

**PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT:  
RECOMMENDATIONS FOR IMPLEMENTATION IN PENNSYLVANIA**

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The Physician Orders for Life-Sustaining Treatment (POLST) form was designed to help individuals in the last stages of life express their wishes regarding life-sustaining treatment. End-of-life care is often provided in a multitude of health care settings including hospitals, skilled nursing facilities, hospice centers, and in patients' homes. Communication failure between these facilities and patients or their families often leads to care that is in opposition to the patient's desires. In addition, living wills and advance directives that are currently in use do not provide health care workers with the information needed to properly carry out the patient's last wishes specific to life-sustaining treatment. POLST seeks to overcome these barriers by creating a simple, understandable form that is easily transferred between care settings. The POLST form was created in Oregon in 1991 and has since been used throughout the state. Numerous studies conducted in the state have found that the use of POLST ensures that patients receive the desired level of care during the end stages of life. The Commonwealth of Pennsylvania has been using the POLST form in a limited number of settings since 2000; however, widespread use of the form has yet to occur. As Pennsylvania has an aging population, quality care for those in the end stages of life is of particular public health importance. This paper examines the literature surrounding the development and implementation of POLST in Oregon, its spread throughout the United States, and its current status in Pennsylvania in order to answer the following

questions: 1) Should Pennsylvania adopt widespread use of the POLST? And (2) if yes, how should the Commonwealth go about overcoming the barriers to implementation?

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## 1.0 INTRODUCTION

The population of Pennsylvania is quickly aging. Twenty percent of Pennsylvanians are over the age of 60, giving Pennsylvania the third highest percentage of people over the age of 60 in the United States (DOA, 2007). In addition, the percent of the population over the age of 75 has increased dramatically in the last two decades (DOA, 2007). Though end-of-life care is not an issue that only affects the aging, a large aging population creates an even greater demand for good end-of-life care and palliative care. As cause of death has shifted from infectious diseases and accidents towards long-term chronic diseases, individuals are living longer, but often with diseases that will eventually kill them. For many of these individuals, medical treatments are only able to prolong their life, not cure them (RWJ, 2002). Thus, once an individual is beyond curative treatments many decision regarding future care and treatment have to be made.

In 2002, the Robert Wood Johnson Foundation released a report grading all the states based on the quality of end-of-life available in the state. States were graded based on the following eight measures: 1) advance directive policies, 2) location of death, 3) hospice use, 4) hospital-based end-of-life care services, 5) care provided in intensive care units at end-of-life, 6) pain among nursing home residents, 7) state pain policies, and 8) number of certified palliative care physicians and nurses (RWJ, 2002). Throughout the report, Pennsylvania scored very low in all seven categories (RWJ, 2002). The most important indicator for this thesis is state advance

directive laws. Significantly, this is one of the lowest scores Pennsylvania received. Along with three other states (Alaska, Kansas, and Vermont), Pennsylvania received the lowest grade possible, an “E” (RWJ, 2002). The following six indicators were used to calculate this score: 1) recommendation of a statewide comprehensive advance directive form, 2) no mandatory form or language required for advance directives, living wills, or power of attorney, 3) precedence is given to the agent’s authority or to the most recent advance directive, 4) a default surrogate, such as a family member, is authorized to make health care decisions, 5) close friends are included in the list of acceptable default surrogate, and 6) there is a statewide out-of-hospital DNR protocol for emergency medical services (RWJ, 2002).

While no single change to the state will account for all of these factors, the Physician Orders for Life-Sustaining Treatment (POLST) form offers a way for individuals to make their wishes regarding end-of-life care known to medical professionals. The form has been used with great success in Oregon and in other states around the country. While Pennsylvania currently has a POLST program, they have not yet moved to a full-implemented design. The purpose of this thesis is twofold. First, to examine the literature regarding the history, implementation, and success of the POLST form in Oregon and around the United States in order to determine if the form should be fully adopted by the Commonwealth of Pennsylvania. Second, to make recommendations to the Commonwealth regarding strategies for implementation of the POLST form.

