

National POLST Founders Story

Celebrating a unique grassroots effort that grew into a national movement

Introduction

POLST—first known as “Physician Orders for Life-Sustaining Treatments”¹—describes a concept and a process for end-of-life planning emphasizing eliciting, documenting and honoring patient treatment preferences for medical emergencies. Fundamentally, POLST is a process; the most visual part of the program is the POLST form. This form is an immediately available, standardized, recognizable, portable, out-of-hospital medical order set that assists emergency personnel in providing treatments aligned with patient preferences during an emergency.

The POLST movement began in Oregon then spread to other states that renamed, adapted and implemented POLST programs to fit their own cultural and regulatory milieus—meanwhile working together as a national community of state leaders and advocates who freely shared their knowledge and experience with each other. The model grew from perceptions by some health professionals in Oregon that advance directives often were not helpful in ensuring that patients’ wishes for care would be honored during a medical emergency.² Starting in 1990 and led by Portland internist Patrick Dunn, MD, a coalition of interested parties began a voluntary task force to work on the Medical Treatment Coversheet, the prototype for POLST. It was tested and then launched statewide in 1995.

The idea spread. Once the word got out, POLST founders started hearing from health professionals in other states asking how to adopt this concept in their setting. Questions arose about how to mobilize necessary support, how much national control or uniformity over the concept is appropriate for this voluntary process versus freedom to innovate in each state, what are the minimum features that could still qualify as a POLST form, and what are the essential ingredients of a successful program.

From these conversations among the leaders of Oregon’s POLST initiative and other states implementing POLST programs of their own, a National POLST Paradigm Task Force (National Task Force) developed. This group of leaders defined the National POLST Paradigm, established a process of endorsement for other state programs conforming to its essential criteria, and opened a national office at Oregon Health & Science University’s (OHSU) Center for Ethics in Health Care to support implementation efforts in other states.³ From the outset, outreach, education, policy development and research were critical components—initially to make sure the form and process actually worked in practice, and then to disseminate what was learned.

Helping Other States

With publication of initial research on the POLST experience in Oregon, starting with a study in the *Journal of the American Geriatrics Society* in 1996⁴ and presentations at national conferences of health professionals by its founders, questions started coming in from leaders in other states looking for solutions to similar problems. From the very beginning, a key characteristic of Oregon’s POLST leaders

¹ The term used to describe POLST varies by state (see [here](#)) and National POLST no longer spells out the acronym but focuses on “POLST” as a [concept](#).

² For more information about how POLST differs from advance directives, see <https://polst.org/about/polst-and-advance-directives/?pro=1>

³ National POLST left the OHSU Center for Ethics in Health Care in January 2017.

⁴ Dunn PM, Schmidt TA, Carley MM, Donius M, Weinstein MA, Dull VT. A Method to Communicate Patient Preferences About Medically Indicated Life-Sustaining Treatment in the Out-of-Hospital Setting. *Journal of the American Geriatrics Society*; 1996 July; 44(7): 785-791. See: <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.1996.tb03734.x/full>.

was their willingness to go out and mentor professional colleagues in other states, not just sharing the standards but walking them through the development process.

The Oregon founders agreed to divide up other states for consultations, often based on pre-existing links or professional focus. For example, says Margaret Carley, JD, an early task force member and former executive director of National POLST, “A lot of us were talking to folks in Washington State, or going to Wisconsin. I made several trips to Maine and Connecticut, where I forged new relationships.” Grant support was later obtained to fund a part-time secretary and to cover mounting travel expenses.

Creating a National Structure

“Programs in early adopter states were progressing and we felt we an organized approach to provide a framework for this work,” says Patrick Dunn, who served as the National Task Force’s convener and first chairperson. “We thought maybe it’s time to take the next step.” Several early adopter states, starting with West Virginia and Wisconsin, also began sharing their own experience to help other states.

