practitioner Orders for Life-Sustaining Treatment (POLST) forms. The Illinois Department of Public Health successfully collaborated with 11 organizations representing various stakeholders for POLST and end-of-life care issues in Illinois to draft this report pursuant to Section b-10 of Public Act 101-0163 (20 ILCS 2310/2310-600).

The report proposes necessary capabilities for a limited statewide registry of POLST forms, describes potential challenges to its feasibility, and suggests ways to improve its viability.

In consultation with the POLST Registry Advisory Committee, the Illinois Department of Public Health concludes that proposed statewide registry for POLST forms is a feasible endeavor for Illinois if the state (1) initially limits registry capabilities and content to solely POLST forms and (2) pursues a public-private partnership to fund the registry using existing technology procured from a third-party vendor. While an ideal registry would include broad user and public education and an expansion to include advance directives as well as POLST forms, such optimization is not feasible at this time.

The committee recommends next steps to put Illinois in the best position possible to implement the statewide POLST registry as proposed, including further defining the system, obtaining rough capital and operating cost estimates, and exploring partnerships with external stakeholders to assist in running the system. Developing the proposed statewide registry will prove a challenge but one the state can overcome in collaboration with the right partners.

I believe this report will prove to be a valuable resource as you continue your progress toward a statewide registry of advance directives and POLST forms to improve end-of-life care for residents of the state of Illinois.

Sincerely,

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Illinois Department of Public Health

**Statewide Registry of Advance Directives and
Practitioner Orders for Life-Sustaining Treatment
(POLST) Forms
Report to the Illinois General Assembly**

December 2020

Table of Contents

Overview of POLST in Illinois	4
Background on POLST.....	4
How POLST Forms are Used	6
Evidence of POLST Effects on Care.....	6
Electronic Registries	7
Registry Types.....	7
States with POLST Registries	8
Proposed Statewide Registry for Advance Directives and POLST Forms in Illinois	8
Proposed Design of a Statewide Registry in Illinois	8
Contents.....	9
Functions	9
Access	10
Administration.....	11
Cost	11
Challenges to Feasibility of a Statewide Registry in Illinois	12
Practitioner Workflows.....	12
Form Incompletion	12
Practitioner Access	12
Up-to-Date Patient Preferences	13
Information Privacy	13
Conclusion.....	14
Recommendations and Next Steps	15
Appendix A: Future Efforts	17
Technology Improvements	17
Embedded Guidance and Prompts.....	17
Integration with Existing Health Information Technology Systems.....	17
Statewide Supportive Programming.....	18
Practitioner Training on Advance Care Planning.....	18
Practitioner Training on POLST.....	19
Public Awareness.....	19
Committee Members.....	20
Bibliography.....	21

Overview of POLST in Illinois

Practitioner Orders for Life-Sustaining Treatment (POLST) language has been part of the do-not-resuscitate (DNR) form provided by the Illinois Department of Public Health (IDPH) since 2013.⁵⁴ There have been several legislative updates related to POLST since then. Legislation enacted in August 2014 expanded the types of health care practitioners authorized to execute the POLST form to include advanced practice nurses, physician assistants, and medical residents after their initial year of experience, in addition to physicians.⁹² Following legislation passed in 2015, IDPH removed “DNR” from the title and border of the form to reduce confusion⁹² and redefined the care options available to patients. The current version of the IDPH Uniform POLST form was established in 2017.ⁱ Supported and led by organizations including the Illinois State Medical Society and POLST Illinois,⁹² each legislative initiative has brought the IDPH POLST form closer to national standards and endorsement by National POLST.⁷⁸ The remaining impediment preventing National POLST endorsement in Illinois is the requirement of a witness signature in section D of the IDPH Uniform POLST form, which is contrary to National POLST recommendations.⁷⁸ Removing the witness signature requirement for a valid POLST form in Illinois will require additional legislation.

A survey fielded by the Illinois State Medical Society in late 2016 found “guarded support” for development of a statewide registry of patients with completed POLST forms. More than 75% of responding physicians, nurses, administrators, care managers, and others involved in end-of-life care would like to see the development of a registry but “comments revealed significant concerns about implementation, including who would maintain the registry, how the information would be updated, and how patient privacy would be protected.”⁵⁴

This report addresses these and other issues that determine the feasibility of a statewide registry of advance directives and POLST forms.

