### **POLST News Conference**

April 18, 2017 Pennsylvania State Capitol Media Center

### **Speakers List**

Sen. Gene Yaw

Sen. Yaw was first elected to represent the 23rd Senatorial District in November 2008.

Rep. Bryan Cutler

Rep. Cutler was first elected to the Pennsylvania House of Representatives in 2006 and began serving as the majority whip in 2015.

### Alexander Nesbit, MD

Dr. Nesbit is a member of the Pennsylvania Medical Society who was part of a workgroup that drafted POLST legislation. He practices family and geriatric medicine in Williamsport.

### Daniel Kimball, MD

Dr. Kimball is a member of the Pennsylvania Medical Society who was part of a workgroup that drafted POLST legislation. He is a retired palliative care and internal medicine specialist from Wyomissing.

For interviews, members of the media can contact the Pennsylvania Medical Society via Chuck Moran, Director of Media Relations, (717) 558-7820, cmoran@pamedsoc.org.



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### News Release

CONTACT: Chuck Moran, Pennsylvania Medical Society, (717) 558-7820 FOR IMMEDIATE RELEASE: April 18, 2017

### Statement: POLST legislation would ensure care is consistent with patients end-of-life preferences

Today, the Pennsylvania Medical Society (PAMED) stood with Sen. Gene Yaw (R-23) and Rep. Bryan Cutler (R-Peach Bottom) to promote an upcoming bill which would codify the "Pennsylvania Orders for Life Sustaining Treatment (POLST)." POLST helps patients with more advanced illness or frailty express their health care wishes, either personally or through a surrogate decision maker, for issues likely to emerge given the patient's current medical condition. The following is a statement on POLST from Charles Cutler, MD, president of PAMED and a practicing physician in Montgomery County.

Many of us want peace of mind during our final days on this earth. Not only is it good for patients, but also for families caring for loved ones who are near the end of life. Unfortunately, without the appropriate conversation between the patient and health care practitioner about treatment options and the use of a standardized POLST form, end-of-life treatment wishes can be unclear and possibly not followed; thus, creating difficult situations for everyone involved.

In Pennsylvania, efforts are underway to help ensure that the health care wishes of patients nearing the end of their lives are honored through the development and codification of "Pennsylvania Orders for Life Sustaining Treatment (POLST)."

POLST is voluntary and differs from advance health care directives in it makes clear an individual's wishes regarding treatment measures via a POLST form, which includes one or more medical orders that are applicable across all health care settings—thereby applicable in emergency medical services, health care facilities, and home care and hospice settings.

POLST is appropriate for individuals with serious illnesses or frailty when their health care practitioner would not be surprised if they died within the next year. POLST is not recommended for healthy individuals or individuals with stable, even if chronic, medical conditions and years of life expectancy.

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The efforts on this issue at the state capitol should be noted. A broad coalition of stakeholders including PAMED were involved in drafting POLST legislation. The coalition met and addressed a wide variety of issues that were of concern to each stakeholder group. Sen. Gene Yaw and Rep. Bryan Cutler should applauded for their willingness to take on this issue on behalf of the broader stakeholder group.

PAMED supports this upcoming legislation, and encourages our legislature to take the appropriate action to ensure terminally ill patients receive care that is appropriate and consistent with their wishes.

# # #

The Pennsylvania Medical Society was founded in 1848. To learn more about PAMED, visit its web site at www.pamedsoc.org or follow on Twitter @PAMEDSociety. Members of the media are encouraged to follow Chuck Moran on Twitter @ChuckMoran7. Dr. Cutler can be followed on Twitter via @PAMEDPrez.

