# POLST Registries Bring Orders for Medical Treatment Choices to the Internet Age

POLST—Physician Orders for Life-Sustaining Treatment—a model for documenting and communicating seriously ill patients' preferences for medical care, originated in Oregon in the 1990s but has gained significant traction in various permutations in other states as a way to honor those preferences in life's final stages. The familiar, brightly colored form contains a portable set of medical orders, signed by a physician, for various treatment options a patient might want or not want. It accompanies seriously ill patients as they move from one care setting to another. Favorable media attention[1] and a recent report highlighting promising practices[2] have accelerated that momentum, and now POLST advocates wonder how far this movement can go.

Meanwhile, in the age of expanding social media, countless new "apps" for computers, smart phones and other communications devices, and emerging systems for electronic health records (EHRs), one obvious next step to explore lies in electronic repositories or registries for patients' legally executed POLST documents, retrievable at a time of need by emergency personnel or other health professionals. Recent experience suggests, however, that these registries are not always successful. Challenges or barriers such as respecting patient privacy rules, ensuring that the most current and valid form is accessed, educating large numbers of health professionals in their use, achieving critical mass of participants, and covering the expense of operating the electronic registries may slow their spread.

---

[1] New Efforts to Simplify End-of-Life Care, *Wall Street Journal*, March 15, 2011; see: http://online.wsj.com/article/SB10001424052748703327404576194942197661606.html.
[2] Improving Advanced Illness Care: The Evolution of State POLST Programs. AARP, April 2011. See: http://www.aarp.org/health/doctors-hospitals/info-04-2011/polst-04-11.html.

Rather than assuming, in our electronic age, that a successful electronic registry is both essential and achievable, some experts say clarity on the goals for the registry and its primary target audiences—whether professionals or consumers—should inform its design from the outset. “How important is a registry and when should it be implemented?” poses Susan Tolle, MD, Director of the Center for Ethics in Health Care at Oregon Health Sciences University (OHSU), the national home for the POLST Paradigm movement. Getting POLST forms to the bedsides of patients who want and need them and then accessing the original POLST form at the scene is still the gold standard, Dr. Tolle says, with the registry as a backup system that comes later.

“*When* is a terribly important question. Many advocates are eager to start registries. People say: We want Oregon’s registry—we want to be able to reach that level of penetration in our first year. But they forget that Oregon’s POLST program has been on the ground since the 1990s. We’ve done conferences all over the state, train-the-trainer programs, slide and video presentations. There isn’t a nursing home or hospital or palliative care physician in Oregon that hasn’t heard of POLST,” she says. “You can’t just drop a registry out of the sky and expect it to take off. In Oregon, we’ve invested over $1.8 million on POLST development and education.”

## Inside the Heartbeat of Emergency Medicine

Oregon also chose to house its electronic registry “inside the heartbeat for emergency medicine in Oregon, at OHSU’s Emergency Communication Center (ECC) The ECC provides a 24/7, toll-free number that EMS, emergency departments and acute care units can call to obtain POLST information. It’s on speed dial for EMTs in the region,” says Terri Schmidt, MD, Director of the Oregon POLST Registry.

Concern over EMS personnel not being able to find a POLST form when they expected one to be on the scene is what sparked initial interest in creating Oregon's electronic POLST registry. It was piloted in 2009 and went online in December of that year. Today it has catalogued over 50,000 active documents for access by emergency medical technicians and hospitals, with about 3,500 new forms uploaded each month. It only contains actionable POLST forms.

Margaret Murphy Carley, who directs the National POLST Paradigm Task Force at OHSU in support of POLST development in other states, says the registry is important for facilitating emergency access to patients' documents by emergency medical personnel, the primary target. It is also used by hospital emergency departments and ICUs, which make three-fifths of registry calls. "The registry also facilitates quality improvement activities and research on an aggregated basis," integrating POLST data with demographics, public health information and, eventually the state's death certificate records, Carley says.

Under Oregon law, executed POLST forms are faxed to the registry from physicians' offices and other health care settings, unless the patient chooses to opt out of the registry by checking a box on the form. Before activating a POLST form in the registry, it is verified, and a second staffer checks the accuracy of the entered data. When emergency personnel want to quickly know if the patient has a POLST form and what it contains, they phone the ECC, where the database is kept behind a security firewall. Dedicated communication specialists search the database to find the patient in question, using identifiers supplied by the EMTs to ensure that the correct individual is identified. Because the registry was mandated by the Oregon legislature, it satisfies HIPAA (Health

Insurance Portability and Accountability Act) requirements and avoids the need for additional patient authorizations.

**What Are Other States Doing?**

New York State implemented a process similar to POLST, which it calls MOLST (Medical Orders for Life Sustaining Treatment). MOLST was piloted over several years, with legislative approval for statewide implementation in 2008, says Patricia Bomba, MD, vice president and medical director, geriatrics, at Excellus Blue Cross Blue Shield in Rochester. She chairs and has led MOLST development since 2001. New York is now developing a web-based application (eMOLST) that initially will make MOLST available through the Rochester Regional Health Information Exchange. Ultimately it will be integrated into the state's 12 Regional Health Information Organizations, the vehicles for deploying community-based EHRs across the state.

"The eMOLST application documents the clinical process, including a goals-of-care discussion, as well as the legal requirements. A MOLST form and chart documentation of the discussion and process are created," Dr. Bomba explains. Unlike the Oregon registry, health professionals will access the information through a web-based program using the patient's eMOLST number or first name, last name, gender and date of birth. "With the web-based application, people will be able to create, review and update the forms under their physician's guidance," Dr. Bomba says. "We're also building apps for smart phones to help providers track patients who have MOLST forms."

