Minnesota POLST Registry Study

KEY FINDINGS & RECOMMENDATIONS

1/31/2024

Minnesota POLST Registry Study

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Introduction

The 2023 legislature directed the Minnesota Commissioner of Health to develop recommendations for a statewide registry for provider orders for life sustaining treatment (POLST) (appendix A and https://www.revisor.mn.gov/laws/2023/0/Session+Law/Chapter/70/). POLST is a portable medical order that can give individuals with advanced serious illness or frailty the means to exercise increased control over the treatment they do and do not want to receive at the end of life. The POLST helps to ensure the individual's wishes are conveyed to emergency medical services (EMS) and other health care professionals. The POLST is voluntary and is one part of advance care planning. POLSTS are already in use in Minnesota, but there is no readily available information on the number of individuals with a POLST or the number of active POLSTS in Minnesota.

A valid POLST in Minnesota must be signed by a licensed physician, advanced practice registered nurse, or physician assistant. The POLST does not need to be signed by the individual, but it is strongly encouraged as a best practice by POLST Minnesota. POLST Minnesota is a community collaboration, managed by the Minnesota Medical Association (MMA), which developed the POLST Minnesota Form (appendix B) and best practices for the POLST discussion and processes. An overview and additional detail on POLST in Minnesota are in appendix C.

Immediate access to individual's POLST is especially important in medical emergencies. Currently, individuals are encouraged to keep the POLST form with them at all times and in a location where it can be readily available and visible for EMS. Unfortunately, this does not always guarantee that EMS and other health care professionals have access to the information at the time it is needed. While there is no information on how often an individual has a POLST, but it was not accessible in an emergency, it is a situation that can and does arise. A potential solution to this problem is a statewide POLST registry – a reliable, secure electronic system for timely access to the POLST information. Other states have implemented or piloted POLST registries with varying strategies and successes (appendix D).

Methods

POLST Registry Environmental Scan

The POLST registry environmental scan focused on POLST registries in other states, national work around standards for POLST, and discussions with national and state experts. In addition, specific Minnesota statutes and policies were reviewed for POLST-related implications. This information was used to structure and inform the discussion of the advisory committee.

Advisory Committee

The POLST study advisory committee was compromised of 28 individuals; see appendix E for membership. The co-chairs were Crystal Houghtaling, LSW, who is the Campus Director at Sholom Home West and Vic Sandler, MD, who practices hospice and palliative medicine and is the Geriatrics Chair at Minnesota Network of Hospice and Palliative Medicine Physicians. The advisory committee also benefitted from the participation of Abby Dotson, Ph.D., who is the executive director of the National POLST Collaborative and director of the Oregon POLST Registry. The advisory committee met six times in the fall of 2023 with active engagement from members across the care continuum. Attendance ranged from 27 to 13, with an average of 20 members at each meeting. The members' discussion focused on key stakeholder perspectives on the considerations, implications, and opportunities for:

- Electronic capture, storage, and access of information in the registry.
- Procedures to protect the accuracy, security, and confidentiality of registry information.
- Limits as to who can access the registry and when.
- Individual-centered or family-centered are considerations for the registry.
- Equity (infrastructure, access, accessibility, training, education, or communication).
- Any other action needed to ensure that patients' rights are protected and that their health care decisions are followed (policy, technical, or best practice).

These discussions led to the development of recommendations and identification of key findings. The recommendations were endorsed by all the advisory committee members except two members who did not vote. During the endorsement process, there were comments on implementation including future discussions on the role of dispatch in the POLST registry and ensuring best practices for POLST are highlighted including an individual's option to opt out and update the POLST at any time.

This work was facilitated by the Center for Health Information Policy and Transformation (CHIPT) in the Health Policy Division at the Minnesota Department of Health (MDH) with key support from MMA.

Key Findings

Several key findings emerged during the study and are addressed in the recommendations.

- A comprehensive POLST program and high-quality POLST implementation are key to a successful POLST registry. This includes a statewide program as well as health care systems and long-term care having robust POLST processes and policies.
- In addition to development of the registry, and in order to ensure its effectiveness, there is a need for broader POLST education and training for health care professionals and health organizations across the care continuum so there is a common understanding of best practices regarding the use of POLST. A POLST public awareness campaign that supports and aligns with POLST education and training is also necessary. The 2019 MMA surveys of EMS and long-term care's knowledge and use of POLST provide more detail on training and knowledge needs (appendix C).
- When the registry is implemented, ensuring that a sufficient number of POLSTs have been added to the registry before EMS and emergency departments begin accessing it is key to user satisfaction and sustained use. User adoption could suffer if searches frequently lead to no results.
- There are POLST-related and other national health information technology standards and policies already in place that can be used to achieve interoperability and support privacy and security of data.
- To ensure statewide access, particularly in rural areas, EMS will need multiple ways to access a POLST registry.
- There is not a single recommended way to implement a POLST registry. States that have implemented POLST registries have used a variety of organizational structures, with lead or coordinating organizations that include the state department of health, health insurance companies, universities, medical associations, and nonprofits. More information on implementation in other states can be found in appendix D.
- Prioritizing shared informed decision making and incorporating cultural, faith, disability, and other perspectives are important.

Recommendations

The following recommendations were developed and endorsed by the POLST registry study advisory committee, representing diverse perspectives from the health care continuum and other stakeholders. In consultation with the POLST registry study advisory committee, its co-chairs, and the study planning team, MDH largely supports the recommendations of the advisory committee. However, it is important to note that implementing the following recommendations would require statutory changes for a state agency, including MDH, to administer due to several legal and policy issues which are identified after the recommendations. MDH recognizes that there are several significant components in developing an effective POLST program. MDH welcomes the opportunity to contribute to future discussions about ways such a program could be implemented and maintained.

Overarching Recommendation

1. The POLST registry should be part of a comprehensive statewide POLST program that:
   a. Supports shared informed decision making between health care professionals and patients along with their family and appropriate surrogates[1].
   b. Ensures patients' rights are protected and their health care decisions are accurately communicated, respected, and followed.
   c. Advances equitable access and use of POLST.

   The POLST program should include education and training, the registry, and a call center. The education and training should focus on POLST discussions, decisions, and best practices; POLST registry training; and POLST public education and awareness. To achieve alignment and accountability the program should have a coordinating organization with stakeholder representation and input.