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### SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

To follow these orders, an EMS provider must have an order from his/her medical command physician



### Pennsylvania Orders for Life-Sustaining **Treatment (POLST)**

Last Name		
First/Middle Initial	 	-
Date of Birth	 	

Relationship (write "self" if patient)

FIRST follow these orders, THEN contact physician, certified registered nurse practitioner or physician assistant. This is an Order Sheet based on the person's medical condition and wishes at the time the orders were issued. Everyone shall be treated with dignity and respect. CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing. Α Check **CPR/Attempt Resuscitation** DNR/Do Not Attempt Resuscitation (Allow Natural Death) One When not in cardiopulmonary arrest, follow orders in B, C and D. MEDICAL INTERVENTIONS: Person has pulse and/or is breathing. COMFORT MEASURES ONLY Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer if comfort needs cannot be met in current location. LIMITED ADDITIONAL INTERVENTIONS Includes care described above. Use medical treatment, IV fluids and B cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. Check **Transfer** to hospital if indicated. Avoid intensive care if possible. One FULL TREATMENT Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer** to hospital if indicated. Includes intensive care. Additional Orders ARTIFICIALLY ADMINISTERED HYDRATION / NUTRITION: **ANTIBIOTICS:** Always offer food and liquids by mouth if feasible No antibiotics. Use other measures to relieve symptoms. No hydration and artificial nutrition by tube. C D Determine use or limitation of antibiotics when Trial period of artificial hydration and nutrition by tube. infection occurs, with comfort as goal Check Check One Use antibiotics if life can be prolonged Long-term artificial hydration and nutrition by tube. Additional Orders Additional Orders SUMMARY OF GOALS, MEDICAL CONDITION AND SIGNATURES: Patient Goals/Medical Condition: Discussed with ☐ Patient Parent of Minor Health Care Agent ☐ Health Care Representative Court-Appointed Guardian Other: E By signing this form, I acknowledge that this request regarding resuscitative measures is consistent with the known Check desires of, and in the best interest of, the individual who is the subject of the form. One Physician /PA/CRNP Printed Name Physician /PA/CRNP Phone Number Physician/PA/CRNP Signature (Required): Signature of Patient or Surrogate

PaDOH version 10-14-10

Signature (required)

Name (print)

### SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED Other Contact Information Surrogate Relationship Phone Number Health Care Professional Preparing Form Preparer Title Phone Number Date Prepared

### **Directions for Healthcare Professionals**

Any individual for whom a Pennsylvania Order for Life-Sustaining Treatment form is completed should ideally have an advance health care directive that provides instructions for the individual's health care and appoints an agent to make medical decisions whenever the patient is unable to make or communicate a healthcare decision. If the patient wants a DNR Order issued in section "A", the physician/PA/CRNP should discuss the issuance of an Out-of-Hospital DNR order, if the individual is eligible, to assure that an EMS provider can honor his/her wishes. Contact the Pennsylvania Department of Aging for information about sample forms for advance health care directives. Contact the Pennsylvania Department of Health, Bureau of EMS, for information about Out-of Hospital Do-Not-Resuscitate orders, bracelets and necklaces. POLST forms may be obtained online from the Pennsylvania Department of Health. <a href="https://www.health.state.pa.us">www.health.state.pa.us</a>

### **Completing POLST**

Must be completed by a health care professional based on patient preferences and medical indications or decisions by the patient or a surrogate. This document refers to the person for whom the orders are issued as the "individual" or "patient" and refers to any other person authorized to make healthcare decisions for the patient covered by this document as the "surrogate."

At the time a POLST is completed, any current advance directive, if available, must be reviewed.

Must be signed by a physician/PA/CRNP and patient/surrogate to be valid. Verbal orders are acceptable with follow-up signature by physician/PA/CRNP in accordance with facility/community policy. A person designated by the patient or surrogate may document the patient's or surrogate's agreement. Use of original form is strongly encouraged. Photocopies and Faxes of signed POLST forms should be respected where necessary

### **Using POLST**

If a person's condition changes and time permits, the patient or surrogate must be contacted to assure that the POLST is updated as appropriate.

If any section is not completed, then the healthcare provider should follow other appropriate methods to determine treatment.

An automated external defibrillator (AED) should not be used on a person who has chosen "Do Not Attempt Resuscitation"

Oral fluids and nutrition must always be offered if medically feasible.

When comfort cannot be achieved in the current setting, the person, including someone with "comfort measures only," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).

A person who chooses either "comfort measures only" or "limited additional interventions" may not require transfer or referral to a facility with a higher level of care.