## **1.1 DEFINITIONS OF END-OF-LIFE AND PALLIATIVE CARE**

End-of-life and palliative care are two concepts that are intricately tied to the discussion of advance directives and POLST. Defining these terms is essential to understanding where the POLST fits into the spectrum of care. These two terms are also tied to each other, as patients often simultaneously receive both types of care. Unfortunately, neither term has a widely accepted definition, making defining and discussing the concepts difficult. The following discussion attempts to uncover the meaning of each of these terms and arrive at a general understanding of what end-of-life and palliative care encompass.

### **1.1.1 Definition of End-of-Life**

End-of-life is not easily defined. Despite the term being used by a number of organizations under a variety of circumstances, there is no accepted definition for the phrase (*National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care*, 2004). Defining the phrase has often proved troublesome because the exact time frame involved varies from disease to disease and from person to person. The National Institute of Health discussed the issue of defining end-of-life at a State of Science Conference held December 6-8, 2004. In the statement issued after the conference, they stated that “There is no exact definition of end of life; however, the evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death“ (*National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care*, 2004). The same

statement cautions against developing a regulatory definition or including a timeframe in the definition, since these aspects create barriers to improving the end-of-life care. The statement states that it is rare for any physician to be able to accurately predict the time-of-death for any individual (*National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care*, 2004). While not having a definition for the term can be troublesome in deciding what constitutes end-of-life care, the above criteria help to determine when a patient is receiving proper end-of-life care.

No clear, overarching guidelines are available for determining what constitutes good end-of-life care. For most common chronic conditions, such as heart disease and cancer, guidelines exist for each disease regarding the types of treatments that should be available. The American Medical Association (AMA) released a position statement in 2007 detailing what they believe to be good quality end-of-life care. In their statement, they listed the following eight criteria: 1) ensure that the patient is treated with respect, dignity, and compassion, 2) ensure the patient is free from unnecessary pain and unnecessary discomfort, 3) attempt to deliver care in the patient's choice of environment, 4) respect the patient's goals and values, 5) respect the patient's privacy and confidentiality, even after death, 6) support the patient's and the patient's family's physical, physiological, emotional, religious, and spiritual need, 7) empower patients and family members to participate in the medical decision making process, and 8) provide counseling to the patient throughout the condition and provide support to the family during the patient's treatment and after the patient's death (AMA, 2007). The second criteria, keeping the patient free from pain and unnecessary discomfort is an area of end-of-life care that is handled by a specific medical discipline, palliative care, which may also be part of a patient's care before they reach the end stages of life.

### **1.1.2 Definition of Palliative Care**

Good end-of-life care involves proper pain management and the use of palliative care. While palliative care can be provided at any time, without the requirement of a patient being at the end-of-life, patients who are at the end-of-life have a great need for quality palliative care. Palliative care has been defined by multiple entities and no consensus on the exact definition exists (Billings, 1998). In order to create a comprehensive and inclusive definition, it is essential to look at a number of definitions that are currently in use by palliative care organization. The National Hospice and Palliative Care Organization (NHPCO) defines palliative care as follows:

Treatment that enhances comfort and improves the quality of an individual's life during the last phase of life. No specific therapy is excluded from consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual's needs must continue to be assessed and all treatment options explored and evaluated in the context of the individual's values and symptoms. The individual's choices and decisions regarding care are paramount and must be followed (NHPCO, 2009).

In addition to NHPCO, the American Academy of Hospice and Palliative Medicine (AAHPM) also has a definition of palliative care. While shorter, this definition touches on many of the same elements as the ones in the definition provided by NHPCO; however, the definition brings in a few new and important elements essential to creating a comprehensive definition of palliative care including the specification that the patient can be using other therapies and can be at any stage in spectrum of disease progression. The AAHPM defines palliative care as follows:

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients facing life-threatening or debilitating illness and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care (AAHPM, 2006).

