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The Center for Public Policy and the Social Sciences

Policy Research Shop

POLST REGISTRIES

Supporting End of Life Decision Making

Presented to the New Hampshire House of Representatives,
Committee on Health, Human Services and Elderly Affairs

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EXECUTIVE SUMMARY

With an aging population and ballooning medical expenditures, end of life care has become an issue of prime importance for the State of New Hampshire and the country as a whole. The Physician Order for Life Sustaining Treatment (POLST) paradigm has become a particularly influential approach to end of life treatment. POLST is focused on forms that allow doctors to transform patients' wishes into medically actionable orders so that a patient's wishes are respected even if that patient loses the ability to communicate his or her treatment preferences. Integral to the success of the POLST paradigm is healthcare provider's access to POLST forms. Seven states have created or hope to create in the near future registries that can store POLST forms to make the information easily accessible in case of an emergency. This report analyzes the various state registries in order to give an overview of how POLST functions in each of those states.

1. INTRODUCTION

1.1 WHAT IS POLST?

The POLST programs provide terminally ill patients with the ability to maintain decision making ability over their treatment. POLST allows patients to transform their medical wishes into brief, actionable physician orders. The most important manifestation of POLST is through brief forms that allow the patient to record his or her wishes. These forms are then kept with the patient and are often also recorded in a centralized registry. They are used by healthcare providers when making treatment decisions.

POLST forms usually record patient wishes in several specific areas. First is what to do if the patient's heart has stopped and he or she is no longer breathing. A do not resuscitate (DNR) order would prevent healthcare providers from administering cardiopulmonary resuscitation (CPR). Such an order could be desirable if the patient is unlikely to regain a good quality of life if CPR is successful. Another important part of the form is what sort of care a patient is provided. Forms usually allow the patient to choose comfort care, limited medical interventions, and full treatment. Comfort care focuses on the relief of pain and symptoms. Comfort care generally seeks to avoid transferring the patient to a hospital, and the patient will only be transferred if comfort needs cannot be met at home. The limited medical interventions option provides patients with medication orally or by IV, provides less invasive airway support, and other appropriate medical treatments. It avoids the most extreme measures like intubation or mechanical ventilation. It allows transfer to the hospital if indicated by the medical situation, but it avoids the intensive care unit. Patients are often not allowed to choose that they prefer CPR and limit care to choose to limit care to comfort measures only. Terminally ill patients in cardiac arrest are in a frail state, and if CPR is successful, the patient will require intensive care. As a result, it is more medically practical to avoid administering CPR in order to allow the



patient to avoid the intensive care unit. Full treatment provides all treatment necessary to maintain life for as long as possible. POLST also normally gives patients control over some more specific parts of their treatment, for example, the use of antibiotics, intubation, and ventilators (see Appendix A for a sample POLST form).

POLST forms should be differentiated from advance directives. Three key differences stand out:

- 1) Current versus future treatment—POLST provides orders for current treatment whereas an advance directive gives instructions on future treatment.¹ Advance directives are recommended for adults of any age or health conditions. POLST is recommended only for the critically ill and may even be appropriate for children in certain circumstances.
- 2) Doctor's order—An advance directive is not an actionable doctor's order like a POLST form.² POLST forms are usually much briefer than an advance directive, and are medically actionable. The practical relevance of POLST forms is that emergency response personnel will normally respect a POLST form, but will not have time to parse through an advance directive.
- 3) Surrogacy—an advance directive can designate a surrogate to make medical decisions if a patient is unable to make those decisions for him or herself. POLST details the patient's own wishes. POLST forms do nothing to give other decision makers the ability to make a medical decision on the patient's behalf.

1.2 WHAT IS A POLST REGISTRY?

For a POLST program to function properly, healthcare providers must be able to rapidly access information contained in POLST forms in an emergency. The purpose of a POLST registry is to allow healthcare providers to access this information if the form is not available or cannot be located. This is accomplished through the compilation of a database of patients' POLST forms, either electronically or in print. Emergency medical technicians (EMT's) can then access patients' data either through their own portal to the online system or by calling the registry itself. It can be ensured through regular use and maintenance of this registry that patients' wishes are followed and excessive treatment is not prescribed. The states with POLST registry programs are New York, Idaho, Oregon, Utah, Washington, and West Virginia. California also has an incipient registry and is producing highly innovative policies.³

1.3 DEFINITION OF TERMS

1.3.1 Palliative Care

Care with the purpose of relieving pain and suffering. It is designed to make patients as comfortable as possible. Instead of receiving therapy to combat disease or other medical problems, palliative care teaches patients how to live with the illness.



1.3.2 Do Not Resuscitate Order (DNR or DNAR)

It is a legal order written either in the hospital or on a legal form to respect the wishes of a patient not to undergo cardio-pulmonary resuscitation (CPR) or advanced cardiac life support (ACLS) if his or her heart or breathing stopped. In hospital environments, this is sometimes called a “No Code.” It does not affect other treatments, such as pain medicine, other medicines or nutrition.

1.3.3 Advance directive (AD)

It is a legal document which allows patients to specify future treatments and appoint medical decision makers on their behalf if they are unable to make a decision. This includes POLST forms, DNRs and Power of Attorneys. It may also be known as a Living Will, Personal Directive or Advance Health Care Directive.

1.3.4 Power of Attorney for Health Care

It allows a patient to designate an adult, called an ‘agent,’ to make decisions regarding the patient’s health care, including life-sustaining treatments. It goes into effect whenever the patient is incapacitated and unable to make or understand the consequences of health care decisions. The agent may also be known as a ‘legally authorized representative.’