An IV medication to enhance comfort may be appropriate for a person who has chosen "Comfort Measures Only."

Treatment of dehydration is a measure which may prolong life. A person who desires IV fluids should indicate "Limited Additional Interventions" or "Full Treatment.

A patient with or without capacity or the surrogate who gave consent to this order or who is otherwise specifically authorized to do so, can revoke consent to any part of this order providing for the withholding or withdrawal of life-sustaining treatment, at any time, and request alternative treatment.

### **Review**

This form should be reviewed periodically (consider at least annually) and a new form completed if necessary when:

- (1) The person is transferred from one care setting or care level to another, or
- (2) There is a substantial change in the person's health status, or
- (3) The person's treatment preferences change.

### **Revoking POLST**

If the POLST becomes invalid or is replaced by an updated version, draw a line through sections A through E of the invalid POLST, write "VOID" in large letters across the form, and sign and date the form.



### Pennsylvania Orders for Life-Sustaining Treatment (POLST) Frequently Asked Questions

### What is the POLST Program?

POLST is a voluntary process that:

- Translates a patient's goals for care at the end of life into medical orders that follow the patient across care settings;
- Consists of physician orders that are based on a patient's medical condition and his/her treatment choices as established in communication between the patient or the legal medical decision-maker and a health care professional;
- Is designed to improve the quality of care people receive at the end of life by turning patient goals and preferences for care into medical orders.

While the program is known by different names elsewhere, in our state POLST stands for "Pennsylvania Orders for Life-Sustaining Treatment".

### For whom is a POLST form appropriate?

Use of the POLST form is recommended for persons who have advanced chronic progressive illness and/or frailty, those who might die in the next year or anyone of advanced age with a strong desire to further define their preferences of care in their present state of health. To determine whether a POLST form should be encouraged, clinicians should ask themselves, "Would I be surprised if this person died in the next year". If the answer is "No, I would not be surprised", then a POLST form is appropriate. Unless it is the patient's preference, use of the POLST form is not appropriate for persons with stable medical or functionality problems who have many years of life expectancy.

### May a health care provider (hospital, nursing home, hospice, other) require completion of a POLST form for all patients?

No. As stated above, use of the POLST form is completely voluntary and completed only after a discussion of
choices between a patient or his/her legal decision-maker and physician. However, facilities may choose to use the
POLST form to document Do-not-Resuscitate vs. full code status for all patients, including those less seriously ill.

### Is POLST an advance directive?

No, the POLST form is NOT an advance directive (i.e., living will or health care power of attorney). A POLST form represents and summarizes a patient's wishes in the form of medical orders for end-of-life care. The POLST form is designed to be most effective in emergency medical situations.

### Is an advance directive required in order to have a POLST?

No, an advance directive is not required for the completion of POLST. The POLST is an instrument that complements an advance directive. An advance directive, in which a healthcare agent is appointed, allows for the designated agent to be engaged in care planning and healthcare decision-making even when a patient is no longer able to be involved in his/her treatment choices. It is recommended that people with advanced illness and/or advanced frailty have both an Advance Directive and a POLST form.

### • Can a POLST form be completed following discussion with someone other than the patient?

Yes, a POLST form can be completed based on a patient's treatment choices as expressed by a health care agent, guardian, health care representative or parent of a minor (legal decision-maker).

### Are there any limitations on a POLST form completed by someone other than the patient?

Yes. Neither a health care representative nor a guardian of the person may decline care necessary to preserve life unless the patient is in an end-stage medical condition or is permanently unconscious. Only a competent patient or a health care agent authorized by a health care power of attorney may decline such care. In addition, if the health care decision-maker is a court appointed guardian of the person, the court order should be examined to determine whether the order of appointment specifically deals with health care decision-making. If it does not specify powers regarding health care, particular care should be exercised to discuss the completion of the POLST with any other available family members, and if there is disagreement, a court order may be advisable.

