

Editor's Note: The following Q & A regarding POLST is reformatted from the written testimony ("Renewing the Conversation: Respecting Patients Wishes and Advance Care Planning") by Amy Vandembroucke, JD, Executive Director, National POLST Paradigm Program, offered to the Senate Special Committee on Aging at a June 26, 2013 Hearing.

What is POLST?

The Physician Orders for Life-Sustaining Treatment (POLST)¹ is a tool for translating patient's goals of care into medical orders so that they are easily located and portable across care settings. POLST is not just a specific set of medical orders documented on a form; it is also an approach to end-of-life planning based on conversations between patients, loved ones, and medical professionals. The POLST Paradigm is designed to ensure that seriously ill patients can choose the treatments they want and that their wishes are honored by medical providers.

A key component of the system is thoughtful, facilitated advance care planning conversations between health care professionals and patients and those close to them. Completion of a POLST form requires shared decision making between the health care professional signing the form and the patient, or his/her legally authorized health care representative identified pursuant to state law. In order to complete the POLST form, there must be a discussion of the patient's diagnosis and prognosis; the available treatment options given the current circumstances, including the benefits and burdens of those treatments; and the patient's goals of care and preferences of treatment. Together they reach an informed decision about desired treatment, based on the person's values, beliefs and goals for care. Then, if they wish, their health care professional completes and signs a POLST form based on the patient's expressed treatment references.

Who is POLST for?

POLST is not for everyone; only patients with serious advanced illnesses should have a POLST form. For patients where a POLST is appropriate, their current health status indicates the need for standing medical orders for emergent or future medical care. For healthy patients, an advance directive is an appropriate tool for making future end-of-life care wishes known to loved ones. The general guidance is that the POLST form is for seriously ill patients for whom their physicians would not be surprised if they died in the next year. It would be inappropriate to provide a POLST to all patients.

Two key tenets of POLST are:

- (1) POLST is voluntary because everyone has the right to make his or her own health care decisions; the National POLST Paradigm Task Force (NPPTF) does not endorse programs where completion of a POLST form is mandatory.

- (2) POLST must be easily modified or revoked. Oregon's POLST Registry shows about 15% of POLST forms submitted to the registry each month are modifications of a previous POLST form. As the disease progression continues, patient desires for certain treatments may change, so it is fundamental to the POLST Paradigm Program that POLST forms be easily modified.

What does the POLST form contain?

The POLST form varies among states but states endorsed by the National POLST Paradigm Task Force have all met the same standards.

POLST forms are divided into a couple of key sections; the order may vary by state. For illustration, the Oregon POLST Form is used as an example.

Section A: Cardiopulmonary Resuscitation (CPR). These orders apply only when the patient has no pulse and is not breathing; this section does not apply to any other medical circumstance. If the patient wants CPR, the box should be checked and full CPR measures should be carried out and 9-1-1 called. If the patient does not want CPR, the box should be checked and CPR should not be performed.

Section B: Medical Interventions. This section is designed to guide care in an acute situation when the patient is not in cardiopulmonary arrest. There are three levels of medical interventions generally found on POLST forms:

- i. **Comfort Measures Only/Allow Natural Death.** The treatment plan is to maximize comfort through symptom management. Antibiotics may be used as a comfort measure. This should be ordered if a patient's goal is to maximize comfort and avoid hospitalizations unless necessary to ensure comfort needs are met.
- ii. **Limited Additional Interventions.** The treatment plan is to hospitalize if needed but to void mechanical ventilation and generally avoid ICU care. This should be ordered if a patient's goal is to obtain treatments for reversible conditions or exacerbations of his/her underlying disease with the goal of restoring the patient to his/her current state of health. Examples include hospitalization for dehydration or for pneumonia.
- iii. **Full Treatment.** The treatment plan should include all life-sustaining treatments possible, including intubation, advanced airway intervention, mechanical ventilation, cardiobypass, transfer to hospital and use of intensive care as indicated with no limitation of treatment.

While it is possible to order Do-Not-Resuscitate (DNR) in Section A, but Full Treatment in Section B, in this circumstance, a patient would want all measures provided but would not want to be resuscitated if those attempts fail and their heart stops. It is not possible to order CPR in Section A

and Comfort Measures Only in Section B because, in providing CPR, the next step is for intubation and ventilation, which is not consistent with the Comfort Measures Only option.