POLST Education and Training Recommendations

POLST Discussions, Decisions, and Best Practices

2. Build upon and expand existing education and training to ensure that all health care professionals involved with end-of-life and emergency care are trained on the POLST best practices and processes. The education and training should be inclusive of cultural, faith, disability, and other perspectives. The ongoing standardized training should include:
   a. Identifying which patients are POLST-appropriate and when the order needs to be created, reviewed, updated, or removed.
   b. Ensuring that POLST conversations and shared, informed decision making occur between health care professionals and patients and their surrogates.

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[1] A surrogate may include a court appointed guardian, Health Care Agent designated in a Health Care Directive, or a person whom the patient's health care provider believes best knows what is in the patient's best interest and will make decisions in accordance with the patient's expressed wishes and values to the extent known, such as a verbally designated surrogate, spouse, registered domestic partner, parent of a minor, or closest available relative.

   c. Recognizing POLST as part of advance care planning and the Patients' Bill of Rights.
   d. Applying guidelines for valid completion of POLST.
   e. Using POLST by EMS and emergency departments.

   Ongoing health care professional trainings should be developed for a variety of scenarios and health care settings to address time and availability barriers. Training strategies should include virtual and in person settings, just-in-time trainings, for continuing education units and continuing medical education, lunch and learns, etc.

3. Expand the reach of currently available education and training for court-appointed guardians and other surrogates to support informed and equitable decisions.
4. Develop tools for organizational readiness to implement POLST. This includes the capacity and policies to implement the POLST and its workflow. Areas of focus should include, but are not limited to, privacy and security, collecting informed consent, billing for advance care planning (POLST discussions), and access to POLST through a patient's personal health record.
5. Medical, nursing, social work, EMS, and other professional associations and schools should include POLST as part of the curricula.

POLST Registry Training

6. Provide ongoing standardized training for health care professionals on the POLST registry including submission and retrieval of POLST, use of POLST in an emergency, access methods, and privacy and security safeguards. The training should be developed for a variety of scenarios and health care settings to address time and availability barriers. Trainings strategies should include virtual and in person settings, just in time trainings, for continuing education units and continuing medical education, lunch and learns, etc.
7. Develop tools for organizational readiness to use the POLST registry. This includes capacity and policies to implement the POLST registry into workflows and how to prepopulate the registry.
8. Provide POLST registry education and training to patients, surrogates, advocates, and others when the consumer access is implemented.

POLST Public Education and Awareness

9. Provide an ongoing active public education and awareness campaign for POLST as part of advance care planning and, when developed, the POLST registry. The campaign should target patients, families, surrogates, and faith leaders; be inclusive of cultural, faith, disability, and other perspectives; and include the common non-English languages spoken in Minnesota (including ASL).

POLST Registry Recommendations

10. The POLST registry should require role-based access for all authorized users with their own unique account login credentials. These authorized users include, at a minimum:
    a. Emergency medical responders (EMRs), emergency medical technicians (EMTs), and paramedics who currently work or volunteer for a licensed ambulance, including advance life support and basic life support, or a registered medical response unit (MRU).
    b. Health care professionals at hospitals, clinics, home care, assisted living, skilled nursing facilities, and hospice.
    c. POLST registry and call center staff as needed to complete their duties.

11. Authorized users are subject to state and federal privacy and security laws and policies as applicable by role and organization.
12. Develop one or more consumer access methods to the POLST registry for patients and their surrogates who participate with the registry.
13. The POLST registry must have multiple methods to obtain POLST and ensure timely access by authorized users regardless of location or technology. The identified methods necessary to achieve statewide access are listed below. Note that to be successful each method has implementation and governance considerations and requirements. POLST registry access methods should include:
    a. Single sign-on via electronic health record (EHR): POLST registry access via single sign-on through integration with an EHR. This method would be used primarily by health care professionals at health systems and facilities that are able to implement this type of integration.
    b. Portal: POLST registry access through a portal/web browser. This method would be used primarily by health care professionals at health systems and facilities that are not able to utilize the single sign-on method.
    c. Cellular phone voice: POLST registry access by calling a POLST call center, where authorized health care professionals would access (through a portal/web browser) the POLST registry and relay back if there is a POLST and its contents. This method would primarily be used by EMS and available for other authorized users who do not have internet access immediately available.
    d. Allied Radio Matrix for Emergency Response (ARMER): POLST registry access by radio to a POLST call center, where authorized health care professionals would access (through a portal/web browser) the POLST registry and relay back if there is a POLST and its contents. This method would primarily be used by EMS when cellular phone is not an option and provides a safeguard to ensure statewide access.
14. Develop both a process for electronic submittal of POLST to the registry, either through the EHR or POLST portal using health information technology standards, and a process for manual input by POLST registry staff to account for the gaps in access to internet and information technology.
15. A health care professional who honors a POLST in the registry, even if the information is relayed via cellular phone or ARMER, should be immune from liability for following the POLST in the registry, so long as the health care professional believes “in good faith” that the POLST is valid and that it has not been voided.
16. The POLST registry needs quality controls and internalized logic to ensure accurate, timely, and complete POLSTs. Areas of focus may include, but are not limited to:
    a. Verification that the person signing POLST holds the correct current licensure (i.e., physician, advanced practice registered nurse, or physician assistant licensure).
    b. Prompt submittal of the information to the registry and approval/verification by POLST registry processes.
    c. Confirmation of the validity of POLST information.
    d. Deduplication of individuals in registry and identification of current information.
    e. Reconciliation of POLST registry against recent deaths using state death records.
    f. Process for removal of POLST no longer consistent with wishes of patient or surrogate.
17. Existing POLSTs should be populated into the registry by the provider’s organization prior to launch. Strategies should be implemented to support providers, especially small and rural providers, in prepopulating the registry and to ensure the registry is adequately prepopulated in a timely manner before going live to EMS.

18. All valid POLSTs should be added to the registry in a prompt manner unless the individual requests to opt-out of the registry. Policy levers and/or incentives may be needed to achieve this prompt submission.
19. An individual may decide to opt-out of participating in the POLST registry. In this case the POLST remains valid. Anyone who initially decides to opt-out should be able to opt-in at a later time. There should not be a penalty for individuals who choose not to participate in the registry.
20. POLST registry privacy and security policies and procedures must include, but are not limited to, the following components:
    a. Data security regulations and standards which may include federal HIPAA Privacy, Security, and Breach Notification Rules.
    b. Risk assessment, analysis, and management and other administrative and technical security controls that prevent, detect, and respond to a breach or attack, address exposed vulnerabilities, and address ongoing security maintenance activities.
    c. Minnesota-specific laws, including privacy laws.
    d. Industry standards as applicable.
21. The POLST registry will align to the most recent national and state health information technology (HIT) standards and policies to achieve interoperability, improve quality, and leverage national and state activities. Examples of standards and resources for consideration, include but are not limited to:
    a. HL7 CDA R2 Implementation Guide: ePOLST: Portable Medical Orders About Resuscitation and Initial Treatment, Release 1 - US Realm.
    b. Post-Acute Care Interoperability (PACIO) Fast Healthcare Interoperability Resources (FHIR) Profile.
    c. Interoperability Standards Advisory (ISA).
    d. United States Core Data for Interoperability (USCDI).
    e. National POLST Technology Guide.