2. STATE PROGRAMS

2.1 CALIFORNIA

2.1.1 Current Status

California has yet to create a registry program, but it has seen success in promulgating the POLST paradigm. In a 2012 UCLA study, the 546 nursing homes that were surveyed reported that 54 percent of residents had a POLST form. The program attributes its success to its outreach to medical leaders and administrators. In addition, California’s POLST form is available in twelve different languages, allowing it to be readily accessible.⁴

2.1.2 Innovation and Challenges

California has yet to create a registry; however, California has already displayed innovation in planning for the eventual creation of a registry. An example of this innovation is California’s idea to have POLST registrants be assigned a scan able form of identification (e.g., a necklace, bracelet, card, or other item). Each of these items would have a design on it that and EMT could scan to directly access that patient’s information, similar to a QR code. This idea utilizes already existent technology. It can maintain privacy by limiting who has access to a patient’s personal information while also guaranteeing access to the patient’s POLST information in less than ten seconds.⁵



One challenge California has encountered is that there is no obvious location for a registry to be housed. California emergency medical services are overseen by 32 different authorities. The state may be forced to construct a centralized registry, independent of any particular agency.⁶

2.2 IDAHO

2.2.1 Implementation and Current Status

Idaho's "POST" system was introduced in 2007, but it was amended in 2012 to expand restrictions on who is allowed to sign POST forms. Idaho's system is designed to be simple and easy to use. Patients submit POST forms via mail, and there is also a seldom used option to submit forms electronically. As of 2012, doctors, nurse practitioners, or physician's assistants can sign the form. Patients can amend their information at any time, and it has been reported that at least 15-20 percent of submitted forms are updates. Submitted forms are entered into an electronic database. Patients who submit forms are mailed a hard copy of their POST form, information about the program, and a special identification card that can be used by an EMT to access a patient's information in an emergency.⁷ (See Appendix B.)

2.2.2 Funding and Oversight

The POST program was developed entirely by the Office of the Idaho Secretary of State. It is also housed, overseen, and maintained by the Office of the Secretary of State. It has proven extremely useful for the program to be overseen by a single entity because it allows use of existing state resources and makes the program easy to modify and maintain. The program is underfunded, and although there is a provision in the law that would allow the state to charge ten dollars per entrant, that provision has yet to be invoked. The registry holds people's living wills in addition to POLST forms. The system is opt-in.⁸

2.2.3 Education and Outreach

The program's lack of funding has resulted in a shortage in education and outreach programs. However, partnerships with AARP and other major stakeholders have helped both to provide some funding for the program to encourage medical professionals to use the system.⁹

2.3 NEW YORK

2.3.1 Background and History

New York's POLST program, Medical Order for Life Sustaining Treatment (MOLST), has been in effect since 2004. It was amended significantly in 2010, when the state passed the Family Healthcare Decisions Act. The major changes due to the Act include addition of provisions for surrogates and the creation of a unified method for guiding patients through discussion about and completion of MOLST forms.¹⁰



2.3.2 Implementation and Functioning

New York's registry is the most electronically advanced of any state's. In Electronic Medical Order for Life Sustaining Treatment (eMOLST), MOLST information is submitted through a standardized electronic form, which is intended to be filled out by a patient and his or her physician as part of a discussion. The discussion is facilitated and guided by an online program, and its goal is to ensure quality discussions between patients and their doctors about end of life care. Doctors are the only medical professionals with the authority to sign and submit a MOLST document, but other medical professionals are permitted to access a patient's forms. Access to forms is strictly monitored. There are four levels of access to patients' information: a patient who can see and edit his or her form, a doctor who can see and edit forms, a nurse, EMT, or other professional who can see but not edit forms, and an overseer whose role is purely administrative and has no need to see personal information. Administrative access is further subdivided based on what type of maintenance a person can perform.¹¹

Currently, MOLST is an opt-in system in New York. It is run by the MOLST Statewide Implementation Team and housed at the Excellus Blue Cross Blue Shield data center in Rochester, but it is expected to transition to the New York Department of Health. It was contractually developed by Fusion Productions. The program is currently funded independently by the state, but it is expected that it will eventually be added to SHIN-NY, a program dedicated to New York state healthcare statistics. There is also a separate registry for advance directives, maintained and operated separately.¹²

2.3.3 Education and Outreach

New York's MOLST program's focus was shifted in 2010 with the passing of the New York Family Health Care Decisions Act. The FHCDA placed emphasis on train-the-trainer doctor education. There is a large focus on education of physicians and other medical professionals about having the conversation with patients and dealing with palliative care in general. The eMOLST system, wherein forms are entered entirely electronically along a guided conversation between a doctor and a patient is intended to ease the strain of the conversation on the doctor. New York attributes much of its success in implementing the MOLST system on its outreach to healthcare administrators and leaders, as well as its innovative technological approach.¹³

2.4 OREGON

2.4.1 Success of the Program and Current Status

Oregon has the oldest and best developed state POLST program. Founded in 1995, the program has grown to encompass over 10 percent of residents over age 65 in some of Oregon's counties. Enrollment has been highest in urban areas and lower in the more sparsely populated eastern half of the state. The Oregon POLST registry stores 100,000 active POLST forms, and receives nearly 4,000 forms a month.¹⁴ Unfortunately, in spite of these high levels of enrollment, Oregon has seen only a few percent increase the

number of deaths that occur at home. Although 70 percent of Americans express a preference to die at home, only 34 percent of deaths in Oregon occur there.¹⁵

Terri Schmidt, MD, MS, director of the Oregon POLST Registry and medical director for Clackamas County, has summarized the success of the Oregon POLST program, “the Oregon POLST Registry provides access to POLST orders 24/7 for EMS, emergency departments and acute care units through a preexisting emergency call center familiar to EMS providers throughout the state. In addition, the Registry fulfills hundreds of non-urgent POLST form requests per year for individuals, long-term care facilities, clinics, health systems, and others during business hours through the Registry office. It has also become an invaluable quality assurance and research tool. Data from the Registry helps guide POLST-related education for health care professionals. Research using the Registry is providing insight into POLST utilization to facilitate continuous quality improvement.”¹⁶