Section C: Artificially Administered Nutrition. These orders indicate the patient's instructions regarding the use of artificially administered nutrition for a patient who cannot take fluids by mouth. Statutes vary among the states as to the standard for evidence required to limit tube feedings. For endorsement, the NPPTF requires POLST forms to clearly state that "food and fluids must be offered as tolerated."²

It is also a requirement that comfort measures always be provided to patients and that information be clear on the POLST form.

How does the POLST form work?

Since POLSTs are medical orders, they can be made to be easily located in an emergency since they are part of the patient's medical record. There is no requirement for electronic medical record (EMR) systems to provide such easy access to a POLST, or an advance directive, but it should be so that health care professionals are confident they can locate patient wishes in an instant during an emergency. Additionally, the original POLST form is given to the patient to keep (copies are put in medical records). States use brightly colored forms for easy identification by emergency personnel.

Several states, including Oregon, West Virginia, Idaho, Utah and New York, have registries for POLST forms, ensuring emergency personnel and health care professionals know the treatment wishes of their patients during an emergency. This provides a third avenue in which a form can be located in an instant, because health care professionals can call the 24/7 registry line and get information about a patient's POLST form.

So, for example, in an emergency in Oregon, when EMTs are called to a scene they will arrive and are trained to look at/in the refrigerator for a bright pink form. Patients and families are told that this is where the form should be kept. Additionally, EMTs are trained to call the Oregon POLST Registry anytime: (1) they suspect a patient has a POLST; (2) they are told a patient has a POLST but are unable to locate it; (3) the patient has a chronic, progressive illness; (4) the patient is a frail or elderly patient; and (5) if a POLST form is produced on the scene but there is a problem or question as to the orders selected, or validity of the form.

The value in having a single form for medical orders allows emergency services personnel to: (1) follow medical orders in the field because they are trained to find information in an instant and (2) incorporate such a procedure in their scope of practice.

May a POLST be revised or voided?

As a patient's disease progresses his/her goals of care may change and so it is important that the POLST be easily amended or voided; both are easy procedures in endorsed states.

Revising a POLST Form.

The health care professional responsible for the patient's care should review and update the POLST form, with the patient or his/her surrogate, as needed based on the patient's medical condition and treatment preferences. At a minimum, the POLST should be reviewed in the following circumstances:

- (a) When the patient is transferred from one care setting or care level to another;
- (b) When there is a substantial change in the patient's health status; and
- (c) When the patient's primary care professional changes.

A patient with capacity, or his/her valid surrogate when the patient lacks capacity, may also initiate a revision of a POLST form at any time.

Revisions of POLST forms generally require voiding the current POLST form and writing/signing a new form, as well as giving the patient the updated form with instructions to destroy all older versions and putting the most current form in the patient's medical record (and archiving the old POLST form).

Voiding a POLST Form.

A patient with capacity, or his/her valid surrogate when the patient lacks capacity, can void the form and request alternative treatment at any time. A form is generally voided when "VOID" is written in large letters across the form, but the process varies by state, particularly if there is a state registry to be notified.

Should POLST forms be signed?

The POLST Paradigm Program requires health care professionals be trained to conduct shared decision-making discussions with patients and families so that POLST forms are completed properly. State law authorizes certain health care professionals to sign medical orders; the POLST form is signed by those health care professionals, who are accountable for the medical orders.

The POLST form may be signed by the patient with capacity or his/her valid surrogate when the patient lacks capacity, but such a signature is not required in all states. In Oregon, the patient or surrogate's signature is only recommended; in New York, the patient or surrogate only attests that the conversation has taken place.

The NPPTF encourages all states seeking endorsement to require a patient or surrogate's signature on the POLST form, but is it not a required form element for endorsement. Since traditional

medical orders are not signed by patients or surrogates, NPPTF’s focus is on encouraging programs to design systems to ensure the conversation about patient’s treatment options and goals has taken place.

Is POLST the same as an Advance Directive?

