



MN POLST Registry Study Advisory Committee

November 17, 2023

Welcome

Agenda

1:00 – 1:05 p.m.	Welcome
1:05 – 1:25 p.m.	Patient and Family Centered Perspective
1:25 – 1:45 p.m.	Disability Services Perspective
1:45 – 2:05 p.m.	Research Considerations
2:05 – 3:00 p.m.	Draft Recommendations Discussion
3:00 p.m.	Closing

- **Advisory Committee Input**

- Raise your hand
- Add comments/thoughts in the chat
- Share thoughts/comment via post meeting link
- Turn on camera when speaking (if prefer)

- **Public**

- Listen to conversation
- Share thoughts/comment via post meeting link found on POLST page:
<https://www.health.state.mn.us/facilities/ehealth/polst/index.html>

Patient and Family Centered Perspective

Primacy of the Patient

Statewide POLST registry can improve death literacy
and promote patients' end of life care treatment
preferences

Death literacy: the knowledge and skills that people need to
make it possible to gain access to, understand, and make
informed choices about end of life and death care options

Che et al (2023 May 11) doi: [10.3389/fpubh.2023.1140475](https://doi.org/10.3389/fpubh.2023.1140475)

Assumptions – THINK BIG

- Inconsistent end of life care concerns everyone in Minnesota
- Minnesotans will appreciate a forthright approach to ensuring their end of life treatment preferences are honored
- We will ask for enabling legislation to fully implement recommendations
- We will request enough resources to transform the status quo
- We expect enabling legislation and allocated resources adequate to assure ongoing evaluation and progress toward stated goals
- Technology should not compromise engagement, utilization, care or equity. It should enhance them.

Equity

- Involve other MDH departments promoting equity, e.g., MDH HEAL (Health Equity Advisory and Leadership) Council
<https://www.lrl.mn.gov/agencies/detail?AgencyID=2332>; Office of Rural Health & Primary Care <https://www.health.state.mn.us/facilities/underserved/index.html>;
Center for Health Equity
<https://www.health.state.mn.us/communities/equity/index.html>
- Involve death doulas
- Tools and PDAs in multiple languages
- Call-center interpreters when interaction with public anticipated
- Promote POLST but do not require them for admission to care
- Involve MNACHC <https://www.mnachc.org/>
- Partner with VA centers/clinics, Indian Health Board

Centered Care

- POLST are the end product, not the beginning, of an iterative process of shared decision-making. Think upstream to primary care.
- Promote use of PDAs (Patient Decision Aids)
- Patient/surrogate access to individual POLST in registry to make sure it is accurate and reflects current preferences
- Frame POLST as more than limiting rescue/restorative care; emphasize focus on evolving patient-defined goals of care
- Add link to POLST info on healthcare directives
- Elder law and estate planning attorneys address POLST

Engagement and Integration

- Baseline study of POLST engagement, integration and impact
- Publicity and framing around release of these recommendations
- Involve Senior Linkage Line, Board on Aging, MAAA, LTC Ombudsman, etc.
- Community-based, culturally competent conversations, blogs, etc.
- Workshops and conferences, e.g., HCH Learning Days
- Provider requirements and reimbursements, e.g., HCH re-certification
- Payer requirements for commercial entities who administer publicly funded programs that serve seniors
- Involve public health agencies throughout MN who know their local providers

Disability Services Perspective

Disability Services Perspective

ARRM members

- Intermediate Care Facilities (ICFs) are facilities that support individuals with disabilities, many of whom have complex medical needs. There are about 1000 people being served in ICFs in Minnesota.
- Community Residential Settings (CRS) also support individuals with disabilities who have complex medical needs. CRS' are often referred to as group homes. CRS providers support about 15,000 people with disabilities in MN.
- Providers in ICFs and CRS' have both electronic and paper files on individuals they support.
- The POLST form sits in both the electronic system and in charts/records of the individual
- If there is a POLST form in place, it needs to be looked at annually as part of the individual's annual plan.
- The creation of a statewide registry is important and disability service providers are not in opposition to it.

Research Considerations



Using the POLST Registry for Research: Considerations and Opportunities

Carrie Henning-Smith, PhD, MPH, MSW
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University of Minnesota School of Public Health

Existing Research on POLST

- Growing body of literature on POLST:
 - From other states (e.g., OR, CA, NY, WV)
 - And other countries (e.g., South Korea, Brazil, Denmark)
 - POLST research dating back to 1998; rapid growth from 2016-on
- Opportunity for research innovation by adding MN to this literature

Potential Areas of POLST Research

- Examples of areas of research that could be added to:
 - Security procedures, confidentiality, and data access limits
 - Electronic medical records, electronic capture, and storage
 - End of life/life sustaining care feasibility
 - Patient rights, concordance with treatment orders, and bioethical implications
 - Health care workers' experiences with/knowledge of POLST
 - Associations between POLST, outcomes, and socio-demographic characteristics and/or risk factors