Background on POLST

The care individuals receive at the end of their lives too often does not reflect their values and preferences,⁸⁸ leading to unwanted resuscitation and hospitalization.⁷³ A review of 38 studies covering more than 1.2 million subjects in 10 countries found, on average, as many as 38% of patients near the end of life received non-beneficial treatments in acute care hospitals.¹⁵ Intensive care unit stays represent a significant portion of end-of-life hospital treatment.³ This pattern characterizes Illinois as well. On average, in 2017, decedents in Illinois spent more days in an intensive care unit (3.99 days) during the last six months of life than in any neighboring state and only decedents in Kentucky spent more days as an inpatient (8.57 days) than Illinoisans at the end of life (8.48 days).²¹ Given evidence that most people prefer to die at home,³⁵ often preferring less aggressive treatment at the end of life,^{85 112} this may represent a failure to meet the wishes of these patients and an excess burden on the health care system,

ⁱ See the IDPH Uniform POLST form at <https://dph.illinois.gov/sites/default/files/forms/polstform.pdf>.

such that the cost of inpatient care per decedent during the last six months of life in Illinois (\$16,063) was well above the national median (\$13,596) in 2015.ⁱⁱ

Advance care planning (ACP) involves an individual learning about the kinds of decisions often made about end-of-life care and treatment, considering those decisions ahead of time, and informing others about their preferences.⁷⁶ Individuals traditionally document their preferences in advance directives, such as living wills, health care powers of attorney, and do-not-resuscitate orders.⁹¹ These are effective only to the extent to which a patient considers their preferences in an ACP discussion⁸⁷ and those preferences are implemented by health care practitioners.^{22 92} Evidence suggests completion of these patient-generated advance directives does not always change the treatments individuals receive or result in higher-quality care at the end of life,⁸⁹ likely because of vague instructions and difficulty determining when to act on an individual's documented preferences.⁴⁶ In 1991, physicians in Oregon developed the POLST program to address this problem.⁷³

POLST is intended for patients 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. POLST serves as a structured framework for ACP conversations for this population with the goal of eliciting a patient's preferences for end-of-life treatment.^{14 38 61} Following the discussion, the practitioner records the patient's preferences for end-of-life care on the POLST form.^{36 88} Unlike advance directives, the POLST form converts a seriously ill individual's preferences for end-of-life care into medical orders that are immediately actionable as the patient moves across care settings,⁴⁵ a preferred practice for end-of-life care recommended for implementation in all states by the Institute of Medicine.^{3 56} In this way, POLST enables the most ethical process whereby patients, not health care providers, decide when their treatment ends. Given the population served, POLST forms are also usually completed closer to an individual's death⁸⁹ than patient-generated advance directives. More than half of POLST forms were completed in the final two months of life in one study of 18,285 Oregon residents who died in 2010 and 2011.¹³³

The goals of care documented by POLST are not predetermined. POLST is an outcome-neutral process that preserves a patient's right to decline aggressive medical therapies in the event of a cardiac arrest or other medical emergency but does not prioritize preventing hospitalizations per se.⁴⁰ POLST can be used either to limit medical interventions or clarify a seriously ill individual's request for any or all treatments.⁷ Older research reported more than 75% of decedents with registered POLST forms requested fewer life-sustaining treatments.¹³² However, more recent trends indicate a rise in POLST orders to attempt resuscitation and full treatment.^{115 133}

ⁱⁱ End-of-life care metrics from the Dartmouth Atlas of Health Care obtained from POLST Registry Advisory Committee member via email on December 14, 2020.

How POLST Forms are Used

POLST forms must be completed by a health care practitioner. National POLST recommends that states permit physicians, advanced practice registered nurses, and physician assistants to execute POLST forms,⁴¹ as is the case in Illinois. Several other members of health care teams also facilitate ACP conversations with patients and help prepare POLST forms,^{22 43 130} including staff from social services,¹³ pastoral care,⁵⁴ and non-clinician health educators.¹⁰¹ No single member of a health care team has sole responsibility over POLST. While this can lead to some confusion about which staff should be responsible for the forms, as was reported by 27% of physicians surveyed in Illinois,⁵⁴ physicians sign the vast majority of POLST forms, including 85% of POLST forms in Oregon between 2010 and 2015.⁴¹ Among physicians, the specialty most represented on POLST forms was primary care followed by oncology and hospice or palliative care.^{62 89 90}

The medical condition of patients most appropriate for POLST corresponds to the care settings and diagnoses most related to POLST form completion. Research has found POLST forms are more common for hospice enrollees than for those not enrolled in hospice^{43 45 46 64 80 89 90 111} and for longer-stay residents in long-term care facilities compared to shorter-stay residents.⁵⁷ One study found the most common diagnoses for decedents with a registered POLST form were cancer followed by heart disease.⁴³

There are also demographic trends in the individuals most likely to have completed POLST forms. As expected given the population appropriate for POLST, ample evidence shows POLST forms are more common for older patients nearer to the end of life,^{32 43 57 91} with studies consistently finding an average or median age greater than 70 years.^{18 38 63 105} Research also finds that patients with completed POLST forms are more likely to be White,^{17 43 46 63 91} with a notable exception among long-term care facility residents in California;⁵⁷ female;^{18 32 57} higher-income;⁸⁰ and located in urban compared to rural areas.³²