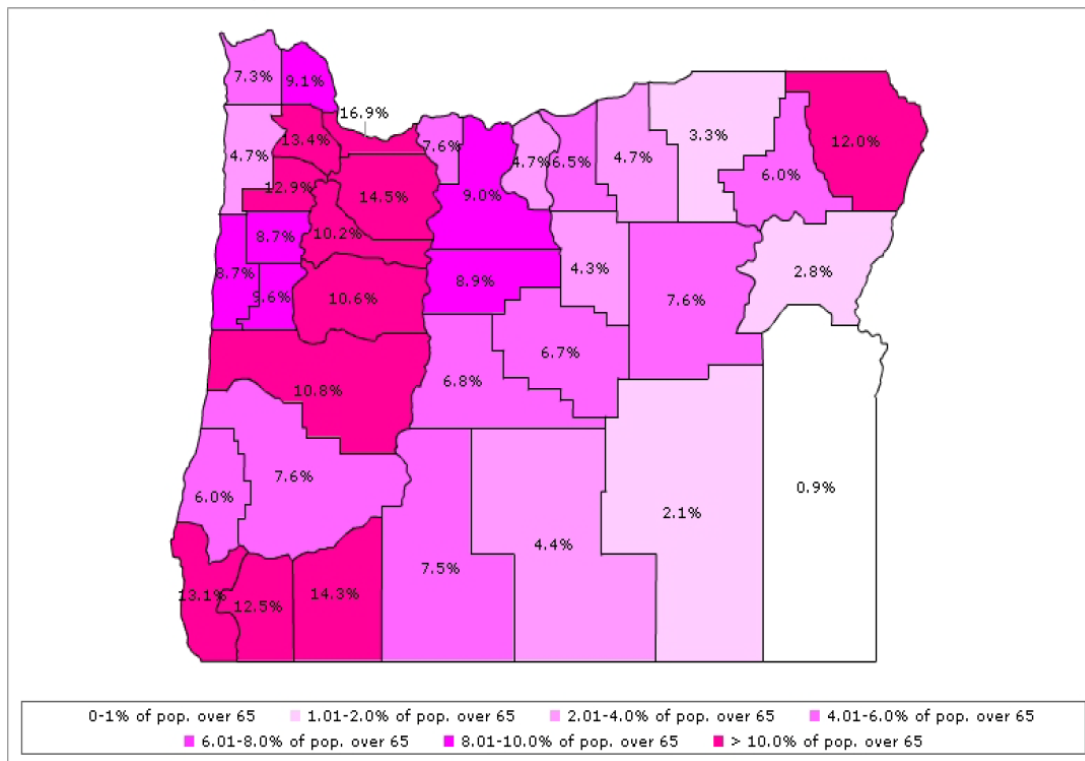


Figure 1. POLST Registrants by County Heat Map¹⁷

2.4.2 Implementation

The Oregon POLST registry is maintained to provide information in two situations: to EMS providers responding to an emergency call and to healthcare providers and long-term care facilities in non-urgent situations.¹⁸ Because of this, the registry has two different methods of responding to information requests. First, specialists at the emergency call center receive calls from receive calls from EMS, emergency departments and acute care units. The specialists then provide POLST information to healthcare providers if there is a match. POLST forms were found for 35.5 percent of urgent POLST



requests in 2012.¹⁹ The registry also handles non-urgent POLST form requests through its business office during regular business hours.

Forms may be submitted via fax, eFax, mail, and electronic secure file transfer. Forms are completed by the patient (or an appropriate surrogate if the patient is unable to sign for themselves), and signed by a healthcare provider. The signer of the form is obligated to submit the completed POLST form unless the patient explicitly opts out. After receiving the forms, the registry begins to process them. The first step is validation.²⁰ During validation, every form is examined to ensure that all necessary components are completed and the selections are medically actionable (for example, a patient cannot choose to receive CPR and limit their treatment to comfort care only). Next, a digital account is made for the patient and the form content is abstracted and manually entered. Once complete, the form and entered data is reviewed, and then the account is activated. The registry is contractually obligated to process and enter forms within ten business days of the forms receipt. The mean time of entry is 1.58 calendar days.²¹

2.4.3 Development and Maintenance

The Oregon POLST registry is funded and overseen by the Oregon Department of Health, but contractually operated by the Oregon Health and Science University.²² The Oregon POLST is supported by state law that officially endorses the registry and requires that all completed POLST forms be submitted to the registry. Although completed forms are required to be submitted unless the patient explicitly opts out, there is no obligation that patients complete a form, or that they even be provided the option to complete one. Unlike some other states, the Oregon registry houses only Oregon POLST forms. It does not store advance directives or living wills.

2.4.4 Education and Outreach

The Oregon POLST program owes much of its success to the level of dedication that its advocates have brought to education and outreach. Since its creation in 1990, the Oregon POLST task force has committed itself to increasing awareness surrounding end of life decision making. It created the nation's first POLST program in 1995, and developed a robust POLST program without state support. It also successfully lobbied for state recognition and funding in 2009. The Oregon POLST task force remains active to this day. Last year the Task Force revised its POLST educational videos, patient brochures and Spanish language resources, and POLST education is regularly conducted across the state.