Research Considerations (1 of 4)

- Where will data be stored and how will it be accessed?
 - At a minimum: secure, password-protected systems with clear procedures for removing data at end of study
- Who will have access to the registry, and when?
 - Collaborations between health systems, MDH, and academic partners will require clear data use agreements (DUAs) and transparency about who is responsible for what

Research Considerations (2 of 4)

- Institutional Review Board oversight
 - Which IRB will oversee each study? (Multiple IRBs in state; clear PI designation will help clarify which IRB has oversight)
- Where will research funding come from?
 - Could impact the focus/direction of research and who is able to participate
 - How will community members and providers be compensated for participating?

Research Considerations (3 of 4)

- Focus of research?
 - Individual-centered or family-centered?
 - Process or outcomes?
 - Person (patient) or provider?
- Methodology
 - Quantitative (using data from registry; merge with other state-level data on demographics, geography, health, and health care access)
 - Qualitative (interviews with individuals, family members, providers, etc.)

Research Considerations (4 of 4)

- Equity issues
 - Who will be represented in the registry, and who won't?
 - Special considerations for rural populations, marginalized racial and ethnic groups, pediatric populations, etc.
 - How will community stakeholders inform the research process and access results?
 - Who holds power? Where should it be held?

Measuring Research Success

- What is the desired outcome?
 - Products? (Peer-reviewed manuscripts, policy briefs, presentations)
 - Reach? (Community, statewide, national, international)
 - Impact? (What is done with results?)
- Iterative, ongoing evaluation process



Questions and Discussions

Carrie Henning-Smith, PhD, MPH, MSW

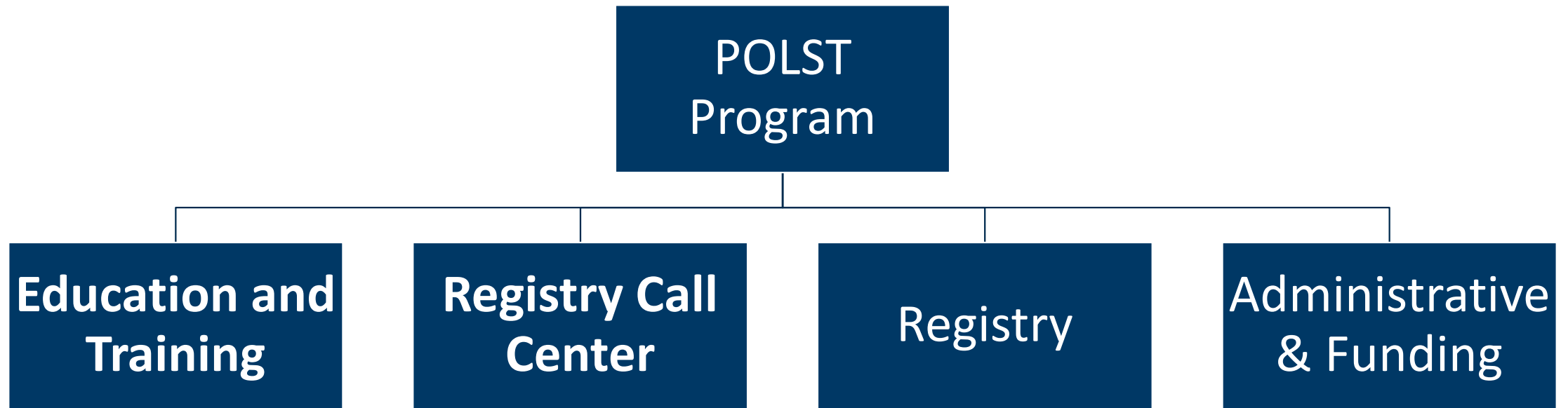
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Draft Recommendations Discussion

Study Outcomes

- The commissioner, in consultation with the advisory committee established, 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.
- The commissioner shall develop recommendations on the following:
 - electronic capture, storage, and security of information in the registry;
 - procedures to protect the accuracy and confidentiality of information submitted to the registry;
 - limits as to who can access the registry;
 - where the registry should be housed;
 - ongoing funding models for the registry; and
 - any other action needed to ensure that patients' rights are protected and that their health care decisions are followed.

Recommendation Structure



POLST Program Recommendation

- A POLST registry needs to be part of a comprehensive statewide POLST program to help ensure patients' rights are protected and their health care decisions are followed. A POLST program should include education and training, a call center, and a registry. The training and education should include education and training for 1) the use of the POLST by health care providers, 2) the use of POLST registry by health care providers; and 3) the public use of POLST. To achieve alignment and accountability, the program should have an administrative entity with stakeholder representation and input.

Education & Trainings

Call Center

Registry

Administrative & Funding

Closing

Thank You!!