Evidence of POLST Effects on Care

The preponderance of evidence suggests ACP and POLST forms effectively alter care delivery consistent with the documented orders.^{4 13 39 43 61 97} There are a limited number of studies with null findings^{5 23 64 125} or negative results showing treatment that did not match care orders documented by POLST,⁶³ particularly related to antibiotic use and artificial nutrition.⁴⁵ More studies demonstrate that nearly all patients with valid POLST forms receive care concordant with the orders documented in the POLST form,^{4 13 45 49 65 97 104} including less intensive interventions, such as hospitalization or intensive care admission.^{9 38 43 63 125} For example, a study of 1,711 nursing home residents in Oregon found residents with POLST orders for comfort measures only were significantly less likely to receive life-sustaining medical interventions than residents with POLST orders for limited intervention ($p = .03$) or full treatment ($p = .004$) or residents with traditional do-not-resuscitate orders ($p < .001$) or full code orders ($p < .001$).⁴⁶

POLST not only alters care delivery but also improves individuals' health outcomes at the end of life, such that an individual is less likely to die in the hospital,^{80 103 111 119 120} one metric for quality end-of-life care.^{89 90} There are similar findings for ACP more generally.⁶ Several studies found that when compared to decedents with other advance directives, decedents with a POLST form were more likely to die at home^{89 90 111} or in a nursing home.³⁸ For example, among 2,027 West Virginian adults who submitted advance directives, POLST forms, or both to the West Virginia e-Directive Registry and died between October 2010 and December 2013, patients who completed an advance directive were significantly less likely to die outside the hospital than those who completed a POLST form.⁸⁸ Further, among individuals with POLST forms, those with orders for comfort measures only were less likely to die in the hospital than those with orders for full treatment.^{31 43 46 75 88}

Electronic Registries

However effective, a POLST form is only beneficial to a patient if it is accessible to all potential health care practitioners managing the patient's care.⁸² Especially during emergency situations, POLST forms need to be current, accurate, and rapidly accessible across care settings serving patients for whom POLST is most appropriate, including emergency medical services (EMS), long-term and post-acute care, physician offices, home health services, assisted living facilities, palliative care, hospice, and hospital emergency departments.⁸² Paper POLST forms, as currently exist in Illinois, may not be readily available to all of these practitioners, may become lost during patient transfer, or not included during patient discharge or transfer between settings.^{25 82 135} One potential solution is the development of an electronic registry of POLST documents: a secure electronic central repository and storage system for POLST forms or other ACP documents that allows submission of both original and updated information and improved access to the information to defined audiences via defined mechanisms.^{122 135} Registries can be run by the state, through a third-party vendor, or by another organization, such as non-profits, colleges or universities, or health care systems.²⁵

Registry Types

A POLST registry usually conforms to one of three models: (1) electronic form completion systems, (2) form repositories, or (3) hybrid form completion and repository systems.¹³⁵ Each model comes with pros and cons and each supports different needs and potentially different users or audiences.

Electronic form completion systems allow electronic documentation of POLST forms or other ACP documents, either as a standalone system or integrated into existing electronic health record (EHR) or health information exchange (HIE) systems.^{82 122 135} There are several benefits to these systems. The programming can feature guided completion to walk practitioners through form completion with prompts providing information or conversation scripts to facilitate the ACP discussion.¹³⁵ Additional programming features can emphasize quality control to prevent combinations of orders that are not actionable or require certain information be captured to reduce data errors or incomplete data.^{87 135} These systems can also allow batch

uploading of existing POLST forms as well as permit electronic signatures from health care practitioners,¹³⁵ which may enable ACP via telehealth and remote participation from the most comfortable environment for all parties. Access to electronic form completion systems often benefits users already registered through health systems or existing data exchange systems.¹³⁵

Form repositories store POLST forms, form content, or both, and make the information available to authorized users when needed, either as a standalone or web-based system or integrated into existing EHR systems.¹³⁵ EHR integration may allow health care practitioners to submit directly to these database systems through their care environments while patients themselves may submit their own documents via postal mail, fax, or in person.¹³⁵ Individuals can access information stored in the repository through secure public-facing or user-limited web-based portals, call centers, HIE systems, or other tightly controlled and Health Insurance Portability and Accountability Act of 1996 (HIPAA)-compliant electronic means.¹³⁵ A single central repository has the benefit of acting as a single source of truth for POLST forms, particularly when submissions identify date of completion, that can reduce confusion over which orders practitioners should follow. The storage-focused repository system usually does not allow for real-time quality controls, but registry administrators may perform quality audits on saved forms.

Hybrid form completion and repository systems combine the two systems described above to allow electronic form completion with form storage or automatic submission to a related repository, either as a standalone system or web-based portal.¹³⁵ The potential for completion and submission may eliminate lag times for registry inclusion of forms^{82 135} but also likely requires the largest investment in information technology to properly manage the system.