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### Pennsylvania Orders for Life-Sustaining Treatment (POLST) Frequently Asked Questions

### What are the requirements for a POLST form?

The POLST form at a minimum must include the patient name, resuscitation orders (Section A) and signature of a physician, physician assistant or certified registered nurse practitioner (Section E). A physician countersignature is required for physician assistant signed forms within ten days or less as established by facility policy and procedure. Sections B, C and D are optional.

### How and when does one review and update a POLST Form?

The POLST form should be reviewed if (1) the patient is transferred from one care setting or care level to another, (2) there is a substantial change in patient health status, or (3) the patient's treatment preferences change. The patient (or person completing the form on behalf of the patient) can also identify when to review the POLST form: closeness to death, extraordinary suffering, improved condition, advanced progressive illness, and/or permanent unconsciousness. An emergency room visit or inpatient hospitalization calls for a review. A person with capacity or the legal decision-maker of a person without capacity can always ask for review or alternate treatment.

### Can a patient revoke a POLST?

Yes. Should a patient revoke a POLST, "VOID" should be written on the front side of the form. A new form can then be completed, but a new POLST is not required.

- Can a copy of the POLST form, rather than the original, accompany a transferring patient?
  - Yes, a copy of the POLST form should be accepted when it is sent with the patient. It is recommended that the copy be made on pulsar pink paper.
- If a nursing home patient with a POLST and an advance directive is being transferred, is the advance directive also sent along with the POLST?

Yes, it is important that the treating facility have all available information including the POLST and advance directive.

- Does one document, the advance directive or POLST, supersede the other?
  - No, ideally the values expressed on the advance directive do not conflict with the medical orders on the POLST. One document does not necessarily supersede the other. If there is conflict between the two instruments, then it is best to amend the one that is not representative of the patient's values and choices for medically indicated treatments.
- What is recommended if the advance directive and the POLST conflict?

The usual process is to carefully elicit patient values from the patient or legal decision-maker, and making sure the POLST is consistent with these values. If in crisis and goals of care are not clear, then provide a higher level of care until more information is known.

- Who is responsible to assure the POLST and advance directive are not in conflict?
  - Ultimately it is the attending physician. It would also be the responsibility of the physician's agent who is helping to complete the document (Nurse or social worker at nursing home, for example).
- Does a DNR order imply that a patient does not want treatment?
  - No, a DNR order is only a decision about CPR and does not relate to any other treatment. An informed patient may recognize the futility of CPR in the presence of advanced or serious illness and may request a DNR order. However, based on their goals for care, the patient may wish to receive further treatment.
- How does the POLST program ensure incapacitated individuals are not harmed by the POLST?
  - The POLST is specifically designed to assure that an individual's treatment choices for end-of-life care are respected whether the choices are full or limited treatment or comfort measures only. The orders on the form are based on a patient's medical condition and his/her treatment choices. <u>Use of the POLST form is completely voluntary</u>. A POLST form is completed only after a discussion of end-of-life choices between a patient or his/her legal decision-maker and physician.

## Information on POLST

for information about POLST. healthcare professional is the best resource Your doctor, nurse, social worker or other loved one, talk to your healthcare provider. If you think a POLST is right for you or your

found at: Additional information about POLST can be

- www.aging.pitt.edu/professionals/resources-
- www.polst.org

You may also contact:

**POLST Coordinator** Marian Kemp, RN

Coalition for Quality at the End of Life

E-mail: papolst@verizon.net



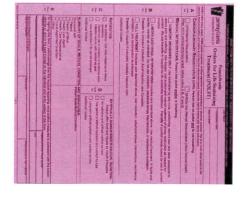
Coalition for Quality at the End of Life Pittsburgh, PA 15222-3922 650 Smithfield St # 2400 Centre City Tower (CQEL)



**Patients and Families** Information for

Do you or a loved one have a serious health condition?

doctors, nurses and other healthcare treatment choices are honored near POLST form to help assure that your Make your wishes known to your providers. They can complete a the end-of-life.



Life-Sustaining Treatment (POLST) Form The Pennsylvania Orders for

### What is POLST?

The POLST Form is a document that helps doctors, nurses, healthcare facilities and emergency personnel honor patient wishes regarding life-sustaining treatments in emergency situations.