2.5 UTAH

2.5.1 Implementation

There are three levels of access in Utah's POLST registry system. Healthcare providers, including EMS, have form access.²³ These professionals are permitted to view forms and form information via a secure web system or revoke them if the information is insufficient or unacceptable. Social workers, nurses, physicians, and physician assistants



conduct form preparation. They can prepare new or replacement forms based on conversations with patients or a patient's surrogate. Finally, physicians, nurse practitioners, and physician assistants have signature authority. In addition to form preparation, they are allowed to authorize the final versions of the form with their signature. Although Utah has the ability to complete each step of its POLST program digitally, the program is still encumbered by the requirement that physical forms be submitted.²⁴ Interestingly, Utah recommends POLST forms for adults with strong treatment preferences (e.g., Jehovah's witnesses preference for no transfusions) in addition to those with serious illnesses.

Utah makes a special effort to ensure that forms are located on a patient. Utah encourages every patient with a POLST form to keep a copy of it on their refrigerator. It also provides "life with dignity" bracelets and necklaces that alert EMS personnel to the patients POLST status.

2.5.2 Development and Maintenance

Utah's POLST program operates with a high level of state support. The registry is operated by the Utah Department of Health's Office of Vital Records and Statistics. Early on, the program gained support from administrative changes in Utah's regulations that gave the forms legal consequence and helped raise the program's public profile. In 2005, the POLST form was codified by the state legislation. This legislation formalized state support of the POLST program and created a requirement that certain classes of patients be offered the opportunity to complete a POLST form.

2.5.3 Education and Outreach

Utah's POLST outreach programs have seesawed in the last several years. Formed in 2002 and supported by the Robert Wood Johnson Foundation and Utah Department of Health, Utah POLST began with an extensive education and outreach program.²⁵ The efforts were aimed at securing institutional support via regulatory changes and raising awareness and respect for the form. However, these early efforts were met with only moderate success. Initial funding was quickly exhausted, and because initial regulatory changes had been justified under Utah's Living Will Act, many healthcare providers were unclear regarding the legal significance of the forms and how they differed from a typical advance directive.

In 2005, POLST in Utah received renewed attention. The Special Committee on Aging turned its attention towards end of life care and created a subcommittee to specifically examine POLST. Although previous efforts to create a POLST system were largely defunct at this point, the committee was able to pull together many members from the previous effort. In 2007, the Utah legislature passed the Utah Advance Healthcare Directive Act, which granted POLST recognition as a legal form to be followed by healthcare providers.



2.6 WASHINGTON STATE

2.6.1 Success of the Current Program and Status

In 2000, Washington's Natural Death Act was amended to allow the creation of a POLST registry. HB 1244, passed in 2009, states "The Department of Health shall maintain the statewide health care declarations registry which contains health care declarations made by residents of Washington. The department shall digitally reproduce and store health care declarations in the registry."²⁶ Before the registry ceased operations two years later due to the lack of state funding, only 3,700 documents, of which only 500 were POLST forms, were stored from just over 2,000 Washington Registrants. Although the registry no longer operates, registrants received a lifetime membership that includes ongoing document storage.²⁷ Currently, POLST forms are kept by individuals and are reviewed periodically.²⁸

2.6.2 Implementation

Washington's Department of Health (DOH) contracted the U.S. Living Will Registry to produce the Washington state repository where groups could purchase 'blocks' of user registrations and storage space. The registry included ADs, POLSTs, Powers of Attorney and Mental Health ADs and was accepted statewide in all settings of care, including nursing homes. POLST was housed in the Washington State Medical Association, and the POLST task force was a subcommittee of the Washington End-of-Life Consensus Coalition that met to review and revise the POLST form.²⁹

2.6.3 Development and Maintenance

Only patients and their agents were allowed to submit materials, which were sent to the registry for scanning. Materials were then accessed through a web-based interface, which required patient identifiers and regular site maintenance. The Emergency Medical Response (EMR) System, GroupHealth, was trained to locate POLST forms rapidly and efficiently. The DOH provided a staff member to support and promote provider registrations and oversee submissions and patient confirmation.³⁰

2.6.4 Education and Outreach

Because of limited resources for training and education, the registry was geographically phased in. POLST registration started in Spokane, then all of Eastern Washington before moving to Western Washington and finishing with the greater Puget Sound area. Efforts focused on agreements among leaders of Emergency Medical Services (EMS), hospitals and long-term care centers followed by training 'front-line' personnel. Piloting POLST in small population centers allowed processes to be well developed for larger centers. The registry was not tied to any local or regional, nor was it connected to a clinical care application or process, which decreased its capacity to build awareness and promote usage. Leadership for POLST was fragmented as stakeholders key to POLST's establishment were not involved in oversight and coordination.³¹



2.6.5 Professional Opinions

Bruce Smith, co-chair of the Washington POLST Task Force and member of the Washington End of Life Consensus Coalition, observed, “Washington’s POLST registry faced a number of challenges. Our POLST program was already well established before the registry became available, and people already had their routines established. As an ‘opt-in’ program, the registry required a significant patient identifier for access that was often unavailable in a medical emergency. Only a few patients submitted documents to the registry, so even when providers took the time to check, they were unlikely to find what they needed. Finally, depending on state funding in a time of financial downturn proved risky. To be successful, I think a registry program should be automatic (‘opt-in’) to ensure broad participation, easily accessible, and supported by adequate staff with stable funding.”³²

Judy Citko, Chair of the National POLST Paradigm Task Force, explained, “First, it is impossible to overstate the importance of building a strong coalition of representatives of all the key constituencies -- including healthcare professional organizations, hospitals and health systems, EMS, long-term care, hospice, and others – who are deeply committed to the development and dissemination of the POLST Program. When selecting those partners, it is essential to use caution when including members of advocacy groups with a political agenda that might conflict with the key organizations you need to be part of the coalition. Before considering the launch of a registry, assess the commitment and capability of your coalition to develop a statewide educational effort because this is critical to success. And, finally, when structuring a registry, develop a system that is integrated into the existing health care system and doesn’t rely on patients to opt-in.”³³