The POLST form is not intended to replace an advance directive document or other medical orders. The two documents differ, as will be discussed below, but they ideally work together. In short, the POLST turns the patient’s wishes expressed in an advance directive into action as a medical order.

a. Key Differences

While all competent adults - regardless of health status - should have an advance directive, not everyone should have a POLST. As discussed above, POLST is for a very specific patient population. The POLST form is a set of medical orders, similar to the do-not resuscitate (allow natural death) order. POLST is not an advance directive. POLST does not substitute for naming a health care agent or durable power of attorney for health care. The differences are best presented in a chart:

POLST Form	Advance Directive
Medical Order Immediately takes effect	Legal Document Needs interpretation and discussion to be effective
Communicates medical treatments specific to patient’s current state of health	Communicates general wishes about medical treatments in future states of health
Does <u>not</u> appoint a health care surrogate or representative	Appoints a health care surrogate or representative
Easy to locate (as medical order is in medical record). May also be in a registry. Most current version can be made easily available in medical record.	Generally not available when needed (patients have onus to ensure a copy is in the medical record and/or given to family to provide at time it is needed). Patients also have the onus to provide new copies when updating the document.
For those with advance illness or frailty- at any age	All competent adults over 18 should have (or whatever age of majority is in specific state)
Signed by health care professional (state law dictates which professionals may sign medical orders)	Signed by individual, his/her health care surrogate or representative, possibly by witnesses and possibly requires notarization (depends on state law)

For healthy patients, an advance directive is an appropriate tool for identifying a surrogate decision-maker and making future end-of-life care wishes known. Advance directives are generally completed when an individual is unaware of what disease or medical issue they may have in the future so it only provides general guidance. Further, it is a legal document requiring interpretation and, because of that, it does not give directions in the field during an emergency.

Conversely, the POLST is a medical order. POLST takes effect as soon as it is signed by the health care professional and gives orders to other professionals, including emergency service personnel, which can be acted on. It is only when a patient is diagnosed with a serious advance illness that a POLST form would be appropriate. For these patients, their current health status indicates the need for standing medical orders for emergent or future medical care and they are able to make decisions about their care knowing their specific diagnosis and prognosis.

POLST orders are more easily located in an emergency. Further, having a single form for medical orders provides consistency that allows emergency service personnel to follow the medical orders in the field because they know where to look for specific information in an instant (this is also helped by the NPPTF encouraging all states to have all medical orders on the front page of the POLST form). This consistency then allows emergency service personnel to incorporate a procedure for using POLST in their scope of practice. Additionally, several states, including Oregon, West Virginia, Idaho, Utah and New York, have registries for POLST forms, ensuring that emergency personnel and health care professionals know the treatment wishes of their patients during an emergency.

While the POLST Paradigm Program supports the completion of advance directives, clinical experience and research demonstrate that these advance directives are not sufficient alone to assure that those who suffer from serious advanced illnesses will have their preferences for treatment honored unless a POLST form is also completed. Max's story can serve as an illustration. Max's wife, Suzanne, shared his story with POLST this year; his story exemplifies the differences between advance directives and POLST and explains why POLST is necessary.

Max was born and raised in rural Oregon; he was a devoted father and doting grandfather, as well as a gifted athlete. He was a champion squash player, who loved to play golf, hunt and fish. His active lifestyle was dealt a life-changing blow around the time of his 75th birthday when he received the sobering diagnosis of aortic stenosis. Open heart surgery was his only treatment option, and the alternative was an increasingly frail state of health as the valve slowly closed. He thought deeply about his choices, especially given his other health problems. And the conclusion he reached was crystal clear: he did not want the surgery.

Although he loved technology, and had embraced it in his life's work, he was, according to his wife Suzanne, "a man of nature." He was adamant that he wanted his life, and death, to unfold naturally—without tubes or machines. So, with great care, he completed an Advance Directive to

document his end-of-life wishes, which he then shared with his family. He took comfort in the fact that his wish for a peaceful, natural death was clearly documented in an Advance Directive.

Suzanne and his family knew what he wanted and were comfortable with his decision. They knew he believed in the quality of life and had thought about it carefully, based on who he was and how he wanted to live out his days.