The POLST form is voluntary and recommended for persons who have advanced chronic progressive illness and/or frailty, those who might die in the next year or anyone of advanced age with a strong desire to further define their preferences of care in their present state of health.

Even for those who have an advance directive, a POLST form is recommended.

The POLST form includes information

- preferences for resuscitation
- medical conditions
- preferences on the use of antibiotics
- preferences for artificially administered fluids and nutrition

The POLST form is completed by a doctor or other healthcare provider only after a discussion of end-of-life choices with a patient or his or her legal decision-maker. The form is then signed by the doctor, nurse practitioner or physician assistant and the patient or his or her legal decisionmaker. It then becomes a medical order that is understood and followed by other healthcare professionals.



# In what setting is the POLST form used?

The POLST remains with and travels with the patient between care settings, home, hospital, long-term care or any other

## Where is the POLST form kept?

In the home, the form is kept in a prominent place, such as the refrigerator, a bedside table or medicine cabinet. For patients who are in a healthcare facility, the form is kept in the medical chart.

# What are some of the terms used when POLST is discussed?

### Artificial Nutrition

When a patient can no longer eat or drink by mouth, liquid food can be given to them by tube

# Cardiopulmonary Resuscitation (CPR)

Attempts to restart breathing and the heartbeat of a person who is not breathing and who has no heartbeat. Typically this involves "mouth-to-mouth" and forceful pressure on the chest. It can also involve electric shock or a plastic tube being placed in the windpipe to assist breathing.

### Comfort Measures

Care undertaken with the primary goal of keeping a person comfortable, rather than prolonging life. With a POLST, a person who requests "comfort measures only" would be transferred to a hospital only if needed for his or her comfort.

## Intravenous (IV) Fluids

Fluids administered through a small plastic tube directly into a vein, typically on a short-term basis.

## Mechanical Ventilation/Respiration

The pumping of air in and out of the lungs through a tube in the throat. Used when a person is not able to breathe on his or her

### Tube Feeding

Short-term basis: Fluids and liquid nutrients can be given through a tube in the nose that goes into the stomach.

Long-term basis: a tube inserted through a surgical procedure directly into the stomach.



**POLST in PA** 

Solid - Implemented Striped - Developing

### SOUNDING BOARD

### Lessons from Oregon in Embracing Complexity in End-of-Life Care

Susan W. Tolle, M.D., and Joan M. Teno, M.D.

Under the incentives of fee-for-service Medicare, the utilization trends among persons with chronic progressive medical illness include more care in the intensive care unit (ICU), more hospitalizations, and often late or no referrals to hospice care (Fig. 1).1 These utilization patterns are strikingly different in Oregon, the second state to legalize an advance directive and the first state to legalize assisted dying. In response to this legislation, the Oregon Health and Science University Center of Ethics embraced a policy of neutrality as a public position on assisted dying while using the vote as a wake-up call to the medical community to improve end-of-life care more broadly.<sup>2,3</sup> The center has served as a convener of statewide education and supported the creation and dissemination of the Physician Orders for Life-Sustaining Treatment (POLST) Program.4 The POLST Program allows patients with advanced illness and frailty and their health care professional to document patients' preferences regarding the use of life-sustaining treatment with medical orders that can be honored across settings of care.5 The POLST form (see the Supplementary Appendix, available with the full text of this article at NEJM.org) is designed to ensure that patients' preferences to use or limit treatment are equally honored.6

Persons dying in Oregon are less likely to be hospitalized and more likely to use hospice services at home than are patients in Washington and the rest of the United States. We selected the state of Washington for comparison with Oregon because of its close proximity and comparable demographic features. Washington has similar liberal political views and racial composition of decedents, has an established POLST Program, and has also legalized assisted dying.<sup>7</sup> In 2013, nearly two thirds of Oregonians who died did so at home, whereas only 39.6% of persons in the rest of the United States who died did so at home. The rate of ICU use in the last 30 days of life in

Oregon was 18.2%, as compared with 23.0% in Washington and 28.5% in the rest of the United States (Fig. 1). Patients who were hospitalized in the last month of life were more likely to be discharged home in Oregon than in Washington or the rest of the United States (73.5% in Oregon vs. 63.5% in Washington and 54.2% in the rest of the United States).