States with POLST Registries

Oregon was the first state to enter POLST forms into an electronic registry in 1991.³² Several states have since adopted a registry to provide centralized and faster access to completed POLST information filed by health care practitioners when the paper form cannot be located, especially during emergencies.⁸² States with active statewide registries for advance directives or POLST forms or both include Idaho, New York, Oregon, Washington, and West Virginia.¹³⁵

Proposed Statewide Registry for Advance Directives and POLST Forms in Illinois

This report studies the feasibility of a statewide registry for advance directives and POLST forms in two parts: (1) proposing the design of such a registry and (2) describing potential challenges to feasibility of the proposed registry.

Proposed Design of a Statewide Registry in Illinois

Feasibility of a statewide registry of advance directives and POLST forms depends on the design of that registry. The committee outlined the following aspects of a proposed registry: contents, functions, access, administration, and cost.

Contents

The proposed statewide registry should include POLST forms only. POLST forms are medical orders signed by health care practitioners⁴⁵ designed to travel with seriously ill patients across care settings and direct other health care practitioners to provide or withhold life-sustaining treatments. Unlike other advance directives available in Illinois, a POLST form includes medical orders that other health care practitioners are required to follow. Based on this distinguishing feature and the relative value its immediate accessibility would provide, the committee does not recommend including any advance directives in the registry at this time for the sake of simplicity. After developing and establishing a successful statewide registry of POLST forms, the state may consider adding advance directives as required by the statute mandating this report.¹

Functions

A statewide registry of POLST forms should be a web-based hybrid form completion and repository system for completed documents to allow health care practitioners, patients and their families, and other authorized users to complete, capture, search, retrieve, and update its contents via the internet 24 hours a day. Functions should be limited initially to reduce complexity and minimize required investments for implementation. The state may consider additional features in future efforts.

In the first phase of development, the registry should allow for electronic completion and capture of new and revised POLST forms. Health care practitioners should access the registry through a HIPAA-compliant web portal to electronically complete all new and revised POLST forms with their patients. Health care practitioners would also have the option of electronic fax submission of newly completed or revised paper POLST forms.²⁵ All documents completed or captured should be available on the registry within 24 hours.²⁵ Initially, the registry would not require storing any POLST forms completed before the establishment of the registry. This would limit the registry's ability to act as a single source of truth for POLST forms as health care practitioners would have no certainty about whether another form was completed with more recent care preferences.^{3 43 87} While some patients would still have paper POLST forms not in the registry and users in health care settings would not be able to look up those orders in the registry, the use of POLST forms could increase and over time the majority of POLST forms would be in the registry.

The second phase of registry development should build on the first to provide a full registry of new and preexisting POLST forms. This would require substantial efforts on the parts of health care practitioners to upload preexisting POLST forms to the registry, whether electronically, manually, or through lower-tech options such as electronic faxing.²⁵ Widespread use of the registry and the inclusion of previously created documents would allow the registry to serve as the single source of truth of the most up-to-date version of POLST forms for any patient. While not prohibited, paper documents should be minimized during implementation of this phase of registry development to avoid the presence of forms that are not current.

At a minimum, the registry should include (1) quality controls and internalized logic to ensure accurate and complete POLST forms^{43 58 95} that demonstrate clear and internally consistent medical orders,^{3 14 18 43 58 61 69 70 71 95 105 109 129} and (2) secure mobile platforms²⁵ that allow search functionalities using continuous predictive searching or quick response (QR) codes²⁶ for practitioners in prehospital settings.

Access

Access to the registry should be strictly limited to four groups: (1) health care practitioners completing POLST forms, (2) individuals benefitting from POLST forms, (3) health care practitioners serving patients with POLST forms, and (4) staff administering the registry.

Access to the proposed registry should include all practitioners authorized to sign POLST forms in Illinois: physicians, usually specializing in primary care, oncology, or palliative medicine;^{62 89 90} advanced practice registered nurses; and physician assistants. These users, known as “signers,” should have permissions to edit, prepare, sign, and upload completed POLST forms to the registry. While not authorized to legally sign or execute POLST forms, there are other health care practitioners who facilitate ACP discussions with patients,^{22 43 130} including staff from social services (e.g., social workers),¹³ pastoral care (e.g., chaplains),⁵⁴ and non-clinician health educators.¹⁰¹ These users, known as “preparers,” should be assigned by and linked to “signers” and have permissions to edit, prepare, and upload POLST forms to the registry. Lastly, there are often administrative staff to support practitioners at health care organizations (e.g., scribes). These users, known as “senders,”¹³⁰ should have permissions to upload existing and recently completed forms (if not submitted by the “signer” or “preparer”), without the ability to edit.

Individuals who benefit from POLST forms should include patients and their families as well as the patient’s health care agent authorized to make decisions on the patient’s behalf in an emergency. These users, known as “patients,” should have permissions to view and sign POLST forms. Patients could also opt in to allow other non-health care-related persons to view their POLST forms.