Sadly, this careful planning was not enough. Five years later, when Max collapsed from heart failure while playing golf on Mother's Day, his strongly-held wishes could not be honored. His Advance Directive, completed with such care and intention, did not serve as the medical orders needed to direct his care in this emergency situation. Max had just hit a good drive off the first fairway when his heart gave out. An ambulance was called to the scene and, when Suzanne arrived about 15 minutes later, she was deeply disturbed by what awaited her.

Emergency medical personnel were clustered around her lifeless husband, doggedly performing CPR in an attempt to revive him. She realized with horror that this was exactly what Max had most wanted to avoid. She begged them to stop, telling them that she had his Advance Directive in her purse. But they kept going. And she looked around, seeing all these people coming to see what was going on. And she felt even worse, knowing that Max—who was a very private man—would not have wanted this at all. He would have hated it.

In a medical emergency, EMTs have no choice but to do everything possible to save a life unless they have *medical orders* to the contrary. The POLST form provides the medical orders necessary to turn patients' wishes about the treatment they do and do not want into action. The advance directive is not even reviewed until Max is at the hospital.

Max's death would have been very different if the EMTs responding to his collapse had had a POLST form to direct the course of his care. He would have been allowed the dignified natural death he deeply desired. And his family, in their grief, would have had the comfort of knowing that his wishes had been both honored and respected.

How do POLST and Advance Directives work together?

Patients with decision-making capacity can modify their POLST at any time to reflect changing circumstances—for example, when treatment has been initiated and more medical information becomes available regarding diagnosis, prognosis, or potential outcomes, the patient's goals and preferences may change. If the patient becomes incapacitated, the advance directive plays an important role in developing goals for care consistent with the patient in his/her new state of health. The surrogate identified by the patient in his/her advance directive would participate in either initiating a POLST or updating POLST orders in a manner consistent with the patient's preferences as the patient's health status changes.

What Is the National POLST Paradigm Task Force (NPPTF)?

The NPPTF was convened in September 2004 to establish quality standards for POLST forms and programs and to assist states to develop such programs. The NPPTF includes one representative chosen by each state endorsed by the NPPTF.

Goals of the NPPTF

In the early 1990s, the POLST Paradigm Program was developed to improve patient care and reduce medical errors by creating a system that identifies patients' wishes regarding medical treatment and communicates and respects them by creating portable medical orders. The system focuses on a growing segment of the United States population, those seriously ill patients with advanced, chronic progressive illness. While the NPPTF supports the completion of advance directives, clinical experience and research demonstrate that these advance directives are not sufficient alone to assure that those who suffer from serious, advanced, progressive chronic illnesses will have their preferences for treatment honored unless a POLST form is also completed.

A key component of the system is thoughtful, facilitated advance care planning conversations between health care professionals and patients and those close to them to determine what treatments patients do and do not want based on their personal beliefs and current state of health. In these conversations patients are informed of their treatment options and, if they wish, their health care professional completes a POLST form based on the patient's expressed treatment preferences.

A number of states have implemented the POLST Paradigm, and most others have expressed interest in doing so. POLST research shows that POLST use results in treatment consistent with patients' wishes more than 90% of the time, significantly reduces unwanted hospitalizations, and decreases medical errors.

The NPPTF is continuing to conduct research and develop quality measures to further assess the impact of the POLST Paradigm Program on patient outcomes. The goal of the NPPTF is to assure that the wishes of those with advanced illness and frailty are elicited, recorded and honored.

Overall, the NPPTF is dedicated to overseeing the success of the POLST Paradigm in every state and to establish clear tenets of the POLST Paradigm Program. Through its various committees, the NPPTF mentors developing states, reviews and approves (or denies) endorsement and mature status applications, and advises on communication, research and registry efforts.

How does POLST develop in the various states?

POLST has developed in states primarily through a grassroots approach, such as in Oregon, or through legislation or regulation. Current legislation in the states can be located in the legislative

guide created by the ABA Commission on Law & Aging. Development of the first twelve states adopting can be found in the AARP Public Policy Institute Research Report entitled “Improving Advanced Illness Care: The Evolution of State POLST Programs” (see Resources).

What is the current status of the POLST Paradigm Program?

The NPPTF categorizes states based on their development status.