It is difficult to disentangle the reasons behind the differences in care at the end of life in Oregon as compared with other states, but we think that the differences in care reflect the complexity and intensity of the initiatives developed in coordination with the POLST Program. Although Washington also has an established POLST Program, it has not developed educational materials, coordinated cross-system conferences. conducted research, and maintained a statewide registry, as extensively as Oregon has done. In this article, we describe the policy changes and educational efforts to improve end-of-life care that were launched in Oregon at the levels of state government and local health systems (Table 1). (Fig. S1 in the Supplementary Appendix provides a timeline for the initiative in Oregon.) We will also outline some of the lessons learned from the successes in Oregon. Transforming care near the end of life requires a willingness to forgo the temptation of an easy fix by merely implementing the use of the POLST forms. Until we embrace the complexity of this social interaction, the need for multifaceted interventions. and the application of public health strategies, we will fail to make the needed improvements in care at the close of life.

Advance care planning and the use of POLST forms is important, but if patients' goals are not linked to actionable care plans that are supported by local health care systems and state regulation, many patients who wish to remain at home will die intubated in the hospital for all the reasons the current system fails them.<sup>8,9</sup> Consider

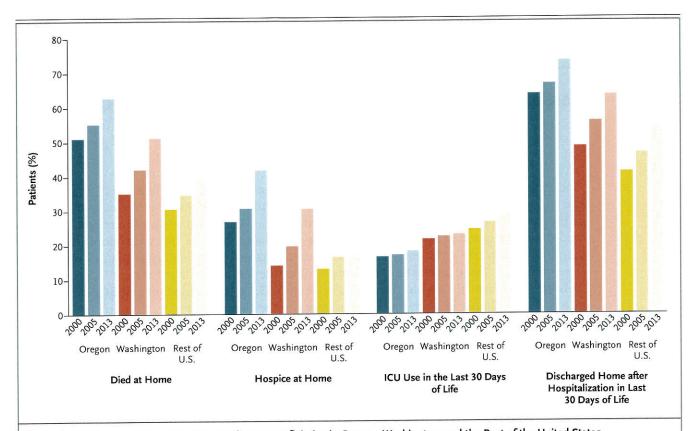


Figure 1. Deaths among Fee-for-Service Medicare Beneficiaries in Oregon, Washington, and the Rest of the United States.

The graph shows changes between 2000, 2005, and 2013 in the rates of death among fee-for-service Medicare beneficiaries in Oregon, Washington, and the rest of the United States (U.S.). Shown are the proportions of patients who died at home, who received hospice services at home, who received care in an intensive care unit (ICU) during the last 30 days of life, and among patients who were hospitalized during the last 30 days of life, the proportion who were discharged home.

the following composite case story, which illustrates the complexity, breadth, and depth of systems changes that are needed to ensure that patient preferences are consistently honored.

Edith, an 84-year-old white woman with oxygen-dependent chronic obstructive pulmonary disease, completed a POLST form after being counseled by her primary care physician. The form recorded her wishes that she would not be resuscitated or placed on mechanical ventilation. Despite having 24-hour care at home, she fell and fractured her hip. Emergency medical services (EMS) providers were called, and they accessed her POLST form from the Oregon POLST Registry. Edith was transported to a regional trauma center, where her condition deteriorated and there were concerns that she might need to be intubated. Per protocol, the trauma surgeon was notified of her POLST form specifying the do-not-resuscitate orders and the use of comfort measures only by accessing documentation in the POLST Registry that provided clear evidence of her wishes. Edith was cared for by the palliative care team in the emergency department with the use of opiates to relieve her pain and dyspnea, and she was transferred home with hospice services, where she died, comfortable and surrounded by her family. The key interventions in Edith's care that made her death at home possible included strategic interventions at four levels that are aimed at the individual person and their health care professional, the local health care system, cross health system collaboration, and state government (Table 1).