POLST Registry Call Center Recommendations

22. The POLST registry call center needs two methods for contacting the call center and ensuring statewide access. The methods are:
    a. Cellular phone/phone when internet or mobile broadband are not an option.
    b. Radio using the existing statewide radio system the Allied Radio Matrix for Emergency Response (ARMER) when cellular phone is not an option.

    Boths options would primarily be used by EMS and provide safeguarded access for all authorized users.
23. The POLST registry call center could leverage current communication systems used by EMS and health care and must have medically trained and knowledgeable staff.
24. The POLST registry call center needs a process to confirm the caller is an authorized user with a recognized need for access, have 24/7 staffing, and adhere to privacy and security laws and requirements.

POLST Program Administration & Funding Recommendations

Program Administration

25. The POLST program requires a coordinating organization with the necessary infrastructure to house and administer the program. The coordinating organization could be either a governmental entity or a non-governmental entity and needs to ensure accountability and alignment between the program components. This organization could house all components or contract out to partners or third-party vendors. The coordinating organization would be responsible for, and should be capable of:
    a. Implementing the recommendations of the MN POLST Registry Advisory Committee, as applicable.
    b. Developing and implementing strategic and operational governance such as decision-making processes, oversight, complaint processes, establishing policies and procedures, ensuring legal and regulatory compliance, aligning with existing standards, and defining use cases, usability needs (including non-standard business hours), workflows, and data definitions.
    c. Facilitating an effective statewide POLST coalition to ensure engagement and collection of input from partners including but not limited to POLST Minnesota, Minnesota Department of Health, Minnesota Department of Human Services, Minnesota Board on Aging, Minnesota Palliative Care Advisory Council, Minnesota Emergency Medical Services Regulatory Board, Minnesota e-Health Advisory Committee, associations from across the care continuum (Minnesota Medical Association, Minnesota Hospital Association, Care Providers of Minnesota, LeadingAge Minnesota, Minnesota Nurses Association, Minnesota Board of Social Work, and others), Honoring Choices, and consumer and advocacy voices that are inclusive of cultural, faith, disability, and other perspectives.
    d. Assessing quality and other measures to ensure oversight and program goals are met.
    e. Ensuring that any vendors and/or technical solutions comply with state and federal laws relating to data privacy and health information exchange.
    f. Ensuring the POLST program aligns with national and state best practices such as HIT standards, guidance from the National POLST Collaborative, and leaders in end-of-life care and advance care planning.
26. The Minnesota POLST Registry Advisory Committee recommends that MDH be the coordinating organization or at a minimum have oversight over the POLST Program to protect the public's interest.
27. The coordinating organization should, with stakeholder feedback and guidance, identify an entity to house the registry. Possible entities to house the registry could include but are not limited to:
    a. State agency
    b. Non-Profit/Foundation
    c. Private Entity
    d. Academic Institution
    e. Collaborative or public-private partnership
    f. Health information exchange organization
28. The Minnesota POLST Registry Advisory Committee recommends MDH as the entity to have authority and oversight over the registry and recognizes that MDH may contract out all or some of the work of the registry.
29. For a state agency to be the coordinating organization for the POLST program, the following must be considered:
    a. State requirements and expectations (e.g., procurement process, information technology processes and standards)

   b. Minnesota Government Data Practices Act
   c. Minnesota Health Records Act
   d. Health Insurance Portability and Accountability Act (HIPAA)

Funding & Resources

30. Public and private funding and resources will be needed to implement and sustain the POLST program.
    a. One-time development and ongoing public funding are needed to support program implementation and maintenance. This includes the registry, call center, and education and training.
    b. Ongoing private resources will be needed by organizations that access the POLST registry and provide POLST access to patients. Examples of areas of private investments include but are not limited to upgrades to EHRs, organizational readiness for POLST and POLST registry, staff time for POLST and registry training, updates to organizational workflows and policies, and subscription fees to health information exchange (HIE) services.
31. Philanthropic funding could be used for any part of the POLST program.

Complementary Recommendations

The following recommendations are not necessary for the development and implementation of the POLST program but are complementary to the above recommendations and include recommendations from the Minnesota POLST registry study advisory committee and the Minnesota palliative care advisory council.

Minnesota POLST Registry Study Advisory Committee

32. Research could be a permitted purpose for use of POLST registry information. Considerations for research must include consent, equity, representation, and impact. Areas of research should inform practice and public policy decision making in population and gerontological health and aging, and could include:
    a. POLST decision durability (e.g., frequency and triggers of change).
    b. Patients' rights, concordance with treatment orders, and bioethical implications.
    c. Health care professionals' experiences with/knowledge of POLST.
    d. Associations between POLST, outcomes, and socio-demographic characteristics and/or risk factors.
    e. Health disparities by race/ethnicity, geography, etc.

Minnesota Palliative Care Advisory Council

33. The Minnesota legislature and state agencies should also implement the recommendations to 1) assess and improve payment and reimbursement models for palliative care, 2) grow the primary and secondary palliative care workforce, and 3) increase palliative care training as identified by the 2023 Palliative Care Advisory Council Annual Legislative Report[2] and previous reports. The following are an excerpt of those recommendations.

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[2] Minnesota Department of Health. 2023. Palliative Care Advisory Council Annual Legislative Report. Available at: [2023 Palliative Care Report (state.mn.us)]

a. Enable Minnesota's Medical Assistance and MinnesotaCare to pay for high-value services such as palliative care and advance care planning to benefit those with serious illnesses or life-limiting conditions using existing CPT or HCPCS codes.

b. Explicitly incorporate palliative care into existing Medical Assistance and MinnesotaCare waiver programs that focus on high need patients.

c. Consider making palliative care coverage a requirement for all Medical Assistance and MinnesotaCare managed care contracts in the next contracting cycle.

d. Consider adding palliative care coverage requirements in all settings to Medical Assistance and MinnesotaCare managed care organization contracts, including special considerations for pediatrics, adolescent, and young adult, and perinatal.

e. Establish or expand reimbursement programs or loan forgiveness for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Work, Chaplain, Child Life Specialists).

f. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.

g. Require medical schools to include minimum standards for primary palliative care education for all students.

h. Require physician residencies to include minimum standards for primary palliative care education for all residents.

i. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.