2.7 WEST VIRGINIA

2.7.1 Success of the Current Program and Status

In 2002, the West Virginia Health Care Decisions Act was amended to authorize the use of a standardized form – “Physician Orders for Scope of Treatment” or POST. The West Virginia Center for End-of-Life Care was established and funded by the West Virginia Department of Health and Human Resources to update and revise the POST forms. Originally, the program was to mirror Oregon’s system and be housed in the State’s EMS Data System but the WV Center for End-of-Life Care created the registry through the West Virginia Health Information Network (WHVIN), which operates under a state contract which provides annual funding which is less than the original start-up costs. The WHVIN is a health information exchange funded through federal HIE grants and allows a portal for communication of patient data between providers and care setting, and is web-accessible, even on mobile devices.³⁴

The established goals were to improve End-of-Life care through education and training and act as a resource for individuals, health care providers and legislators to ensure that West Virginians have their pain controlled and their wishes respected at the end of life. West Virginia’s registry started receiving forms in October 2010, but delays forced the



registry to go live in August 2012. Now, the registry receives about 700 forms per month.³⁵

2.7.2 Implementation

Individuals can sign up for the e-Directive Registry using existing completed documents or the new versions of the Registry-eligible documents with checkboxes to ‘opt-in’ to the registry. Individuals or their agents submit the materials primarily by fax, mail or in-person. The registry also receives forms from clinics, hospitals, nursing homes and hospices. The Public Employee’s Insurance Agency offers a discount for a completed AD, which helps increase registration numbers.³⁶

2.7.3 Development and Maintenance

Registry staff manually enter the demographic information, DNRs, Sections A and B of the POST form and ADs with special directives and saved scanned images available for review. The registry contains ADs, POSTs, Surrogate Selection Checklists, Combined Medical Power of Attorney and Living Wills and Miscellaneous related documents. The staff proof reads each form and notifies patients or providers of any problems or concerns. Patients receive a confirmation letter whenever they submit forms as well as an annual letter to ensure that their most current documents are in the registry.³⁷

The e-Directive registry generates data reports indicating monthly form volume and distribution and basic POST form content. Registered providers are granted access to forms and the Network’s master patient index is searchable with a specific tab indicating registry contents. The e-Directive Registry is still being established and will soon be available to all participating providers. Right now, the registry collects materials in a freestanding repository.³⁸

2.7.4 Education and Outreach

Patients are made aware of the registry through advertising and conference exhibits. Professional outreach and training through the center includes social workers, nurses, physicians, professional organizations and statewide and regional networks of committees and EMS medical directors. The registry is overseen by the WV e-Directive Advisory Committee with membership drawn from health care facilities, state EMS, state government and other stakeholders.³⁹

2.7.5 Professional Opinion

According to Dr. Alvin Moss, initiatives to educate and get buy-in from legislators were well worth the effort. “By working with the system and using relationships developed over many years, we were able to educate the legislators about the value of these forms and a registry.” Dr. Moss is the Director of the Center for Health Ethics and Law as well as a professor of medicine at the Robert C. Byrd Health Sciences Center of West Virginia University.⁴⁰



2.8 COMPARISON OF STATES

	Active Registry?	Electronic or Paper?	Housing	Funding	Method of Submittal	Method of Access	Methods of Proliferation	Success
California	No	N/A	No Obvious Place for Housing	California Department of Health	N/A	Possibly Utilizing QR Code Technology	Partnership with Health Leaders	54 Percent of Nursing Home Residents Have a Form
Idaho	Yes	Both	Office of the Idaho Secretary of State	Idaho Secretary of State— Possibility of Charging \$10 per Registrant	Mail or Electronic	ID Card	Education Initiatives and Giveaways	No data
New York	Yes	Electronic	Excellus Blue Cross Blue Shield Data Center	New York Department of Health	Electronic	Searching Registry for Patient	Standardized Conversation Dictated by Legislation	No Data
Oregon	Yes	Paper	Oregon Health and Sciences University	Oregon Department of Health	Mail, Fax, or Electronic	Calling in to 24/7 Staffed Data Center with Forms Accessible	Opt-Out System and Education Initiatives	Up to 15 Percent of Seniors in Some Counties are Registered; 4000 New Registrants per Month
Utah	Yes	Both	Utah Department of Health	Utah Department of Health	Mail, Fax, or Electronic	Searching Registry for Patient	Legislative Recognition and Mandate	No Data
Washington	No	Both	US Living Will Registry	Washington Department of Health— Defunded	Mail or Fax	Searching Registry for Patient	Geographical	2000 Forms In 2 Years— Low Numbers Led to Cancellation
West Virginia	Yes	Both	West Virginia Health Information Network	West Virginia Department of Health and Human Services— Aided by National Grants	Fax, Mail, or In Person	Searching Registry for Patient	Financial Incentives	700 New Registrants per Month