### INTERVENTIONS AIMED AT INDIVIDUAL PERSONS

Extensive local media coverage, public education, and the experience of friends in her community made Edith and her family aware of their options for advance care planning and support for

Table 1. Key Interventions and Effects on Care of Patient	
Level and Intervention	Application to Edith's Experience of Dying
Individual persons and their health care professionals	
Public education through media coverage and local community events	Raises Edith's awareness to complete a POLST form with her health care provider and discuss plans with daughter
Education of health care professionals about communication and completion of POLST forms	Facilitates sensitive communication and proper completion of the POLST form as well as creation of an action plan to honor the patient's preferences
State government	
Creation of Registry and enactment of regulation that allow EMS to honor POLST forms	Ensures that EMS is able to obtain Edith's POLST form and honor those wishes in the field
Quality monitors at the Registry in place to ensure the accurate completion of POLST forms	Ensures that POLST forms are completed correctly
Local health care system	
Change in culture to support health care professionals in counseling patients and the completion of the POLST forms	Values the time spent in the completion of the Edith's POLST form
Registry raises awareness to review the POLST forms in medical decision making; EMR of the health care system provides an alert that made the health care professionals aware of the patient's POLST form	Ensures that Edith's POLST form is available to the surgeon, who decides with Edith's daughter not to operate; in her medical record, EMR prominently provided an alert that the made all health providers aware of the patient's advance directive
Arrangement by local hospice for services for a dying person at home in transition from an acute care hospital	Ensures that Edith receives home hospice services that allow her to die at home, comfortable and surrounded by her family
Local champions and state coalition	
Ability to solve system and regulatory barriers nimbly and quickly	Champions played a key role in changing regulations to allow EMS to honor the POLST form and enhance hospice capacity to take admissions from the emergency depart- ment to home
Development of educational tools and identification of patients' stories	Enables design of educational interventions and hosting of regional conferences
Coordination of the implementation of systems change as a result of quality-improvement efforts	Promotes collaboration and conduct quality-improvement efforts across various settings of care

<sup>\*</sup> Shown are key interventions, such as policy changes and educational efforts at various levels of local systems and government, to improve end-of-life care in Oregon and their effects on the care of a case-study patient (Edith). EMR denotes electronic medical record, EMS emergency medical services, and POLST Physician Orders for Life-Sustaining Treatment.

person-centered care. The Center for Ethics has hosted more than 200 conferences for health care professionals about ethics, palliative care, and communication skills. The development of educational resources such as the *Understanding POLST* video and lay brochures made talking with her primary care professional a process rather than a single discrete event (Fig. S1 in the Supplementary Appendix). Approximately 8 years before her death, Edith told her doctor that she wanted her daughter to be her surrogate. When Edith required oxygen support at home, her doctor encouraged her to complete an advance directive. At a visit 1 month before her death, Edith talked about never wanting to be intubated again, and

she and her doctor completed a POLST form after she and her daughter watched the *Understanding POLST* video with a clinic social worker. Edith's primary care physician counseled Edith about her prognosis and treatment options, and through shared decision making they documented her treatment goals. The physician then worked with Edith's family to develop a plan that would allow her to remain at home with 24-hour care. The completion of her POLST form was not a single event but was part of a multistep process that was facilitated by her primary care team. <sup>12</sup> Key to Edith's care was that her EMS providers and all the members of her primary care team had been trained in how to record preferences for

care accurately on the POLST form and in the importance of honoring those preferences.

### INTERVENTIONS AT THE LOCAL HEALTH CARE SYSTEM AND STATE GOVERNMENT LEVELS

The process of creating and documenting POLST orders serves as a tool to record conversations regarding goals of care, but in isolation this process is not sufficient to ensure that Edith's wishes will be honored once she leaves her home. The creation of systems to ensure that health care professionals are aware of the directives and that EMS providers are able to honor those wishes is equally important. In Edith's case, the ability of EMS providers and the local health care system to obtain and honor her POLST form was key. In Oregon, state regulations allow EMS providers to follow the directives of a POLST form and to honor a person's wishes by not intubating or resuscitating the patient.13 Similarly, although the physician who signed Edith's POLST form did not have admitting privileges at the trauma facility, Oregon Medical Board regulations ensured that the orders could be honored.14 The traumasystem protocol enabled the POLST form to be obtained for the surgeon and other health care professionals to use in decision making.