A third definition to consider is provided by the Center to Advance Palliative Care (CAPC). While this definition contains many of the components seen in the two prior definitions, it contains important information regarding when palliative care can be provided. CAPC's definition is as follows:

Palliative care is the medical specialty focused on relief of the pain and other symptoms of serious illness. The goal is to prevent and ease suffering and to offer patients and their families the best possible quality of life. Palliative care is appropriate at any point in a serious or life-threatening illness. It is not dependent on prognosis. It can also be provided at the same time as curative and life-prolonging treatment. Palliative care is not dependent on prognosis and is appropriate at any point in an illness. It can also be provided at the same time as treatment that is meant to cure you (CAPC, 2008).

In 1998, palliative care specialist Andrew Billings critically examined the components of several previous definitions of palliative care and proposed a new definition that has since been widely accepted. Billings' defined of palliative care as follows: "Palliative care is comprehensive, interdisciplinary care, focusing on promoting quality of life for patients living with a terminal illness and for their families" (Billings, 1998). In a meeting held February 23, 2009, an advisory team was charged with the task of creating a service delivery model for end-of-life care for the Commonwealth of Pennsylvania, a more encompassing definition of palliative care was developed using the original Billings definition. This definition combines many of the qualities that have come to be associated with palliative care over the years. The following was the definition created that will be recommended to the state for official adoption: "Palliative care is

comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a chronic, life-limiting illness that will eventually be fatal and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include: assuring physical comfort, psychosocial and spiritual support, and the provision of coordinated services across various sites of care.” Where chronic, life limiting illness is defined as illnesses whose natural history is characterized by progressive illness and decline with a high probability of death within a predetermined time period, and provision of coordinated services is defined as the provision of care by multiple disciplines with a focus on promoting the patient and family’s quality of care (Palliative Care Service Delivery Model Team Lead, personal Communication, February 23, 2009).

## **1.2 DEFINITIONS OF ADVANCE DIRECTIVE, DNR, AND POLST**

Patients who are receiving end-of-life and palliative care have many decisions to make. These patients are aware that their condition will most likely be the cause of their death. This knowledge leads the patient, the patient’s family, and the patient’s providers to make many difficult decisions regarding care practices. Many patients do not want to spend their last days hooked up to increasing amounts of medical equipment. These patients are aware that treatments being provided have the possibility of prolonging their life, but that they will not cure them of the disease. Patients have the option to express their wishes regarding which medical interventions they would like to receive using advance directives, DNRs, and POLST forms.

### **1.2.1 Definition of Advance Directive**

An advance directive is a legal document that states the treatment a person wishes to receive if he or she is no longer able to make medical decision (NCI, 2009). Advance directives are also a place for patients to designate a proxy, the person who should make medical decisions if the patient is not able to make decisions him or herself (Gillick, 2004). Despite the fact that advance directives are cheap, low-tech, and have the ability to be very useful, they are largely underutilized. A study done in 2004 found that completion rates of advance directives by older adults ranged from four to 20%, depending on the population sample (Gillick, 2004). All 50 states have passed legislation making adherence to advance directives mandatory for physicians (Gillick, 2004). Perhaps the most common and well-known version of an advance directive is the do-not-resuscitate order.