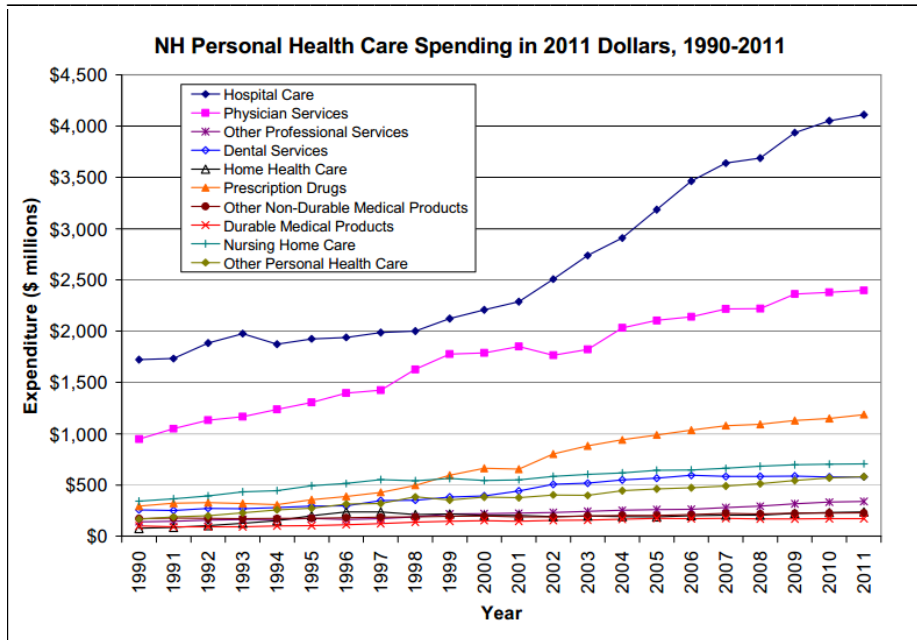
3. EFFECT ON HEALTHCARE SPENDING

3.1. Background

New Hampshire has a high cost, high quality healthcare system. Growth in healthcare spending has significantly outpaced growth in income. Today healthcare spending makes up seventeen percent of gross domestic product, up from eight percent in 1970.⁴¹ This high level of healthcare spending indicates that there are potentially large savings to be gained from the dissemination of POLST forms.⁴² A high level of healthcare spending indicates that a presumption to provide more care regardless of effectiveness. This high



level of spending is especially true at end of life when costs often skyrocket, but the prognosis is equally dire.



Source: Centers for Medicare and Medicaid Services (CMS)

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3.2 The Effect of POLST Registries

We predict that establishing a New Hampshire POLST registry would save approximately \$504,900 per year once the registry is fully operational. This estimate was accomplished by multiplying an estimate of the amount of money saved per patient with a POLST form with an estimate of how many form requests the registry would receive per year.

3.2.1 Estimate of Savings per Completed POLST Form

Although there have been no studies completed that analyze the amount of savings per patient with a completed POLST form, there have been a number that have looked at the effect of care limiting advance directives. In order to create our estimate of expected cost savings from a completed POLST form, we conducted a meta-analysis of five studies that looked at the cost of savings of ADs. The Table below summarizes these studies.

Study	Est. Savings (\$)	Est. Savings (Inflation Adjusted)	Year	type	Comments
Schneiderman et al.	0	0	1992	Control-Intervention	Studied last five years of life – POLST focuses on the last year
Maksoud et al.	50,584	79,163	1993	Retrospective review	Focused on DNR orders, not AD



Weeks et al.	18,700	28,523	1994	Retrospective Review	Only study conducted in New Hampshire
Molloy et al.	1,749(Can)	1,565 (US)	2000	Control-Intervention	Canadian Study
Nicholas et al.	5,585	5,702	2011	Retrospective review	Focused on costs from medicare patients

3.2.2 Estimate of Enrollment

We used data from the Oregon POLST registry in order to estimate the likely enrollment of a well-established POLST registry in New Hampshire. We relied on data from the Oregon POLST registry because Oregon has the oldest and most established registry in the country and because it publishes the most comprehensive reports on its users. It is important to remember that our estimate is for the savings that the registry will generate when it is fully operational. Savings from the years after its initial construction, when enrollment is likely to be lower, will be substantially reduced.

3.3 Biases

This cost estimate is likely to be too conservative. There are several factors that may have caused this estimate to be too low. Selection bias⁴⁴

First is *selection bias*. A difficulty with studies examining advance directives is that the sort of patient that has an advance directive is also the most likely to refuse care in other circumstances. As Dr. Ezekiel Emmanuel describes, “patients that ... complete advance directives are systematically different: They have both preferences to avoid aggressive care and medical interventions at the end of life and, of equal importance, the fortitude to actually refuse care and interventions at the end of life.” This bias is not a concern when assessing POLST registries because the registry will only be used when the patient for whom the form has been completed is incapable of making his or her own decisions. A patient who does not have their POLST form available will not have another way of making their wishes known.

Second is *location*. Only one study was conducted in New Hampshire, and it yielded a substantially larger cost estimate than studies conducted elsewhere.⁴⁵ Moreover, New Hampshire is a state with comparatively high healthcare spending, and care limiting advance directives are generally more effective at reducing healthcare spending in high spending areas.⁴⁶

Third is *DNR orders*. Our analysis focused on care limiting advance directives because they attempt to limit care in a way that is similar to a POLST order. However, advance directives are not actionable medical orders like POLST forms are. It is possible that DNR orders could be a better model for savings from POLST forms. Since the Maksoud et al. study indicated that savings from DNR orders are substantially greater than those



provided by advance directives, it is possible that savings from a POLST registry are substantially greater than this analysis would estimate.

There are also some reasons to believe that this estimate is too high. The largest concern is that our estimate of registry enrollment is too high. Oregon is the only state with a well-developed registry that provides detailed information on registry enrollment, so there is obviously a large degree of uncertainty associated with the estimate. However, this factor should be equally as likely to bias our estimate in either direction.

There is also concern about the timeframe of the studies. Many of the studies began when the advance directive was created. While advance directives are recommended for people of any age, POLST forms are targeted only at the last year of life. Many of the studies evaluating advance directives aggregated savings since the form was created, which would include savings outside the timeframe that a POLST form would be in use.

4. OPPOSITION TO POLST

There appears to be no opposition to the creation of a registry that stores POLST forms and offers easy access, but there has been significant opposition to POLST forms, primarily from Catholics and Catholic organizations, while disability rights groups offer questions about certain issues. However, not all Catholics oppose POLST. For example, Father John Tuohey, director of the Providence Center for Health Care Ethics in Portland, Oregon, and Marian Hodges, a member of the Connections palliative-care team at Providence Portland Medical Center, have written an article in support of POLST in *Health Progress*.⁴⁷ Meanwhile, Catholic churches and institutions have supported POLST implementation in states like California and Oregon.