The Minnesota POLST Registry Advisory Committee recognizes a broader set of professions that need POLST and palliative care training and educational support including EMS, social work, chaplain, registered nurse, and others.

Implementation Considerations of a POLST Program at MDH

The advisory committee recommends that MDH be considered as an administrator for a statewide comprehensive POLST program. If MDH were to administer a statewide comprehensive POLST program, including responsibility for a POLST registry, there are several policy and legal considerations that would need to be addressed for such a program to be successful in Minnesota. This is because a POLST program and registry is primarily about end-of-life care communications between patients, their families or other caregivers, their providers and others that may be caring for them, such as EMS and emergency departments. Creation of a POLST registry and call center administered by MDH would require consideration of the data laws that apply to health care providers as well as those that apply to MDH.

Authority for providers to share POLSTs with MDH

The HIPAA Privacy Rule (45 C.F.R. Parts 160 & 164) limits the situations in which a "covered entity" may disclose protected health information (PHI) or a patient's personally identifiable information (PII). The definition of PHI is broad and likely includes information contained in a POLST. MDH is not a covered entity, but many, if not most, of the healthcare providers who would be creating and supplying the POLSTs are "covered entities" under

HIPAA. As such, these covered entities must have a legal basis supported by HIPAA to submit POLSTs or information from POLSTs to an MDH-administered registry. Relevant here, HIPAA authorizes covered entities to disclose PHI if the disclosure is required by law or if the patient authorizes (i.e., consents to) the disclosure. Likewise, a POLST would appear to fall within the definition of "health record" under the Minnesota Health Records Act (MHRA), Minnesota Statutes, sections 144.291-144.298. The MHRA generally prohibits a healthcare provider from disclosing a patient's health record unless there is a "specific authorization in law" to share the health record or the patient has consented to the disclosure. One option for providing healthcare providers with the authority to submit POLSTs to a registry, while complying with applicable health privacy laws, would be language in state statutes requiring providers to submit POLSTs to the registry. Including such a requirement in statute would create a legal basis supported by HIPAA and the MHRA for providers to submit POLSTs or information from POLSTs to an MDH-administered registry. This is the approach taken by Oregon in their POLST registry statutes.

In the alternative, the POLST registry and call center could be structured on a consent management framework. This would require providers to obtain the patient's or authorized decisionmaker's written informed consent prior to submitting the POLST to the registry. To authorize sharing with the registry, the consent would need to comply with all applicable requirements in HIPAA and the MHRA. The operational challenges of such an approach and potential impact on utilization of a POLST registry would need to be considered.

Data Classification and MDH Data Sharing Authority

If the POLST Registry is administered by MDH, the Minnesota Government Data Practices Act ("DPA") will apply to the data in the registry and all other data related to the program. Accordingly, attention will need to be paid to how the data in, and relating to, the registry is classified under the MGDPA to ensure both that: (1) information in the POLSTs and other sensitive information relating to the registry are classified as not public (e.g., "private" or "nonpublic") to protect the data from public access; and (2) there is authority for MDH/the registry to allow certain individuals or entities (e.g., health care providers) to access POLST information in order to operate the registry.

For any statutory sharing authority, the language should explicitly authorize the sharing of the POLST data and identify the authorized recipients and/or circumstances when such sharing is permitted or required. The POLST Advisory Committee has identified users based on role-based access, which could be included in this statutory authority. For circumstantial sharing authority, additional language regarding emergencies or other appropriate situations in which immediate access may be necessary could be expressly addressed. As an example, this authority could mirror the current emergency exception in the MHRA without the health care provider limitation. An operational consideration is whether any user-based identity verification is appropriate for authorized users and how this could be operationalized.

Note that an MDH-operated registry will receive and maintain potentially sensitive data beyond that contained in the POLSTs themselves, such as user access information. As a result, consideration should be paid not just to the classification and access authority of data in the POLSTs, but also to other types of data that will be created or received by MDH in the course or operating a registry.

An additional data-related consideration is language in Minnesota Statutes, section 144.293, subdivision 8, stating that MDH "may not access the record locator or patient information service or receive data from the service." In the event that the registry would potentially involve access to or receipt of data from a record locator or patient information service, as those terms are defined in state statute, it would be useful to have language in statute specifying that this provision does not apply to the POLST registry to prevent any potential confusion or limitations on MDH's ability to operate the registry.

Similarly, it would be useful to have statutory language specifically stating that a POLST is not a "Health Information Exchange," and MDH is not a "Health Information Organization" by virtue of operating a POLST registry, for purposes of Minnesota Statutes, sections 144.498 through 144.4982. The requirements in Minnesota Statutes, sections 144.498 through 144.4982 that apply to Health Information Organizations are not a good fit in the context of the limited purposes of a POLST registry. Additionally, it should be noted that MDH has certain oversight responsibilities with respect to Health Information Organizations.

Conclusion

Creation of a POLST registry, whether housed at MDH or a different government entity, will require consideration of applicable data laws, both on the side of health care providers submitting POLST data to a registry (primarily HIPAA and the Minnesota Health Records Act) and on the side of the entity operating the registry (in the case of MDH, the Minnesota Government Data Practices Act). Legislation can be used to create authority allowing access and sharing of POLSTs by those that need access to them to support patient care decisions, while allowing MDH (or another government entity operating the registry) to limit accessibility of registry data only to authorized users. If specific legislation is enacted to govern POLST registry and call center data, the Legislature may also consider including rulemaking authority to allow MDH to promulgate additional guidance and specific procedures for access to registry data and other aspects of the registry's operation.

Successful implementation of a POLST registry would need to be part of a statewide comprehensive POLST program that ensures timely and accurate use of POLST and a POLST registry. MDH recognizes the significant complexity involved in developing this type of program and welcomes the opportunity to contribute to future discussions on this topic.

Appendix

Appendix A: Legislative Language

Laws of Minnesota 2023, chapter 70, article 3, section 100

STUDY OF THE DEVELOPMENT OF A STATEWIDE REGISTRY FOR PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT.