### **1.2.2 Definition of DNR**

A do-not-resuscitate (DNR) order is a type of advance directive wherein a person expresses their wish not to have cardiopulmonary resuscitation (CPR) performed if his or her heart stops beating (Smith & O'Neill, 2008). CPR is a rescue therapy that is performed when a patient does not have a pulse and is not breathing. CPR combines breathing and chest compressions to keep blood flowing to the heart and brain until normal heart function is restored (AHA, 2009). Advance directives are typically vague, DNR orders provide health care professionals with clear instructions on what to do in a very specific situation. Unfortunately, these orders are often misunderstood by providers to mean that the patient has a preference for less aggressive treatments on a broader scale (Hickman, Tolle, Brummel-Smith, & Carley, 2004). Having a

DNR order does not keep a patient from receiving any other life saving treatments and only applies if the patient is in full cardiopulmonary arrest (Smith & O'Neill, 2008). The American Medical Association (AMA) has recognized the fact that having a DNR order may keep health care providers from providing other treatments and has issued a statement saying that having a DNR order “should not influence other therapeutic interventions that may be appropriate for the patient” (AMA, 1991).

In recent years a new type of DNR order has appeared called the out-of-hospital DNR. In Pennsylvania, the Out-of-Hospital Nonresuscitation Act was enacted as a statute (P.L. 1484, No. 169) on November 29, 2006. This statute repealed the prior DNR act and allowed patients or their advocates to obtain an out-of-hospital DNR order. These orders are able to be enacted by emergency medical services personnel when the patient is in a non-medical setting, such as a home (DoH, 2008). This is usually in the form of a bracelet or necklace that the patient wears at all times to ensure that if he or she is found not breathing and without a pulse that his or her wishes will be honored (DoH, 2008).

### **1.2.3 Definition of POLST**

The Physician Orders for Life Sustaining Treatment (POLST) is a one-page form that was created in 1991. The form was conceived by a task force at the Center for Ethics in Health Care at Oregon Health and Science University (Dunn, 2008). The form expands on the idea of DNR orders, extending to three other medical areas: 1) medical interventions when the patient has a pulse and/or is breathing, 2) antibiotics, and 3) artificially administered nutrition (see appendix A) (Dunn, 2008). The completed form is signed by both the primary care professional and either the patient or the patient’s guardian. The form is placed in the front of the patient’s chart when

he is in a medical facility and on the refrigerator, or another obvious place, when the patient is at home. In order to ensure that the form is recognizable it is always printed on brightly colored paper, usually hot pink (Dunn, 2008).

The POLST extends a DNR order past the practice of cardiopulmonary resuscitation, providing the patient an opportunity to express his or her wishes regarding the medical interventions mentioned previously (Hickman et al., 2004). The POLST takes the guesswork out of deciding whether a patient with a DNR order wishes to exclude other aggressive treatments or if he wants to pursue every option except CPR. Unlike other medical forms, the POLST does not stay in the patient's file at the facility where the form was completed. Instead, the form follows the patient when he is transferred from one setting to another and if he is at home. The transferrable form keeps patients from having to reiterate preferences to multiple providers and ensures that the patient's wishes are respected even if the patient is not longer able to competently complete the forms (Hickman et al., 2004).

#### **1.2.4 Importance of DNR Orders**

Cardiopulmonary resuscitation was designed to be used on healthy individuals who had suffered a sudden, acute condition. For those suffering from long-term, chronic illnesses that are in the end stages, CPR is unlikely to be of any benefit to the patient. In this scenario, success rates of CPR are extremely low and those who survive frequently suffer from a lower quality of life than they had prior to the cardiac event (Johnson & Nelson, 2008). For elderly patients, only about 22% survive initial resuscitation and only between 10 and 17% survive to discharge. Those who are discharged usually suffer from impaired function (Longstreth, Cobb, Fahrenbruch, & Copass, 1990). More importantly for patients at the end-of-life, chronic illness has been found to play a

larger role in determining whether a patient survives CPR. Studies have shown that less than 5% of those with chronic disease who receive CPR actually survive initial resuscitation (*EPEC Project*, 1999). Though portable DNR orders have been growing in popularity, they are not as effective as they should be. The two main reasons for this lack of effectiveness are that they are not widely used and that they do not provide guidance for EMTs when they see patients who are breathing and have a pulse (Schmidt, Hickman, Tolle, & Brooks, 2004).