Amy Vandenbroucke, executive director of the National POLST Paradigm Program, offered written testimony to the United States Senate Special Committee on Aging on June 26, 2013 claiming, “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 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.”⁴⁸

4.1 CATHOLIC OPPOSITION

There is no overarching Catholic opinion on POLST. Some members and organizations support the program while others protest its implementation. In Wisconsin, members argued that the usage of POLST forms would be a slippery slope to euthanasia. And in Massachusetts, Peg Sandeen, who writes for the blog *Living with Dying*, claimed that 71



percent of all money raised by the anti-Death with Dignity campaign could be attributed to Catholic resources.⁴⁹

John Brehany, executive director of the Catholic Medical Association, wrote: “What POLST does is roll together several end-of-life instruments to bring clarity and certainty to treatment decisions. It tilts in favor of not doing things because the presumption is in favor of treatment. If you go into Cardiac arrest, they have to treat you unless you have a Do-Not-Resuscitate order... The problem is that you’re trying to make decisions today that may not come into effect for five or ten years. You don’t know what your condition will be and what medical advances will have been made by then. You’re 60 and healthy, and you’re asked ‘Do you want to be hooked up to a lot of machines?’ But when the same person is 70 and might be going through a temporary rough patch, nothing will be done because of the POLST signed a decade earlier.”⁵⁰

E. Christian Brugger, holder of the Cardinal Stafford Chair of Moral Theology at St. John Vianney Theological Seminary in Denver, describes POLST as “a living will on steroids.” Brugger co-authored an opposition article entitled “POLST and Catholic Health Care: Are the Two Compatible?” He claimed “the real danger is that people who sign a POLST often don’t understand how powerful this instrument can be,” and urged Catholic health care institutions to refuse to accept POLST forms or to revise them to make their use fully consistent with good health care practice and the full dignity of the human person.⁵¹ “Based on a review of [POLST facilitators] statements and training materials, we have found that this program for facilitators is heavily fear-based, is biased in favor of refusing life-sustaining treatments, and emphasizes all possible burdens of accepting treatment while minimizing burdens associated with refusal of treatment.”

Brugger’s article asserted that there were seven ethical problems with POLST: “(1) POLST forms may be implemented when the patient is not terminally ill, (2) no patient signature is required for their implementation, (3) no signature is required of a physician attending the patient when the orders are implemented, (4) the orders travel with patients from one health care facility to another, (5) the orders are effective immediately, (6) they are implemented by non-physician “facilitators,” and (7) they utilize a simplistic check-box format for directing complex decision-making.” Later in his article, Brugger writes, “The national push for the implementation of the POLST paradigm seems to be fiscally driven.”

Opposition members often refer to a 2004 address by Pope John Paul II.⁵² Paul proclaimed: “There are some who cast doubt on the persistence of the ‘human quality’ itself, almost as if the adjective ‘vegetative’ (whose use is now solidly established), which symbolically describes a clinical state, could or should be instead applied to the sick as such, actually demeaning their value and personal dignity. In this sense, it must be noted that this term, even when confined to the clinical context, is certainly not the most felicitous when applied to human beings. In opposition to such trends of thought, I feel the duty to reaffirm strongly that the intrinsic value and personal dignity of every human



being do not change, no matter what the concrete circumstances of his or her life. A man, even if seriously ill or disabled in the exercise of his highest functions, is and always will be a man, and he will never become a ‘vegetable’ or an ‘animal.’... The sick person in a vegetative state, awaiting recovery or a natural end, still has the right to basic health care (nutrition, hydration, cleanliness, warmth, etc.) and to the prevention of complications related to his confinement to bed. He also has the right to appropriate rehabilitative care and to be monitored for clinical signs of eventual recovery... The administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.”

The issue that directly relates to the Pope’s comments is nutrition and food intake. Oppositionists like Brugger argue that the options on the POLST form stipulate that people could be forced to ingest food and water through intubation if they don’t want to. Additionally, oppositionists argue checking off certain boxes could result in a patient receiving no food or water, leading to the patient’s death from dehydration or starvation. Since POLST forms are a medically actionable order, failure to follow the POLST to the letter could result in a medical lawsuit, causing doctors to refrain from feeding a patient if the order states the patient wants to die normally while not stipulating the patient’s nutritional preferences.

4.2 DISABILITY RIGHTS OPPOSITION

Other groups that have lobbied against POLST are disability rights groups, specifically because of the issue of patient signatures. Without one, Diane Coleman, president of the disability rights group, Not Dead Yet, asks, “How do we know the POLST medical order actually reflects the desires of the individual?” Coleman claims that depending on how POLSTs are presented, they may make life-sustaining treatments like feeding tubes seem unbearable.⁵³ Coleman submitted video and written public comments to the Institute of Medicine’s Committee on Approaching Death.⁵⁴ Coleman’s efforts have impacted, at minimum, POLST efforts in Connecticut. Her impact on other states’ POLST initiatives has yet to be determined.

5. CONCLUSION

The POLST paradigm is an innovative solution to the problems presented by end of life decision-making. Avoiding the vagueness of an advance directive, POLST allows patients to transform their wishes for medical treatment into actionable medical orders. However, in order to be useful, POLST forms must be easily accessed by healthcare providers and emergency response personnel. POLST registries help ensure this. By



creating a centralized repository for form storage, POLST registries allow healthcare providers to quickly and easily access a patient's POLST information.