New York has complex advance care planning and end-of-life statutes, with specific rules for special populations (e.g., the developmentally disabled who lack medical decision-making capacity) and specific requirements regarding withholding and withdrawing of treatments based on who makes the decision and where the decision is made. The registry approach has been shaped to conform to those statutory requirements.

The West Virginia Center for End-of-Life Care is pursuing a somewhat different networking approach, called the eDirective Registry, now under development for the state's POST (Physician Orders for Medical Treatment) system—which went into effect in 2002. "We already have 3,000 forms ready to register," says Alvin "Woody" Moss, MD, director of the West Virginia Center and professor of medicine at the University of West Virginia.

"We have a sign-up sheet that West Virginians can download, complete and fax in to the West Virginia Health Information Network, which is HIPAA-compliant behind its firewall. We're also looking at automating the technology with fax scanners, although you'd still need humans to review and validate the document. We've worked with the Governor's privacy officer," as well as with state provider groups and a statewide network of ethics committees. Consumers will be able to confirm online accuracy of their password-protected documents in this system, expected to launch by the end of 2011.

Grant support is helping with design, testing and launching the registry. Supplemental funding is being sought from the state to sustain the registry through its first few years. The registry will encompass advance directives, including living wills and medical power of attorney, DNR cards and surrogate selection forms, as well as POST, Dr. Moss says. "It's real one-stop shopping," accessible 24 hours a day. "I think having these forms on the registry is the final step in implementing a system that will work."

Washington State, which adopted POLST in 2000, established a state registry in 2008 to include both POLST forms and advance directives. The Washington Registry recently lost legislative support and essentially has been shut down, reports James Shaw, MD, Medical Director of the Providence Center for Faith and Healing. The state's Health Department recently announced that it is no longer accepting new entries to the registry because the program ran out of money. However, people who registered by June 20 will maintain a free lifetime registry with the U.S. Living Will Registry, a private company.

"The POLST program has been very successful in Washington. But the registry, which seemed to be a good idea and generated a lot of enthusiasm, was woefully underfunded," Dr. Shaw explains. It did not include financial support for statewide education. "We didn't have an automatic and easy way for people to register their documents, and after three years, we only had 2,000 to 3,000 forms on file—one-quarter of them POLST." Dr. Shaw suggests that if the system had focused only on POLST, it might have been easier to implement. The large HMOs in Washington now have EHRs incorporating easily accessible advance directives and POLST for their members.

## Reaching a Critical Mass

Other states are also exploring the question of POLST registries. Previous efforts to launch online registries for advance directives, including by private companies, by and large failed to make significant inroads into the consumer population. But with the explosion of interest in POLST as a medium for communicating treatment preferences for serious illnesses, the idea of a registry continues to come up, both at the state level and in the private sector.

The national POLST Task Force has a registry committee now looking at the key components of a successful registry. California is conducting a feasibility study of developing a POLST registry for the large state and its challenges of scale—possibly to start pilot testing in 2012. It will try to address the issues contained in the "Key Components" document developed by the Registry Subcommittee of the National POLST Task Force (link here:_).

Although California has extensive POLST implementation efforts underway across the state, using standardized educational materials adapted to local needs, the ultimate challenge for its or any registry remains the same: getting the word out. There should be a critical mass of physicians, other professionals and consumers aware of the benefits of entering a POLST form into a registry, leading to a critical mass of documents completed and filed. If EMS contacts the registry several times without successful matches, they may decide to stop calling. But with a populous registry at the time of launch, the registry will be a useful service to emergency personnel and others who need to gain access to the information.

*Written by Larry Beresford, Freelance Writer*

## Key Components and Timing of POLST Registry Implementation

## Source: National POLST Task Force, Registry Subcommittee

Timing of implementation is key to effectiveness and ultimate success of a POLST registry. Early experience demonstrates that having the right model, adequate resources and support from health care professionals and public policy makers is essential for a new registry. The following document developed by the National POLST Task Force Registry Subcommittee includes recognized key components of a POLST registry. It is expected that these components will be refined as additional experience with registry implementation is gathered.

### Form Entry and Update

1. A searchable database to maintain forms.
2. A mechanism to assure that a large percentage of existing forms is entered into the registry.
3. Timely entry of the forms into the registry.
4. A mechanism to assure accurate entry into the registry.
5. Unique identifier.
6. A mechanism to update the form for a person in the registry when the person voids a present form and completes a new one.
7. A mechanism to identify a deceased person's forms, archive them, and remove them from the searchable portion of the registry.

### Access to the Forms

1. 24/7 access to the information in the registry by health care professionals such as EMS and acute care hospitals who need them at the time of a crisis.
2. Non-urgent access for other health care professionals who are members of the patient's care team.
3. A mechanism that protects the information from unauthorized access.
4. A mechanism that assures correct match of the patient and the form so that the wrong information is not provided.
5. Mechanism for patients, signers and others, as needed, to access information about forms in the registry.

### Quality Assurance and Research

1. A quality assurance program that assures that the key components are monitored.
2. Ability to produce de-identified reports about forms in the registry.

### Initial and Ongoing Education about Use of the Registry

1. EMS/ED/Acute Care hospital professionals (users).
2. A mechanism to provide all health care professionals who counsel, complete and sign POLST Paradigm forms (senders) about entry into the Registry.

Legal Considerations

1. Assurance that the form is HIPPA-compliant.
2. A mechanism to assure data security.
3. Definition of who is authorized to enter forms.
4. Review of specific state requirements.
5. Consideration of medical legal concerns for risk management.