- (1) States With Contacts.** When states are exploring the development of a regional or statewide POLST Paradigm program they can formally connect with the NPPTF. This level is for states not yet ready to complete the Developing POLST Paradigm documentation but who would like to participate in the National POLST Paradigm Program (e.g., receive emails from the national office, attend various education sessions put on by the National Office or the NPPTF, etc.). Oklahoma and Arkansas are currently in this category.
- (2) Developing States.** Programs are recognized by the NPPTF as “developing” when they have both: (1) submitted the Developing State Status Application form and (2) presented the state’s POLST form and progress to the NPPTF’s Developing State Assistance Committee. Developing POLST Paradigm Programs may be at various stages of development, ranging from the initial design of a POLST form to active usage of POLST forms, but are working towards the goal of implementing the POLST program statewide. In general, programs at this step are starting to contemplate addressing all Seven Core Elements of Sustainability (Attachment 5). There are currently 22 Developing States: Arizona, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Michigan, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, Ohio, Rhode Island, South Carolina, Virginia, Vermont and Wyoming).
- (3) Endorsed States.** The NPPTF will endorse state POLST programs when they have developed and implemented a POLST program and form meeting the NPPTF standards (See Request for Endorsement Status Form, Attachment 6). Endorsed programs are statewide or regional POLST programs that have become standard components of advance care planning in their location. These programs have addressed legal and regulatory issues associated with POLST, and have developed strategies for ongoing implementation and quality assurance. There are currently 14 endorsed states: California, Colorado, Georgia, Hawaii, Idaho, Louisiana, Montana, New York, North Carolina, Pennsylvania, Tennessee, Texas, Utah, Washington, and Wisconsin, however, Wisconsin is only regionally endorsed.
- (4) Mature States.** Mature status is the highest level of endorsement by the NPPTF and is reserved solely for states with statewide POLST programs that, among other requirements (see Request for Mature Program Status Form, Attachment 7) are the standard preferred

method of advance care planning for persons with advanced illness or frailty. Mature POLST programs are used by 50% or more of hospitals, nursing homes, and hospices in each region (as defined by established criteria such as EMS, Department of Health, or the Dartmouth Atlas) of the state. These programs are actively gathering data for quality assurance programs and have considered centralized POLST databases. There are two states with Mature Program status: Oregon and West Virginia.

- (5) States with Programs that do not conform to POLST Requirements. There are some states that have developed POLST-like programs that, either due to how the program was implemented, the development of the form, or for legislative reasons, will not be endorsed by NPPTF in their current form. There are four currently identified:
- a. Minnesota: Currently their form expressly states 911 should not be called when a patient's POLST orders are for "Comfort Measures Only". This violates the tenet of the POLST Paradigm Program that comfort measures are always provided to the patient; Minnesota's form overlooks instances where a patient cannot be provided comfort care in his/her current location. For example, if the patient falls and breaks a bone at home, it is unlikely their comfort can be adequately addressed in that location and it is likely the patient must go to the hospital for treatment to control their pain.
 - b. Maryland: Legislation going into effect this year requires POLST forms be completed for all patients except those in three limited categories. Their program violates the POLST Paradigm's tenant that a POLST is always voluntary.
 - c. Delaware: This program requires a patient be diagnosed as terminal before a POLST can be completed. Focus groups have shown that patients find the term "terminal" offensive. This program is too narrow in limiting the patient population that can access POLST; the target POLST population includes those patients where his/her health care professional would not be surprised if the patient died within the next year.
 - d. Massachusetts: The current form does not include the Section B discussed in Section 2(a) above but, instead, has a variety of questions. This lack of structure in the form causes confusion and lacks clarity.

Since this is a relatively new distinction, the NPPTF is working to evaluate other states currently in the "Developing State" category in light of recent legislation or form development. It is important for the NPPTF to clarify this category as the principles are important to the program; only mature and endorsed states should be used as examples of the POLST Paradigm Program.

We currently do not have contact with five states: Alabama, Alaska, Mississippi, Nebraska, and South Dakota.

What Are the Benefits of POLST?

POLST improves the quality of patient care and reduces medical errors by creating a system that identifies patients' wishes regarding medical treatment and communicates and respects them by creating portable medical orders.