Subdivision 1.

Definitions.

(a) For purposes of this section, the following terms have the meanings given.

(b) "Commissioner" means the commissioner of health.

(c) "Life-sustaining treatment" means any medical procedure, pharmaceutical drug, medical device, or medical intervention that maintains life by sustaining, restoring, or supplanting a vital function. Life-sustaining treatment does not include routine care necessary to sustain patient cleanliness and comfort.

(d) "POLST" means a provider order for life-sustaining treatment, signed by a physician, advanced practice registered nurse, or physician assistant, to ensure that the medical treatment preferences of a patient with an advanced serious illness who is nearing the end of life are honored.

(e) "POLST form" means a portable medical form used to communicate a physician's, advanced practice registered nurse's, or physician assistant's order to help ensure that a patient's medical treatment preferences are conveyed to emergency medical service personnel and other health care providers.

Subd. 2.

Establishment.

(a) The commissioner, in consultation with the advisory committee established in paragraph (c), shall develop recommendations for a statewide registry of POLST forms to ensure that a patient's medical treatment preferences are followed by all health care providers. The registry must allow for the submission of completed POLST forms and for the forms to be accessed by health care providers and emergency medical service personnel in a timely manner for the provision of care or services.

(b) The commissioner shall develop recommendations on the following:

(1) electronic capture, storage, and security of information in the registry;

(2) procedures to protect the accuracy and confidentiality of information submitted to the registry;

(3) limits as to who can access the registry;

(4) where the registry should be housed;

(5) ongoing funding models for the registry; and

(6) any other action needed to ensure that patients' rights are protected and that their health care decisions are followed.

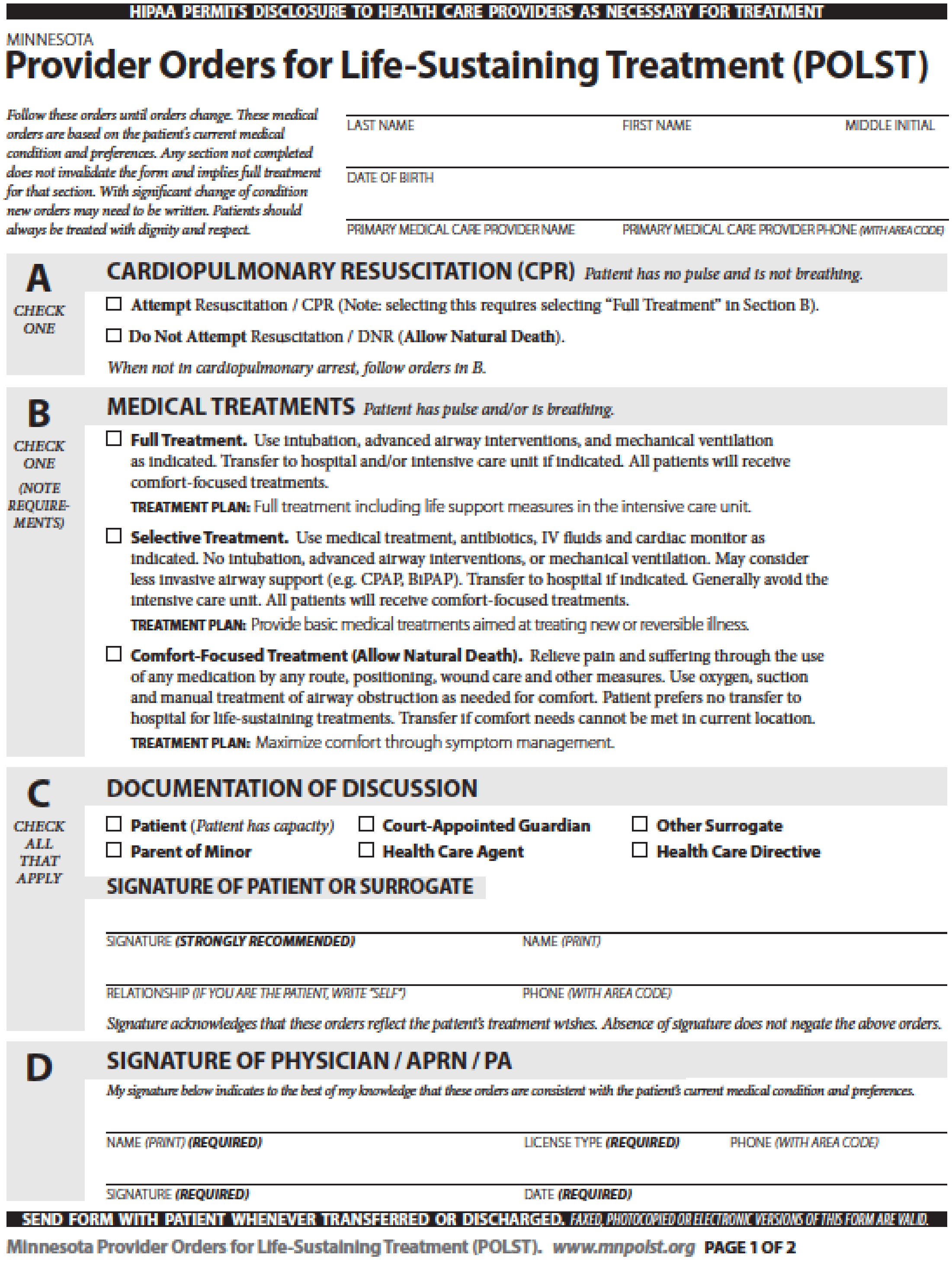
(c) The commissioner shall create an advisory committee with members representing physicians, physician assistants, advanced practice registered nurses, registered nurses, nursing homes, emergency medical system providers, hospice and palliative care providers, the disability community, attorneys, medical ethicists, and the religious community.

Subd. 3.

Report.

The commissioner shall submit recommendations on establishing a statewide registry of POLST forms to the chairs and ranking minority members of the legislative committees with jurisdiction over health and human services policy and finance by February 1, 2024.

Appendix B: Minnesota Provider Orders for Life-Sustaining Treatment



HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT

MINNESOTA

Provider Orders for Life-Sustaining Treatment (POLST)

Follow these orders until orders change. These medical orders are based on the patient's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written. Patients should always be treated with dignity and respect.