Health care professionals and providers that serve patients with POLST forms should have access to the registry. They should include practitioners from various settings and facilities, including EMS, long-term and post-acute care, physician offices, home health services, assisted living facilities, palliative care, hospice, and hospital emergency departments.⁸² These are essential end users who would use the registry to determine whether a new client has an existing POLST or check medical orders for life-sustaining treatments for a patient in transport, transferred or discharged from another setting, or arrived in a hospital emergency department. These users, known as “viewers,” should have permissions to search and view completed POLST forms for any patient, in accordance with existing privacy laws, preferably marked by date to identify the most up-to-date version.

Staff from the organization(s) administering the registry should have access to provide oversight and manage other users' permissions. These users, known as "admin," should verify the identity and credentials of authorized users,^{25 26 84} establish user authorization standards, designate user permissions, and onboard users to the platform, without the ability to edit POLST forms.

Administration

A statewide registry for POLST forms requires a lead organization with the necessary infrastructure to house and manage the system and any related program efforts.^{25 77 82 129 135} The committee recommends against the state operating the proposed registry internally. Illinois currently administers several registries, including the Illinois Prescription Monitoring Program at the Illinois Department of Human Services; Illinois Comprehensive Automated Immunization Registry Exchange and Health Care Worker Registry, both at IDPH; and the Life Goes On organ and tissue donor registry at the office of the Illinois Secretary of State. Each of these state-based registries is mandated by statute,ⁱⁱⁱ which requires ongoing participation and cooperation from external users to address operational issues and likely accelerated development.^{130 135} To date, no such mandate exists for a statewide registry of POLST forms in Illinois. Without a mandate, there are few resources and little capacity to develop and manage the registry within an existing state agency or program. In the absence of a state agency to serve as lead organization, a new public-private partnership could manage and sustain the proposed registry as a statewide health service; similar to the Illinois Poison Center, for example, which is a not-for-profit, affiliated entity of the Illinois Health and Hospital Association regulated as a human poison control center by IDPH and funded by the state, grants, and other public and private entities.⁵³

Cost

A further consideration against a state-run registry is cost. Costs for existing state-based registries are not currently available but each requires significant investments from state-based information technology services, which programs the registry software, and personnel who manage the users and data. There are existing systems available for implementation in Illinois. The state should procure an existing software solution from a third-party vendor to operate the registry, preferably in financial partnership with external organizations likely to benefit from the use of the registry, such as health systems and health insurers.²⁵ A third-party product is likely cheaper than internal administration at IDPH.^{iv} The Illinois State Trauma Registry housed at IDPH is similarly operated using a third-party vendor product.^v

Ultimately, the proposed registry will require sustainable long-term funding.^{77 82 130 135} The most feasible avenue for the necessary funding is in financial partnership with external

ⁱⁱⁱ Personal communications with IDPH staff on December 1, 2020; December 4, 2020; and December 7, 2020

^{iv} Personal communication with IDPH staff on December 7, 2020.

^v Personal communication with IDPH staff on December 1, 2020.

organizations likely to benefit from the use of the registry, such as health systems and health insurers.²⁵ For example, following seed funding from the state, a non-profit insurer in upstate New York, Excellus BlueCross BlueShield, provides full support for that state's registry.^{82 130 135} Health systems, EMS, health insurers, or other organizations that bear some risk for the cost of care at the end of life are likely to recognize the value of a statewide registry²⁵ given the evidence of substantial cost savings associated with advance directives and POLST forms.^{9 55}

Challenges to Feasibility of a Statewide Registry in Illinois

Creation of an electronic statewide registry will not in and of itself resolve all issues with POLST forms but, if designed correctly, can help reduce these concerns.

Practitioner Workflows

Practitioners often do not have the time or systems to conveniently conduct ACP conversations and complete POLST forms with their patients.^{10 13 14 25 43 48} ACP conversations can take an average of nearly 40 minutes⁴⁸ and completing a POLST form can take at least 60 minutes.³³ This may explain why more than 40% of physicians surveyed by the Illinois State Medical Society reported "lack of time" as a barrier to providing patients with information about POLST.⁵⁴ Time and workflow issues are likely to be compounded by introduction of the proposed registry as it creates another data repository that will require practitioners' attention. These issues could be addressed by emphasizing patient-facing capabilities. For example, patients seeking POLST forms could submit a request to their health care practitioner who would verify their appropriateness for POLST and, if applicable, set up the patient's account in the registry and assign a qualified health care professional to discuss and prepare the POLST form.