In 2004, leaders of the POLST movement in Oregon and other states (New York, Pennsylvania, Washington, West Virginia and Wisconsin) joined together to found the National Task Force, the group that would establish quality standards and provide assistance to other states developing a POLST program. Records kept by National Task Force member Susan Hickman, PhD, an Oregon POLST researcher and National Task Force member, indicates that six additional states (Georgia, Idaho, Maryland, Nevada, Utah and Vermont) had POLST programs in various stages of development by the time of the National Task Force’s first meeting in 2004.

The National Task Force started out with 13 individual members, including several leaders from Oregon and representatives from the five other early adopter states, all of which had at least three years of experience working on POLST initiatives.⁵ In 2005 this group drafted a description of POLST, defining elements of a POLST program and contents of POLST forms, along with a process for formally endorsing POLST programs. Eventually this model formalized and solidified into a “National POLST Paradigm,” which we now simply call POLST.

For practical reasons, the National Task Force’s initial and subsequent meetings were held by telephone, although individual members continued to visit other states. By 2007, it was clear that a gathering was needed to bring the members together, face-to-face. This meeting was combined with a pre-conference educational seminar on POLST held at the National Hospice and Palliative Care Organization’s conference in New Orleans in late November of that year.

“We had been talking for three years, developing virtual relationships. The conference in New Orleans was a crystallization of our ideas,” Carley says, and a chance to share everybody’s experience in a more personal way. About 95 people from several dozen states attended the day-long POLST pre-course.

A lot of planning went into the program, recalls Oregon POLST leader Susan Tolle, MD, Director of the OHSU Center for Ethics in Health Care. “We shared our pathway and had an EMS presentation by Terry Schmidt, MD. Susan Hickman, PhD, talked about her research in long term care settings.” The gathering also included a session on sustainability for states with active programs. A second in-person meeting was

⁵ The 13 founding members of the National POLST Paradigm Task Force (National Task Force) were Patrick Dunn, MD, Chair (OR) and Susan Tolle, MD, Treasurer (OR), Bud Hammes, PhD (WI), Woody Moss, MD (WV), James Shaw, MD (WA), Sally Denton (WA), Judith Black, MD (PA), and Patricia Bomba, MD (NY) with advisors Terri Schmidt, MD (EMS), Margaret Carley, JD (Long-term Care), Susan Hickman, PhD (Research), Charles Sabatino, JD (Legal), and Malene Davis (Hospice).

held in 2009 in conjunction with the American Academy of Hospice and Palliative Medicine's national conference in Austin, Texas.

National POLST Emerges

Developing national standards was not an initial focus for the National Task Force, Tolle says. "Pat Dunn and I thought mutual learning was our first priority. Second was to help the people who were calling us and to share the load by matching them to other states like their own. We were still learning and still had much to learn."

Susan Hickman recalls the kinds of issues that came up during the meetings: "Did the research even apply because we were doing different things in different states, with different forms under different names? That question moved us toward trying to create more structure, first with the Task Force, then in developing the 'POLST Paradigm,' with a concrete focus on defining elements." The group quickly recognized that the National Task Force could facilitate dissemination of the 'POLST Paradigm' concept through program endorsement, education, policy development and research.

The POLST decision-making process and resulting medical orders are intended for patients who are 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.⁶ POLST is a process designed to improve patient care and reduce medical errors by creating a system using a portable medical order form (aka "POLST form") that records patients' treatment wishes in what may be their last year of life. The POLST process starts with a conversation: a patient and his/her health care professional discuss the patient's goals for care consistent with their values and beliefs, and the patient's diagnosis, prognosis, and treatment options, including the benefits and burdens of those options. Together they reach an informed shared decision about what treatments the patient wants in case of medical emergency; those decisions are documented on a POLST form.