LAST NAME FIRST NAME MIDDLE INITIAL

DATE OF BIRTH

PRIMARY MEDICAL CARE PROVIDER NAME PRIMARY MEDICAL CARE PROVIDER PHONE *(WITH AREA CODE)*

A *CHECK ONE*

CARDIOPULMONARY RESUSCITATION (CPR) *Patient has no pulse and is not breathing.*

☐ **Attempt** Resuscitation / CPR (Note: selecting this requires selecting "Full Treatment" in Section B).

☐ **Do Not Attempt** Resuscitation / DNR (**Allow Natural Death**).

When not in cardiopulmonary arrest, follow orders in B.

B *CHECK ONE (NOTE REQUIREMENTS)*

MEDICAL TREATMENTS *Patient has pulse and/or is breathing.*

☐ **Full Treatment.** Use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. All patients will receive comfort-focused treatments.

TREATMENT PLAN: Full treatment including life support measures in the intensive care unit.

☐ **Selective Treatment.** Use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. All patients will receive comfort-focused treatments.

TREATMENT PLAN: Provide basic medical treatments aimed at treating new or reversible illness.

☐ **Comfort-Focused Treatment (Allow Natural Death).** Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.

TREATMENT PLAN: Maximize comfort through symptom management.

C *CHECK ALL THAT APPLY*

DOCUMENTATION OF DISCUSSION

☐ **Patient** *(Patient has capacity)*
☐ **Parent of Minor**
☐ **Court-Appointed Guardian**
☐ **Health Care Agent**
☐ **Other Surrogate**
☐ **Health Care Directive**

SIGNATURE OF PATIENT OR SURROGATE

SIGNATURE ***(STRONGLY RECOMMENDED)*** NAME *(PRINT)*

RELATIONSHIP *(IF YOU ARE THE PATIENT, WRITE "SELF")* PHONE *(WITH AREA CODE)*

Signature acknowledges that these orders reflect the patient's treatment wishes. Absence of signature does not negate the above orders.

D

SIGNATURE OF PHYSICIAN / APRN / PA

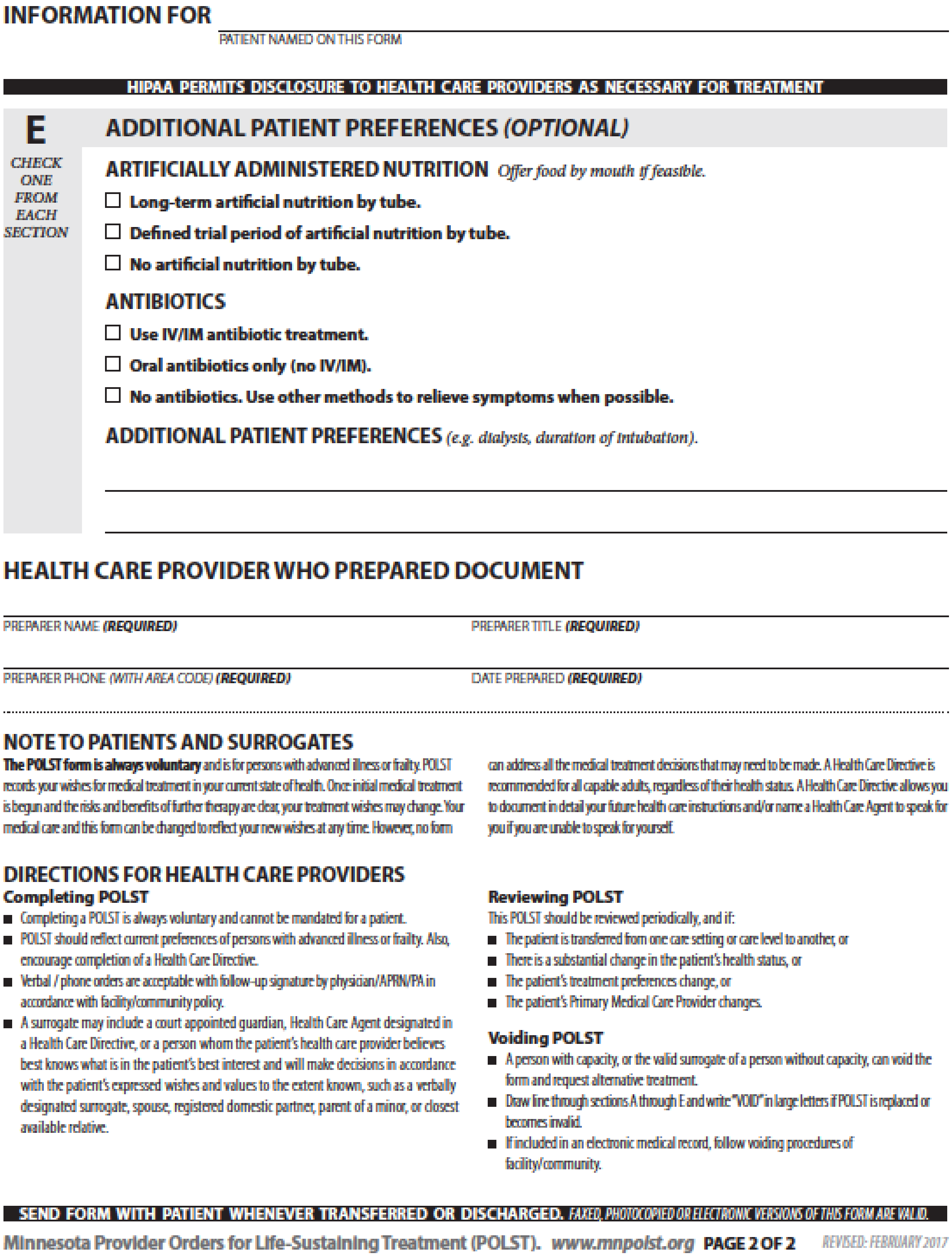
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's current medical condition and preferences.