A 2010 study by Susan Hickman in the *Journal of American Geriatric Society* showed that there was a reduction by 67% of medical interventions unwanted by the patients (mainly emergency room visits and hospitalizations) for patients with POLST forms with orders for Comfort Measures Only by compared with POLST orders for Full Treatment and 59% less than traditional Do-Not-Resuscitate orders. In short, POLST orders for Comfort Measures Only reduces hospitalization, readmissions and emergency room visits, as well as reducing care patients do not want to receive.³

What is needed for POLST to be successful?

Although it is a state effort, a uniform standard for electronic medical records should be a requirement that all EMR systems be designed in ways that POLST orders, as well as advance directives, be found quickly so they are easily accessible during an emergency. EMR systems are complicated and while a document may be “in the record” it may not be easily located. For documents that may be urgently needed—in order to ensure a patient’s autonomy is respected—the NPPTF strongly recommends POLST forms be in a unique field/tab that can be accessed instantly, ideally in a single click.

What else is it important to know about POLST?

POLST orders honor patients following their religious values. For example, the POLST form allows Catholics to make decisions consistent with the United States Conference of Catholic Bishops *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (2009) and ensures that those decisions will be honored in an emergency and across care transitions.

In general, the POLST form enables physicians to order treatments patients want and to direct that treatment that patients would not want, including those a patient and his/her health care professional would consider “extraordinary” and excessively burdensome. Further, the POLST form requires that “ordinary” measures to improve the patient’s comfort and food and fluid by mouth, as tolerated, are always provided. The POLST form is actionable and prevents initiation of care the patient does not want and that the patient considers disproportionately burdensome, extraordinary treatment.

POLST orders record patient wishes to have or limit treatment but it is never the intent for the orders to be written with the goal of hastening death. POLST recognizes that allowing natural death to occur is not the same as intentionally shortening life. Some patients near the end of their lives

wish to stop treatments they find burdensome and have the primary focus of the care on their comfort. For these patients, POLST orders for Comfort Measures Only document their wish to step aside from medical treatments and allow nature to take its course. Comfort Measures Only is sometimes referred to as “Allow Natural Death”.

In Oregon all of the hospitals, including the Catholic health systems, participate in the POLST program and use POLST orders to record the wishes of some of those with advanced serious illness under their care. For those patients desiring Comfort Measures Only, the POLST form documents orders to refuse treatments the patient finds overly burdensome in the advanced stage of their illness.

This is in stark contrast to physician-assisted suicide. Not a single Catholic hospital participates in the Oregon Death with Dignity Act, which is the deliberate hastening of death. Though this Act and POLST both came to fruition first in Oregon, there is no relationship between them. The POLST Program is completely separate from “death with dignity” and POLST forms do not allow orders to be written for medication with the goal of hastening death.

What other resources are there regarding POLST?

The National POLST Paradigm website (www.polst.org) has additional information, including a variety of videos, POLST forms and educational materials, FAQs and resources. It has citations of the research done about or related to POLST and provides materials for states participating in the POLST Paradigm Program, such as the POLST Quality and Research Toolkit (PQRsT). This toolkit was designed to facilitate the study and improvement of POLST programs through data collection and analysis. The PQRsT consists of 30 instruments that have been created to study POLST for research or quality improvement projects, along with related research materials. POLST programs and researchers who have studied POLST programs have generously shared the instruments in the PQRsT in order to benefit POLST programs nationwide. Each instrument is paired with a summary, which provides more information on utilizing the instrument in data collection.

¹ POLST is known by different names in different states, including MOLST (Medical Orders for Life-Sustaining Treatment), MOST (Medical Orders for Scope of Treatment), POST (Physician Orders for Scope of Treatment), LaPOST (Louisiana Physician Order for Scope of Treatment), COLST (Clinician Orders for Life-Sustaining Treatment), IPOST (Iowa Physicians Orders for Scope of Treatment), SMOST (Summary of Physician Orders for Scope of Treatment), TPOPP (Transportable Physician Order for Patient Preference), and SAPO (State Authorized Portable Orders). For simplicity, the term POLST is used when referring to POLST Paradigm forms or programs in general.

² POLST Request for Endorsement Program Status Form; Item 9 under “Form Information”.

³ Hickman, Susan E. et al, (2010). “A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program.” *Journal of the American Geriatric Society* 58:1241–1248.