Critical elements of POLST programs include organizing a coalition, establishing an administrative center to facilitate the project's growth, and obtaining funding to support its work. Other core elements of any successful, quality program include the imperative for education, an ongoing leadership team, and a broad spectrum of stakeholders with a few committed champions at their head. POLST forms, developed at the state level, needs to spell out life-sustaining treatments options and should meet [other national requirements](#). It also needs to be voluntary for the patient.⁷

National Task Force members agreed that the name POLST was not a prerequisite, and that other names and variations on the concept of medical orders could be used in other states.⁸ "We weren't hung up on the name but on the criteria—we wanted it to be voluntary for the patient and for the system. The further along we got, the more pressure there was for a uniform form, but again, it depended on each state and what state law would permit," Carley says. The goal became creating standards and guidance to develop consistency and uniformity in the process and form so that a patient would be able to get a POLST form in one state and have confidence it could be honored in another. Endorsement was a way of saying that a program met National POLST minimum standards and could take its place alongside the established POLST programs in other states.

⁶ In the beginning, the National Task Force described the intended population for using POLST as those individuals who are seriously ill or frail and whose health care professional wouldn't be surprised if they died within a year. This was updated in 2018: <http://polst.org/guidance-appropriate-patients-pdf>

⁷ A national policy discussing appropriate ways to use POLST forms was developed in 2017: <http://polst.org/appropriate-use-pdf>

⁸ <https://polst.org/program-names/> provides a full list of names used by states.

“We wanted to be clear that our program was about respecting patients’ wishes within the bounds of ethics and the law. Susan Tolle did not want us to suggest that we were about saving money,” Moss says. “That was never our intent with POLST.” Adds Tolle, “There was consensus when we said there are some things we’ll accept, but other lines we cannot cross. I think POLST’s reputation of trust is genuine and can be easily damaged.”

Hammes adds that POLST leaders did not set out to be national leaders. “But we were getting so many requests for support that it became overwhelming. We felt some leadership was required for it to spread in a way that represented best practice. Not that we had discovered the truth or that our idea didn’t need further work or testing. But the only way for that to happen was for this group to take the lead,” he says. “The biggest challenge for me with the POLST Paradigm was to find the balance between providing guidance without being inflexible or failing to respect and honor differences between state projects. These were things we argued about. I think we did find the right balance in the end.”

Moving Forward

As these fundamental questions were being worked out, the POLST Paradigm movement continued to grow and evolve. A statewide electronic POLST registry of medical orders was first piloted in Oregon in 2009. Leadership and succession planning were explored. In 2012, Pat Dunn retired as Chair of the Oregon and National Task Forces and Margie Carley stepped up to serve for a year. Amy Vandenbroucke, JD, stepped in as Chair of the Oregon POLST Task Force and Executive Director of the National POLST Paradigm in 2013.

By 2015, “[we’d] grown to where we needed a new organizational structure for a movement where now 49 out of 50 states either have a program or are working on it,” Moss says. The logical next step was to completely separate its own staffed national office, apart from the OHSU Center for Ethics in Health Care. That process ramped up in 2015 when Amy Vandenbroucke, who initially divided her time between the National Task Force and Oregon’s POLST activities, stepped down as chair of the Oregon POLST Task Force to devote full time effort to the National POLST Paradigm.

“The National POLST Paradigm has so much potential to be bigger and stronger as its own 501(c)(3),” Tolle says. “There is a need to go to Washington, DC, more often than I, for one, have any interest in doing, while there is a growing desire for Oregon to continue innovating with its own program – most heavily in information technology such as the online registry.” The basic concept of the POLST Paradigm will not change, but its implementation will keep evolving.

“The National Task Force has been the North Star of the POLST Paradigm,” Sabatino says. “Without it, states would be all over the map with their forms and implementation and there would be no standardization. The National Task Force is trying to move us toward the standard of care; it is the entity building consensus. Lack of standards would be the demise of our model. We already deal with criticism of the POLST Paradigm model, but at least we can say we follow a defined set of principles and standards.”

For current information, please review:

- [Conflict of Interest Policy & FAQs](#)
- [Governance Structure and Leadership](#)
- [Strategic Plan](#)
- [Policies and Guidance](#)