Form Incompletion

POLST forms are too often found incomplete^{3 18 25 58 95} or containing inconsistent or confusing medical orders difficult for practitioners to interpret,^{3 14 18 43 58 61 95 105 129} especially for EMS.^{69 70 71 109} An important piece of information often missing is the practitioner's signature.^{25 43 58 95 129} A survey of physicians in Illinois found 38% reported POLST forms had not been signed by the attending practitioner.⁵⁴ One study found the share of registered POLST forms documenting contradictory orders was about 0.1% in Oregon and nearly 3% in West Virginia⁷⁴ while another study found about 7% in the Oregon registry.¹⁰⁵ The systems-focused quality controls and internal logic for electronic form completion as proposed could minimize these issues.^{25 43} The state could also develop quality audit processes managed by the administering organization(s) to ensure signers accurately and completely finish POLST forms^{109 117} before they are added to the registry.²⁵

Practitioner Access

A primary challenge for implementing POLST orders is limited access to the forms when they are needed most, particularly during emergency situations^{3 122 125 131 135} and when patients are transferred between care settings^{14 58 91 129} or across state lines.¹¹³

EMS personnel are a primary user group for retrieval of registry forms who should be further targeted for improved access.^{82 vi} The state should facilitate their access by authorizing emergency dispatchers as registry viewers who would then communicate a patient's POLST orders to prehospital providers. The state could also consider other methods to improve EMS access to registry contents, such as training prehospital providers on manual search processes for the registry;^{25 82} lower-tech options for form retrieval, such as a 24-hour call center or electronic fax;^{25 26} or secure mobile platforms²⁵ that allow search functionalities using continuous predictive searching or quick response (QR) codes.²⁶

As a web-based registry requiring only an internet connection, the proposed registry likely needs less investment of information technology resources than other access methods and offers wide access to health care practitioners.

Up-to-Date Patient Preferences

Registry documents may not be the versions representing patients' most recent treatment preferences.^{3 43 48 87 99} Practitioners can confirm POLST information with their patients and families^{49 58} as is recommended best practice, particularly at changes in patients' clinical status,^{48 69 78 123} but there is no current mechanism to assure this is done.⁷³ This issue may be alleviated by allowing authorized viewers to search and retrieve current and historic POLST forms sorted by date signed.²⁵ The state might also consider promulgating rules that upon establishment of the registry the most recent orders included in the registry prevail and enacting liability protections for health care practitioners using the registry in good faith. Forms for recently deceased patients could be removed through the administering organization(s) reconciling registry forms against information from state death records,²⁵ as was done in the former POLST registry in Utah.²⁶

Information Privacy

The web-based registry as proposed presents some privacy concerns. The platform should comply with HIPAA rules to address these concerns. Staff administering the proposed registry would be responsible for mitigating other privacy issues by providing oversight to verify authorized users' identities and credentials and offering secure invitations for authorized users to complete signatures and provide consent.

^{vi} Personal communication with POLST Registry Advisory Committee member on December 14, 2020.

Conclusion

The proposed statewide registry limited to POLST forms addresses a significant need in Illinois to improve patient care and to reduce expensive, unnecessary treatments at the end of life for seriously ill and frail patients. To best serve those populations, the state should procure a vendor-based electronic registry containing only POLST forms that allows health care practitioners and patients and their families to complete, capture, search, retrieve, and update medical orders for life-sustaining treatment 24 hours a day. Finding the funding necessary to establish the registry as proposed presents a significant challenge to implementation. The state is most likely to overcome that challenge by exploring necessary funding and resources in collaboration with the right partners. A statewide registry of POLST forms is most feasible if implemented as a public-private partnership with health systems or health plans that supports an existing technology solution procured from a third-party vendor. Long-term optimization of programs to support a statewide registry, including public education, provider education, and enhanced technological features would need to be deferred until further resources are identified.

A sustainable statewide registry needs considerable long-term funding from multiple sources.¹³⁵ The state can reduce the funding necessary by focusing first on technology costs and limiting programming supports to future efforts. Until researchers develop a sustainable funding model for state registries,²⁶ Illinois must pursue its own public-private model and explore all potential avenues to build the necessary funding. The federal government has available funding at the 90% matching rate for state expenses that may be used to support POLST registry development,⁸² as stated in State Medicaid Director Letter 16-003 issued by the Centers for Medicare & Medicaid Services.¹²⁶ The state should also seek private funding from health systems and payers dedicated to value-based care and high-quality end-of-life care who are most likely to benefit from the registry both financially and in improved patient care.²⁵ Targets should include health plans engaged in Medicare Advantage and those involved in funding POLST registries in other states.⁸² Although these are viable funding options, until additional work to coordinate and to execute these options takes place, the funds necessary to implement the proposed statewide registry are not currently available.

A successful and useful statewide registry of POLST forms will require a sustained high volume of completed documents.^{25 82 135} A robust database of completed forms allows for better results when practitioners search for patient records. Otherwise, end users may discontinue accessing the registry if routine searches do not locate completed information.^{25 82} There is little information about how many POLST forms have been completed in Illinois. To operate the proposed statewide registry of POSLT forms, the state needs more information about the available capacity and willingness among practitioners to complete POLST forms and participate in a statewide registry. To date, the only state-specific information available to the Committee on this issue indicates that more than 70% of physicians surveyed in 2016 reported having

implemented POLST in their institution^{vii} while physicians, nurses, administrators, care managers, and others involved in end-of-life care in 2017 reported only “guarded support” for development of a statewide registry.⁵⁴ POLST Illinois has developed a survey to further assess practitioners’ registry readiness based on a model from California. There are also existing efforts across the state to improve end-of-life care that should be better understood. Alongside the statewide exploration of financial support for a statewide registry of POLST forms, the state should seek out and analyze further information about the capability and commitment of external stakeholders.