APPENDIX A – SAMPLE POLST FORM

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT			
Physician Orders for Life-Sustaining Treatment (POLST)			
Follow these orders until orders change. These medical orders are based on the patient's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written. For more information on Oregon POLST visit: www.orpolst.org	Patient Last Name:	Patient First Name	Middle Int.
	Date of Birth: (mm/dd/yyyy)	Gender: <input type="checkbox"/> M <input type="checkbox"/> F	Last 4 SSN: <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
	Address: (street / city / state / zip)		
A Check One	CARDIOPULMONARY RESUSCITATION (CPR): <i>Patient has no pulse and is not breathing.</i>		
	<input type="checkbox"/> Attempt Resuscitation/CPR <input type="checkbox"/> Do Not Attempt Resuscitation/DNR		
When not in cardiopulmonary arrest, follow orders in B and C.			
B Check One	MEDICAL INTERVENTIONS: <i>If patient has pulse and/or is breathing.</i>		
	<input type="checkbox"/> Comfort Measures Only (Allow Natural Death). Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location. Treatment Plan: Maximize comfort through symptom management.		
	<input type="checkbox"/> Limited Additional Interventions In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Treatment Plan: Provide basic medical treatments.		
	<input type="checkbox"/> Full Treatment In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. Treatment Plan: Full treatment including life support measures in the intensive care unit.		
Additional Orders: _____			
C Check One	ARTIFICIALLY ADMINISTERED NUTRITION: <i>Offer food by mouth if feasible.</i>		
	<input type="checkbox"/> No artificial nutrition by tube. Additional Orders: _____		
	<input type="checkbox"/> Defined trial period of artificial nutrition by tube. _____		
	<input type="checkbox"/> Long-term artificial nutrition by tube. _____		
D	DOCUMENTATION OF DISCUSSION:		
	<input type="checkbox"/> Patient (Patient has capacity)	<input type="checkbox"/> Health Care Representative or legally recognized surrogate	
	<input type="checkbox"/> Parent of minor	<input type="checkbox"/> Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.)	
	<input type="checkbox"/> Court-Appointed Guardian	<input type="checkbox"/> Other _____	
Signature of Patient or Surrogate			
Signature: <u>recommended</u>		Name (print):	Relationship (write "self" if patient):
This form will be sent to the POLST Registry unless the patient wishes to opt out, if so check opt out box <input type="checkbox"/>			
E	SIGNATURE OF PHYSICIAN / NP/ PA		
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's current medical condition and preferences.			
Print Signing Physician / NP / PA Name: <u>required</u>		Signer Phone Number:	Signer License Number: (optional)
Physician / NP / PA Signature: <u>required</u>		Date: <u>required</u>	Office Use Only
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED. SUBMIT COPY TO REGISTRY			



HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Information for patient named on this form PATIENT'S NAME: _____

The POLST form is **always voluntary** and is usually for persons with advanced illness or frailty. POLST records your wishes for medical treatment in your current state of health. Once initial medical treatment is begun and the risks and benefits of further therapy are clear, your treatment wishes may change. Your medical care and this form can be changed to reflect your new wishes at any time. However, no form can address all the medical treatment decisions that may need to be made. The Oregon Advance Directive is recommended for all capable adults, regardless of their health status. An Advance Directive allows you to document in detail your future health care instructions and/or name a Health Care Representative to speak for you if you are unable to speak for yourself.

Contact Information

Surrogate (optional):	Relationship:	Phone Number:	Address:
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Health Care Professional Information

Preparer Name:	Preparer Title:	Phone Number:	Date Prepared:
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PA's Supervising Physician:	Phone Number:
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Primary Care Professional:

Directions for Health Care Professionals

Completing POLST

- Completing a POLST is always voluntary and cannot be mandated for a patient.
- Should reflect current preferences of persons with advanced illness or frailty. Also, encourage completion of an Advance Directive.
- Verbal / phone orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.
- Use of original form is encouraged. Photocopies, faxes, and electronic registry forms are also legal and valid.
- A person with developmental disabilities or significant mental health condition requires additional consideration before completing the POLST form; refer to *Guidance for Health Care Professionals* at www.orpolst.org.

Sending to Oregon POLST Registry (Required unless "Opt Out" box is checked)

<p>For the Oregon POLST Registry the following must be completed:</p> <ul style="list-style-type: none"> • Patient's full name • Date of birth • Section A • MD / DO / NP / PA signature • Date signed 	<p>Send a copy of <u>both</u> sides of this POLST form to the Oregon POLST Registry.</p> <p><u>FAX or eFAX:</u> 503- 418-2161</p> <p>or</p> <p><u>Mail:</u> Oregon POLST Registry CDW-EM 3181 SW Sam Jackson Park Rd. Portland, OR 97239</p> <p><u>Registry Phone:</u> 503-418-4083</p> <p>*Please allow up to 10 days from receipt for processing into the Registry. Mailed confirmation packets may take four weeks for delivery.</p>	<p>Date Submitted _____ / _____ / _____</p> <div style="border: 1px solid black; padding: 5px; text-align: center;"> <p>MAY PUT REGISTRY ID STICKER HERE:</p> </div>
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Reviewing POLST

- This POLST should be reviewed periodically and if:
- The patient is transferred from one care setting or care level to another, or
 - There is a substantial change in the patient's health status, or
 - The patient's treatment preferences change, or
 - The patient's primary care professional changes.

Voiding POLST

- A person with capacity, or the valid surrogate of a person without capacity, can void the form and request alternative treatment.
- Draw line through sections A through E and write "VOID" in large letters if POLST is replaced or becomes invalid.
- Send a copy of the voided form to the POLST Registry as above (required).
- If included in an electronic medical record, follow voiding procedures of facility/community.

For permission to use the copyrighted form contact the OHSU Center for Ethics in Health Care. Information on the POLST program is available online at www.orpolst.org or at polst@ohsu.edu.

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED, SUBMIT COPY TO REGISTRY



APPENDIX B



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