NAME *(PRINT)* ***(REQUIRED)*** LICENSE TYPE ***(REQUIRED)*** PHONE *(WITH AREA CODE)*

SIGNATURE ***(REQUIRED)*** DATE ***(REQUIRED)***

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED. *FAXED, PHOTOCOPIED OR ELECTRONIC VERSIONS OF THIS FORM ARE VALID.*

Minnesota Provider Orders for Life-Sustaining Treatment (POLST). *www.mnpolst.org* **PAGE 1 OF 2**



INFORMATION FOR ______________________________

PATIENT NAMED ON THIS FORM

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT

E

CHECK ONE FROM EACH SECTION

ADDITIONAL PATIENT PREFERENCES *(OPTIONAL)*

ARTIFICIALLY ADMINISTERED NUTRITION *Offer food by mouth if feasible.*

☐ **Long-term artificial nutrition by tube.**

☐ **Defined trial period of artificial nutrition by tube.**

☐ **No artificial nutrition by tube.**

ANTIBIOTICS

☐ **Use IV/IM antibiotic treatment.**

☐ **Oral antibiotics only (no IV/IM).**

☐ **No antibiotics. Use other methods to relieve symptoms when possible.**

ADDITIONAL PATIENT PREFERENCES *(e.g. dialysis, duration of intubation).*

____

____

HEALTH CARE PROVIDER WHO PREPARED DOCUMENT

PREPARER NAME ***(REQUIRED)***	PREPARER TITLE ***(REQUIRED)***
PREPARER PHONE *(WITH AREA CODE)* ***(REQUIRED)***	DATE PREPARED ***(REQUIRED)***

NOTE TO PATIENTS AND SURROGATES

The POLST form is always voluntary and is for persons with advanced illness or frailty. POLST records your wishes for medical treatment in your current state of health. Once initial medical treatment is begun and the risks and benefits of further therapy are clear, your treatment wishes may change. Your medical care and this form can be changed to reflect your new wishes at any time. However, no form can address all the medical treatment decisions that may need to be made. A Health Care Directive is recommended for all capable adults, regardless of their health status. A Health Care Directive allows you to document in detail your future health care instructions and/or name a Health Care Agent to speak for you if you are unable to speak for yourself.

DIRECTIONS FOR HEALTH CARE PROVIDERS

Completing POLST

- Completing a POLST is always voluntary and cannot be mandated for a patient.
- POLST should reflect current preferences of persons with advanced illness or frailty. Also, encourage completion of a Health Care Directive.
- Verbal / phone orders are acceptable with follow-up signature by physician/APRN/PA in accordance with facility/community policy.
- A surrogate may include a court appointed guardian, Health Care Agent designated in a Health Care Directive, or a person whom the patient's health care provider believes best knows what is in the patient's best interest and will make decisions in accordance with the patient's expressed wishes and values to the extent known, such as a verbally designated surrogate, spouse, registered domestic partner, parent of a minor, or closest available relative.

Reviewing POLST

This POLST should be reviewed periodically, and if:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change, or
- The patient's Primary Medical Care Provider changes.

Voiding POLST

- A person with capacity, or the valid surrogate of a person without capacity, can void the form and request alternative treatment.
- Draw line through sections A through E and write "VOID" in large letters if POLST is replaced or becomes invalid.
- If included in an electronic medical record, follow voiding procedures of facility/community.

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED. *FAXED, PHOTOCOPIED OR ELECTRONIC VERSIONS OF THIS FORM ARE VALID.*

Minnesota Provider Orders for Life-Sustaining Treatment (POLST). ***www.mnpolst.org*** **PAGE 2 OF 2** *REVISED: FEBRUARY 2017*

Appendix C: Overview of POLST in Minnesota

The POLST Minnesota steering committee led the development of POLST in Minnesota. This interdisciplinary steering committee, established in 2008, is led by the Minnesota Medical Association. The first Minnesota POLST form was released in 2010 and updated in 2018. The POLST Minnesota Form is available on the POLST Minnesota website (appendix B). In addition, the POLST Minnesota steering committee develops the best practices and educational materials for completing and discussing the POLST including two frequently asked questions documents. Information on these two documents includes[3,4]:

- POLST is appropriate for a limited patient population – patients who have serious advanced illness or frailty whose health care provider would not be surprised if they died within a year or two.
- Completion of a POLST is always voluntary.
- Most POLST discussions take place between nurses or social workers and patients/families. The POLST must be signed by a licensed physician, advanced practice registered nurse, or physician assistant to become an actual medical order.
- A patient's or surrogate's signature is not required on a POLST, it is strongly recommended as a best practice.
- Photocopied, faxed, or electronic versions of the POLST form are all valid and recognized.
- A patient's POLST should be reviewed periodically, particularly if:
    - the patient is transferred from one care setting or level of care to another (including upon admission or at discharge); or
    - there is a substantial change in the patient's health status; or
    - the patient's goals of care and/or treatment preferences change; or
    - the patient's primary health care provider changes.
- There are key differences between a POLST and a health care directive.

The number of individuals with POLST and POLSTs active in Minnesota is unknown. In 2019 MMA conducted surveys of EMS's and long-term care's knowledge and use of POLST. Key findings relating to the POLST registry study included:

- 43% of EMS respondents were familiar with POLST and of those:
    - 34% had received formal training.
    - 54% believed that a quarter or less of those frail or seriously ill in the county have a POLST.
    - 69% had first-hand experience with use of POLST in the field.
    - 42% believe the inability of EMS to find a patient's POLST as the largest barrier to successful implementation[5].
- 87% (Care Providers) and 91% (LeadingAge) programs or facilities used the POLST to document medical orders for life-sustaining treatment.
    - Physicians, PAs, APRNs, social workers, and nursing staff most frequently complete the form (note this is not always the person that signs that POLST).

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[3] POLST Minnesota. 2017. POLST Minnesota: Frequently Asked Questions. Available at https://www.mnmed.org/application/files/7516/7154/4802/FINAL-POLST-general_FAQs-Oct-2017.pdf.

[4] POLST Minnesota. 2017. POLST Minnesota: Information for Patients and Family Members. Available at https://www.mnmed.org/application/files/3016/7154/4866/FINAL-POLST-for-patients-and-families-nov-2017.pdf.

[5] Minnesota Medical Association. 2019. POLST EMS Actual Final, Survey Results. June 7-26, 2019

- Almost 70% of programs or facilities have a policy, formal or informal, that every patient or resident should be offered a POLST.
- POLSTs are updated at numerous points including patient care conferences, upon patient or family request, and upon staff or provider initiation.
- Long term care providers indicated varying levels/frequency of difficulty receiving POLST forms from other facilities or programs and finding the POLST form in a resident or patient's living space[6].

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[6] Minnesota Medical Association. Care Providers and LeadingAge/Long Term Care POLST Survey (Combined) Final. Survey Results. May 3-31, 2019 (Care Providers). April 26-31, 2019 (Leading Age/Long Term Care).