Recommendations and Next Steps

The Committee recommends the state address the following activities to put Illinois in the best position possible to implement a statewide registry of POLST forms as proposed.

1. **Direct IDPH to narrow contents for a statewide registry to only POLST forms.** Consider adding advance directives, such as Power of Attorney for Health Care forms and living wills, after Illinois has established a robust POLST registry.
2. **Direct IDPH to collect information on statewide use of POLST forms.** There is a lack of data about whether and how the POLST form is being used.⁵⁴ The state should consider collaborating with trade organizations and other groups (e.g., POLST Illinois) that can convene stakeholders and other interested parties in order to find this information.
3. **Direct IDPH to explore public-private partnerships for sustainable operation of a limited registry as proposed.** After obtaining rough capital and operating cost estimates for the registry as proposed, the state should prioritize a public-private partnership model that leverages 90/10 funding from the Centers for Medicare & Medicaid Services^{82 126} and emphasizes financial support for the registry from stakeholders most likely to benefit from its operation, especially health systems and health plans.²⁵
4. **Direct IDPH to procure services from a third-party vendor to operate the technology for the statewide registry of POLST forms.** Consider using the registry design and functions proposed by the committee to develop a request for proposal. The state and its private partner(s) will need to further define the registry at this point to properly procure a technology solution.
5. **Consider legislation to establish a statewide registry as proposed in this report.** Such legislation can accelerate development of the registry and secure cooperation from necessary partners to address operational issues.^{130 135} The General Assembly should also consider any necessary legal adjustments to ensure use of the statewide POLST registry is consistent with related statutes (e.g., practitioner liability).
6. **Direct IDPH to conduct an evaluation once the registry reaches a critical mass of completed POLST forms.** Continued spending on the proposed statewide registry should depend on results of an evaluation demonstrating the effect of POLST forms on processes

^{vii} [Illinois Health and Hospital Association] 2016 POLST Survey results obtained from POLST Registry Advisory Committee member via email on December 21, 2020.

and outcomes of end-of-life care in Illinois^{73 99 100 116} as compared to a suitable control group.⁷²

Appendix A: Future Efforts

An ideal statewide registry of POLST forms would leverage long-term sustainable funding to cover both additional technological features and functions and programming costs.^{25 48 61 82 100}

Technology Improvements

Additional technological features could prove more convenient for practitioners and patients while also facilitating complete and more accurate POLST information.

Embedded Guidance and Prompts

The registry could provide guidance to help practitioners complete the POLST form. Important information could include conversation guides on how to facilitate a high-quality ACP discussion¹³¹ or an option in the user interface to indicate whether end-of-life care choices were discussed with the patient.¹² Registry software could also provide patient-facing educational components to enable patients to prepare in advance of ACP conversation.

The registry could also prompt practitioners to send an invitation to the patient to access, view, download, or print the documents. Patients could then have the option to share the documents with loved ones, caregivers, or others. Further prompts could remind practitioners and patients and their families to revisit their POLST form on a regular basis,^{49 58 99 135} as is recommended best practice,^{69 73 78 123} or deactivate older forms when a more recent version is uploaded, thereby leaving patients with any number of inactive POLST forms but only one active form at any one time.^{26 135}

These features could alleviate some of the workflow disruptions for health care practitioners that often limit POLST use.

Integration with Existing Health Information Technology Systems

The registry could provide close to real-time information from POLST forms to health care practitioners 24 hours a day through bidirectional integration with EHR systems. This could allow digital submission of completed POLST forms directly from an EHR system to the proposed registry⁸² while also automatically displaying changes in the registry in the electronic record for patients at participating health care facilities. Further changes would likely be needed, however, as EHRs are often not optimized for ACP documents.^{87 91 117}

Procuring registry software through a third-party vendor could also facilitate integration with HIE networks or EHR systems, such as the web-based, EHR-embedded application allowing real-time education and completion of POLST forms in Oregon.^{25 117 131} If pursued, EHR integration could begin with the EHR systems most prevalent in Illinois,⁸² particularly Epic Systems Corporation, the single vendor that dominates the state's market for EHR systems.⁵² Epic served 24% of hospitals and 40% of physician practices in Illinois as of June 2017.⁸³ EHR

integration in Illinois is almost entirely accomplished through software solutions provided by EHR vendors.⁵² Procurement could bypass some of the financial and human resources necessary to establish point-to-point connections from the registry to each participating EHR system,⁸¹ while also emphasizing interoperability functions, such as push notifications for completed POLST forms^{25 117 123 131} and single sign-on.⁸² These features would likely require substantial investment, particularly if integration were to be provided to practitioners free of charge as is done for two other state registries, the Illinois Prescription Monitoring Program and Illinois Comprehensive Automated Immunization Registry Exchange.