In addition, Edith's physician was supported by a culture that valued team collaboration, and the health care team had participated in systems integration of educational materials to enhance patients' participation in goals-of-care planning, which optimized Edith's understanding and used the physician's time effectively. The electronic medical record (EMR) tagged the POLST forms, linking them to the patient-information header that alerts all the members of the health care system to the presence of the patient's POLST form.15 A separate EMR tag confirmed the presence of the advance directive, and each form could be viewed with a single click, making her wishes clear as Edith moved from one care setting to another.

### LOCAL CHAMPIONS AND STATE COALITION

Champions who are part of state coalitions can be nimble and help to address key leverage points in ensuring that patients' wishes are honored as

transitions occur across care settings and that persons wishing to die at home have excellent palliation with hospice providers who are able to respond to the need for timely referrals. Education is important both within health systems and statewide, but local champions also play a vital role in removing system barriers, particularly in addressing barriers across care settings. The timeline in Figure S1 in the Supplementary Appendix shows a few of the dozens of interventions that have been facilitated by champions and coalition members. The development of educational tools and the removal of barriers are not enough. Even with an exemplary advance care planning process in place, if the patient and family do not have timely access to home hospice care, the advance care planning process may be of little value. If hospice had not been able to enroll Edith within 24 hours after her discharge, it would not have been possible for her to be discharged home from the emergency department observation unit.

Narrative stories are important in helping stakeholders understand the effect of each change in improving care, and these stories have proved to be vital to public education and media engagement. However, anecdotal case reports are not sufficient for the evaluation of success. We also need to track quality rigorously and to prevent unintended consequences. Oregon is currently using version 11 of the POLST form. Changes are made to the form by the statewide POLST Program coalition after extensive review to respond to new research data and changes in statutes or regulations and to address the use of new medical treatments. End-of-life champions in Oregon advocate broadly for improvements in best practices. When data showing that tube feeding did not extend life or enhance comfort in persons with advanced dementia,16-19 broad and far-reaching public health efforts were implemented in the 1990s and were used to discontinue the practice. The effectiveness of these efforts is associated with remarkably low rates of tubefeeding use in Oregon, dating back to 2000.20

Finally, to sustain change from the beginning requires a stable financial base, leadership, and an administrative home. Although private philanthropy funded the development of the innovative POLST Program in Oregon, the Registry operations are now funded by the state, and the Oregon POLST Program is building an endowment

to sustain operations. The Center for Ethics in Health Care, which administers the Oregon POLST Program and coordinates efforts to improve end-of-life care statewide, does not accept funding from health care industry sources. Important to the success of this work is the public trust that efforts are being made to honor patients' preferences and improve quality rather than to cut costs. The public trust can be damaged when incentives appear to have cost savings rather than patients' wishes as their primary goal (e.g., Liverpool Care Pathway of the Dying Patient and "death panels"). 21

Without a complex, multifaceted, and longitudinal set of interventions, Edith would have been intubated and would probably have died in an ICU, and the high rate of death at home with hospice in Oregon might look more like the rate in Washington (Fig. 1). Although Oregon has made great strides, our systems are far from perfect. One-click access to the POLST form in the EMR is not yet available in most hospitals. We are aware that finding Edith's POLST form was important to her achieving her wishes, but it was not sufficient. Replication of the experience in Oregon requires the development and adoption of interventions at every step in this complex medical and social interaction. With alignment of our health care systems incentives for value (i.e., quality and health care expenditures) over volume of services, fundamental change and improvement are within our reach. We must embrace the complexity, develop dynamic and multifaceted interventions, track the quality of care, and embed these interventions in the local and national health care culture, while avoiding incentives that might undermine the public trust and integrity of the process.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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