POLST* in Illinois:
A Survey of Health Professionals

*Practitioner Orders for Life-Sustaining Treatment
Background

According to the National Institute on Aging, more than 25 percent of people who face decisions about medical treatments toward the end of life are incapable of making or communicating those decisions. Old age, serious chronic conditions, and catastrophic accidents can all result in individuals losing their ability to make health care decisions.

Advance care planning is a process meant to help patients make decisions about their future health care before they become unable to do so. There are many steps to the process, including engaging patients in discussions about who should make medical decisions for them if they are unable to do so themselves, priorities and expectations regarding quality of life, and the level of medical treatment they would want in the event of a terminal condition.

A POLST (Practitioner Orders for Life-Sustaining Treatment) form is a signed medical order that documents the type of treatments that a seriously ill person wants to receive at end-of-life. Discussion and completion of the POLST form are among the final steps in the overall advance care planning process; patients for whom death in the next year would not be unexpected are good candidates for POLST discussions. The presence of a POLST form can help health care professionals know and honor a patient’s wishes when the patient is unable to communicate them directly.

ISMS has long been a leader in encouraging physicians and patients to work together to help patients articulate and document their wishes about medical care at the end of life. To help work through these difficult conversations, we make the following resources available for free download:

- A Personal Decision: Practical Information About Determining Your Future Medical Care. ISMS members can request 300 free print copies of this resource for sharing with patients.
- A Case Study on engaging patients in advance care planning

Although POLST language has been part of the Illinois Department of Public Health “do-not-resuscitate” form since 2013, there is a lack of data about whether and how the form is being used, and what challenges physicians and other health care professionals face related to the use of POLST.

In late 2016, ISMS conducted a survey to assess awareness of the POLST form and its use by physicians and others involved in end-of-life care activities. The goal of the survey was to identify areas where additional education or outreach could be beneficial.

About the Participants

The survey was distributed broadly to physicians and others involved in end-of-life care activities, such as nurses, administrators, care managers and others. More than half of the respondents were physicians, with 55% indicating a specialty of either internal medicine or family medicine. Nearly 40% of all respondents work in a hospital-inpatient setting; 30% work in the outpatient setting.

Note: Because of the nature of the organizations that partnered with ISMS on the distribution of this survey, we believe that the results may reflect a higher level of knowledge about POLST than is representative of the general population of physicians and other health care professionals in the state. A full list of organizations that distributed the survey is included at the end of this document.
Findings

As noted, many survey respondents are involved with organizations whose members work in nursing homes, provide hospice or palliative care, or otherwise might be expected to be familiar with the POLST paradigm. Not surprisingly, a large number of survey respondents reported that they discuss POLST with their patients. Nevertheless, respondents indicated several areas where additional training and outreach could help with POLST implementation.

More Training Is Needed

Although nearly 80% of survey respondents indicated that they often or sometimes discuss POLST with their patients, more than half reported that they would be interested in receiving additional assistance or training on the use of the POLST form. Just over 42% of respondents are aware of POLST training being provided to staff, either in-house or by a third party.

Notably, in response to the question “What barriers do you face to providing your patients with information about POLST?,” 12% of respondents indicated they were unaware of POLST prior to the survey.
More Clarity Is Needed About When POLST Discussions Are Appropriate

One area of potential confusion is the type of patient for whom POLST is appropriate. Nearly 20% of respondents indicated that uncertainty about when POLST is appropriate for individual patients is a barrier to providing POLST information.

According to the National POLST Paradigm Task Force, “POLST is not for everyone. POLST is for those with serious illness or frailty—such as advanced heart disease, advanced lung disease or cancer that has spread—for whom their health care professional wouldn’t be surprised if they died within a year.”

Nearly 60% of survey respondents indicated that POLST is appropriate for healthy patients. While patients can always change or revoke their POLST wishes, there are other advance care planning discussions and documents that may be more appropriate for healthier patients.

I worry about DNR [do not resuscitate] being conflated with advance directives.

Other Barriers and Challenges

As noted, a few respondents indicated the lack of general knowledge about POLST and when to engage patients in POLST discussions as barriers to providing POLST information. But several other barriers and challenges were also reported, including practitioner or family discomfort with discussing death and dying, lack of time, and lack of clarity about which staff should be responsible for the conversation.

I feel staff don’t understand how to explain POLST to patients.
Even when the POLST paradigm is used, physicians and other practitioners can experience significant challenges to ensuring that a patient’s wishes are appropriately documented and followed. Improperly completed POLST forms and a family’s inability to produce a completed POLST form are among the top POLST-related challenges identified in the survey.

“Publicity regarding POLST should be directed toward patients, encouraging them to discuss this with their primary care physician.”

Many Members of the Health Care Team May be Involved with POLST

Uncertainty about who on the health care team should be initiating or participating in POLST discussions was identified by survey respondents as a barrier to implementing POLST. The survey indicates that no single member of the health care team holds sole responsibility for helping patients complete POLST. Physicians, social services staff, APNs/RNs, and pastoral care staff are most likely to help patients with the form.

Given the broad range of individuals who are potentially involved in the POLST process, it is important to consider opportunities to ensure that all members of the health care team can benefit from POLST training.

“There has been a lot of interest about this matter and most do not realize exactly what POLST is.”
The Majority of Respondents Are Not Reimbursed for End-of-Life Care Discussions

Survey respondents identified lack of time to discuss end-of-life decisions with patients as another significant barrier to the use of POLST. ISMS was one of the leading advocates for the creation of a CPT code that would recognize physician work related to end-of-life care planning discussions with patients. The codes were created in 2015, and the Centers for Medicare and Medicaid Services began reimbursing physicians and other qualified health professionals under the Medicare Physician Fee Schedule in 2016.

Fewer than 2/3 of the survey respondents are aware that these codes even exist. And of those who know about the codes, less than 20% have received reimbursement.

There is Guarded Support for the Development of a Registry

Nearly 45% of respondents indicated a family’s inability to produce a completed POLST form was a barrier to honoring a patient’s wishes at the end-of-life. The development of some kind of a state-wide registry of patients with completed POLST forms has been discussed as a possible solution to the problem of being unable to locate a POLST form at the time when it is needed most.

ISMS does not have a position on whether a registry or other central repository for POLST forms should be created. However, we did ask survey respondents to share their feelings about the development of such a registry. There was strong support for the concept, 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.

“ I foresee gaps in accessibility in a statewide electronic registry, and wonder how the information would be updated.”
Conclusion

This survey demonstrates strong support for the POLST process, but highlights several areas where additional outreach, education, and training for physicians, health care professionals, and patients could help increase the use and ultimately the effectiveness of POLST.

Results of this survey will be shared with our partners at POLST Illinois and the other organizations that joined us in promoting the survey among their members and constituents. We encourage you to take advantage of the available resources to learn more about POLST in Illinois and efforts to promote advance care planning.

ISMS has developed several resources for physicians related to advance directives. Visit www.isms.org/APD to access:

- A Personal Decision, a booklet available in print or online that provides Illinois patients with relevant forms and practical information about determining future medical care;
- Individual medical-legal guidelines on health care surrogates, living wills and organ donation; and
- An on-demand CME course on Advance Directives and POLST.

Other links:


POLST Illinois Task Force – www.polstil.org

Resources to help improve communication between patients and physicians – www.vitaltalk.org

Respecting Choices® evidence-based advance care planning model of care – www.respectingchoices.org

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