Integration with existing EHR systems^{26 82 96 135} and their solutions for HIE⁵² might also address workflow issues that limit practitioners' use of POLST forms, especially if a single sign-on system were established^{25 82} to limit additional time and effort associated with another log-in or data system. This is especially true for emergency situations where integration with existing EMS electronic patient care record systems could proactively inform prehospital practitioners of the presence of a registry document.

Statewide Supportive Programming

Organizations such as POLST Illinois and health systems throughout the state are presently engaged in programming efforts to support POLST use. As the state develops and establishes its registry of POLST forms, these efforts could be scaled to reach a broader audience statewide. Education, training, monitoring, and evaluation are critical to strengthening the quality and sustainability of a statewide registry.^{25 135} Building on existing programs will likely require a significant investment of resources including dedicated staff, training, and support.⁴⁸ Given the likely cost, the state should consider adopting the public-private approach to financing the registry by leveraging existing efforts led by private organizations across the state to improve end-of-life care and develop a statewide POLST registry.

Practitioner Training on Advance Care Planning

POLST forms are meant to be the result of reflective and iterative conversations between practitioner and patient about end-of-life care.^{12 34 48 99} Unfortunately, many practitioners are uncomfortable with the problems raised during ACP conversations⁴³ and feel ill-prepared to initiate¹²² or facilitate them,¹⁰ leading to only limited discussions with patients and their families.^{14 47 61 124 129} Despite billing codes authorized in 2015 to reimburse health providers for engaging patients in ACP discussions,¹¹ a 2016 survey found only 36% of responding physicians in Illinois were aware of the payments and fewer than 20% of those physicians received reimbursement.⁵⁴ This may explain data showing only 1% of Medicare beneficiaries in Illinois had a claim that included ACP in 2016.^{viii} The state could support its registry by supporting and extending existing programming to promote reimbursable ACP visits with appropriate patients and provide ACP communication training^{10 61 100} to all practitioners involved in the POLST

^{viii} End-of-life care metrics from Illinois Performance on the Advanced Care Transformation (ACT) Index for 2016 obtained from POLST Registry Advisory Committee member via email on December 23, 2020.

process. A goal of extended communication training could be to institute statewide one or more of the many systematic approaches to ACP, such as Respecting Choices[®],^{27 36 66} Last Stages,¹³ the Conversation Project, Preference Aligned Communication and Treatment, Vital Talk, or others.

Practitioner Training on POLST

A recent review of existing POLST programs suggests the greatest implementation challenge for states is uneven education about POLST for practitioners,^{14 18 22 43 47 58 61 69 100 122 124 129} which can lead to misuse of the form¹²⁶ as was the case in Delaware where the state discontinued its POLST form.⁷¹ The state could again support and extend existing training for practitioners involved in the POLST process on topics such as which patients are appropriate for POLST⁹⁹ and other content based on an educational feedback loop identifying deficiencies in POLST forms submitted to the registry.²⁵ A training topic for special emphasis is interpretation of POLST orders,^{14 18 58 70 73} which particularly affects emergency situations.⁶⁹ Additional training and education for prehospital practitioners could emphasize how to retrieve POLST forms from the registry²⁵ and introduce practice protocols or decision-support tools^{39 43} to prevent discordant care when encountering registry documents.^{68 69 70 72 109}

Public Awareness

There is a general lack of public awareness and education about ACP,¹²⁷ particularly POLST forms.¹²⁸ The state could grow existing community-based education campaigns to reach audiences across the state about the importance of having an up-to-date POLST form for seriously ill and frail patients.⁸² Collaboration with coalitions of community-based organizations across the state^{110 129} could also improve uptake of advance directives and POLST forms while educating the public about palliative care, home-based primary care, ACP, and POLST forms. Practitioners could also benefit from these community coalitions through best practice guidelines and hands-on technical assistance to support them through necessary change management activities²⁵ that can lead to greater use of POLST forms.¹³⁵

Committee Members

Pursuant to Public Act 101-0163, IDPH drafted this report “[i]n consultation with a statewide professional organization representing physicians licensed to practice medicine in all its branches, statewide organizations representing physician assistants, advanced practice registered nurses, nursing homes, registered professional nurses, and emergency medical systems, a statewide bar association, a national bar association with an Illinois chapter that concentrates in elder and disability law, a not-for-profit organ procurement organization that coordinates organ and tissue donation, a statewide committee or group responsible for stakeholder education about POLST issues, and a statewide organization representing hospitals...”¹

IDPH thanks the following representatives appointed to the POLST Registry Advisory Committee for their service in studying the feasibility of a statewide registry of advance directives and POLST forms:

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