Appendix D: Summary of POLST Registries

National POLST defines registry as a "repository that houses POLST forms to make them available to health care professionals when they are needed, across care settings." POLST registries operate in a few states including Oregon, Idaho, Louisiana, New York, and West Virginia. Almost 20 states are in the development or piloting phases[7]. Various reports, including lessons learned and analysis on active and piloted registries, were used to develop discussion with the Minnesota POLST registry study advisory committee and understand how other states fund and administer the POLST registries or programs. Key resources and useful findings include:

- Pathways to POLST Registry Development: Lessons Learned[8] which provided critical questions to address in the POLST registry development.
- California's POLST Electronic Registry Pilot: Lessons for All States[9] listed lessons learned falling into five areas: organization readiness and commitment, community engagement/stakeholder and participant education, workflow considerations, POLST document practices, and technology features and functions.
- Statewide Registry of Advance Directives and Practitioners Orders for Life-Sustaining Treatments (POLST) forms, Report to the Illinois General Assembly[10] identified challenges to feasibility to a statewide registry including practitioner workflows, form incompletion, practitioner access, up-to-date patient preferences, and information privacy.

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[7] National POLST. 2022. National POLST: State Registries. Available at https://polst.org/wp-content/uploads/2022/03/2022.02.28-National-POLST-State-Registries.pdf.

[8] Zive, D and Schmidt, T on behalf of National POLST Paradigm Task Force. 2012. Pathways to POLST Registry Development: Lessons Learned. Available at https://polst.org/wp-content/uploads/2012/12/POLST-Registry.pdf.

[9] California POLST e-Registry Pilot Evaluation Team. 2019. California's POLST Electronic Registry Pilot: Lessons for All States. Available at https://www.chcf.org/wp-content/uploads/2019/09/CaliforniasPOLSTElectronicRegistryPilot.pdf.

[10] Illinois Department of Public Health. 2020. Statewide Registry of Advance Directives and Practitioner Orders for Life-Sustaining Treatment (POLST) Forms, Report to Illinois General Assembly. Available at https://dph.illinois.gov/content/dam/soi/en/web/idph/files/publications/polst-registry-advisory-committee-report-2020.pdf.

Appendix E: Minnesota POLST Registry Study Advisory Committee Members

Abby L Dotson, Ph.D.
Executive Director, National POLST Collaborative
Director, Oregon POLST Registry
Research Assistant Professor, OHSU Emergency Medicine
Representing: Technical Expertise

Abigail Houts, MD
Medical Director for Ambulatory Services
Direct Care and Treatment
Minnesota Department of Human Services
Representing: Health and Health Care At-Large

Adam Shadiow
Executive Director
Arrowhead EMS Association *(Northeast EMS Region)*
Representing: Emergency Medical Providers

Andrea O'Hern
Methodist Hospital
Representing: Health and Health Care At-Large

Barb Blumer, JD
Barb Blumer Law, P.A.
Representing: Attorneys

Brian Burroughs, PA-C, AQH, BC-ADM, CDCES, CHC
Physician Assistant, Family Medicine & Hospital Internal Medicine
Instructor in Family Medicine, College of Medicine and Science
Mayo Clinic Health System, Red Wing
Representing: Physician Assistants

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Associate Professor, Division of Health Policy & Management
Deputy Director, Rural Health Research Center
Director of Graduate Studies, Health Equity Minor
Co-Director, Rural Health Program
University of Minnesota
Representing: Academia

Clinton Billhorn, PA-C
MAPA President-Elect
Hospital Medicine
Regions Hospital and Lakeview Hospital
Representing: Physician Assistants

Crystal Houghtaling, LSW
Advisory Committee Co-Chair
Campus Director, Social Services Licensed
Sholom Home West
Representing: Nursing Homes/Long Term Post Acute Care

Dylan Ferguson
Executive Director
Emergency Medical Services Regulatory Board
Representing: Emergency Medical Providers

Eileen Weber, DNP, JD, BSN, PHN, RN
MN POLST Taskforce Co-Chair
Retired Clinical Associate Professor Ad Honorem, Population Health and Systems
University of Minnesota School of Nursing
Member, University of Minnesota Medical Center (Fairview) Clinical Ethics Committee
Representing: Registered Nurses

Fr. Tom Knoblach, Ph.D.
Vicar for health care ethics for the Diocese of St. Cloud
Pastor of Sacred Heart in Sauk Rapids and Annunciation in Mayhew Lake
Representing: Religious Community & Medical Ethicist

Jana Keefe, Community Paramedic (CP), BSP-RRT, MALM
Cuyuna Regional Medical Center
Representing: Health and Health Care At-Large

Joel Wu, JD, MPH, MA, HEC-C
Clinical Ethics Assistant Professor
University of Minnesota, Center for Bioethics
Clinical Ethics Lead, M Health Fairview
Co-Chair, Ethics Committee, University of Minnesota Medical Center
Co-Director, Clinical Ethics Consultation Service, University of Minnesota Medical Center
Senior Lecturer
Division of Health Policy and Management
University of Minnesota, School of Public Health
Representing: Medical Ethicists

Kari Everson, DNP MSN MHA RN LNHA LALD PHN DNS-CT QCP
VP Clinical Services
LeadingAge
Representing: Nursing Homes/Long Term Post Acute Care

Laura Borris, LNHA LALD
Administrator, Sacred Heart Care Center
Representing: Nursing Homes/Long Term Post Acute Care

Lori Sylvester
Lifetime Resources, Inc.
Representing: Disability Community

Merari Morales Rosales, MBA, PA-C, CCPA
Representing: Physician Assistants

Michaun Shetler, LALD RN
Director of Assisted Living, Care Providers of MN
Representing: Nursing Homes/Long Term Post Acute Care

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Chief Medical Officer
Benedictine
Representing: Religious Community

Peter Tanghe, MD
North Memorial
Representing: Emergency Medical Providers

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Clinical Nurse Specialist
M Health Fairview
Representing: Health and Health Care At-Large

Sara McCumber DNP, APRN, CNP, CNS
President
MN Nurse Practitioners
Representing: Advance Practice Registered Nurses

Shamsah Rehmatullah, MSN, RN
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University of Minnesota Medical Center
Fairview Health Services
M Health Fairview
Representing: Health and Health Care At-Large

Sue Schettle
Chief Executive Officer
ARRM
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Geriatrics Chair, Minnesota Network of Hospice and Palliative Medicine Physicians
Co- Chair, Minnesota POLST Task Force
Co-Chair, University of Minnesota Bioethics Committee 2000-2020
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Essentia Health- Advance Care Planning
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