### **1.2.5 Importance of POLST**

The POLST is significantly different than an advance directive. Advance directives are designed to be used by any adult. When completing an advance directive, individuals must consider a number of future treatments that they may require. The individual has to consider a wide variety of circumstances under which they may require life-sustaining treatment. Individuals state what they believe their preferences will be under these imagined circumstances. When the need to consult the living will arrives, the document must be retrieved from the patient's lawyer or from the place where it was being stored. It is then up to medical personnel to translate the listed preferences into medical orders, a process that is difficult for both the provider and the patient (Fagerlin & Schneider, 2004; Hickman, Sabatino, Moss, & Nester, 2008). Importantly, the POLST form is very different than an advance directive. The POLST form is only for patients who are nearing the end-of-life. Individuals completing a POLST form choose from decisions that are listed on the form and check the box next to their preferred option. The completed form follows the patient from location to location, allowing it to be easily accessed anytime a provider needs to refer to it. The patient's request listed on the form are physician orders that are able to be acted on by health care professionals without first having to be interpreted (Black, 2008).

## **2.0 POLST HISTORY AND DEVELOPMENT**

The POLST form was the creation of a group of representatives from stakeholder health care organizations in Portland, Oregon. These stakeholders were convened in a task force headed by the Center for Ethics in HealthCare at Oregon Health and Science University (OHSU). The goal of this task force was to create a way for patients with progressive illnesses to ensure that their preferences for life-sustaining treatment were honored (Foreman, 2008). The result of this original meeting was the development of a form titled Medical Treatment Coversheet. This sheet provided a set of portable standard medical orders for life-sustaining treatment. The overall categories included were those usually included in advance directives (Foreman, 2008). The Medical Treatment Cover Sheet used similar categories to what is now found on the POLST. The four categories included were (1) resuscitation, (2) emergency medical services, (3) antibiotics, and (3) artificial fluids and nutrition.

## **2.1 POLST VALIDATION AND TESTING**

Implementation of the Medical Treatment Cover (MTC) Sheet began slowly through a grassroots movement. Though the taskforce relied on administrative rule changes, they chose not to attempt any legislative changes at the onset. In 1993, three focus groups were held to assist with the implementation of the MTC. The first focus group was held with 28 physicians from urban and

rural settings. Independently, each physician indicated that the form would be useful for his or her patients and that he or she would use the MTC. The second focus group was conducted with five female long-term care nurses. Overall, they agreed that the form was simple, concise, and understandable. The only major concern for implementation was whether physicians would be willing to follow the instructions on the form. The third focus group was comprised on paramedics and physicians who write the protocols for the Portland area Emergency Medical System. These individuals agreed that the form was not only understandable, but could be used by paramedics in the prehospital setting (Dunn et al., 1996). The same study also evaluated the accuracy of MTC interpretation. The study included 19 primary care physicians, 20 emergency physicians, 26 paramedics, and 22 long-term care nurses. Each was provided with three scenarios, once without a MTC and once with a MTC. Without the MTC, all groups chose a larger percent of available treatments (56%) than when they were provided with a MTC (29%) (Dunn et al., 1996). In the latter instance, treatments chosen were both medically indicated and more consistent with patient preferences. The only situation that concerned the authors was in the scenario where the patient had indicated Care Level 3 in the Emergency Medical Services section of the MTC. In Care Level 3 the patient is asking to have every available method of life-sustaining treatment. A significant number of physicians chose to withhold treatment in this patient, even after seeing the MTC. Though the authors feel that this situation is concerning, they feel that “the MTC implementation in selected patients is warranted given the much greater frequency of treatment that is unwarranted and/or medically not indicated” (Dunn et al., 1996).

After the conclusion of the focus groups and initial evaluation, pilot implementation began in the State of Oregon. Four months after implementation, 36 facilities had ordered an excess of 7,350 MTCs. Investigators followed up with facilities using the forms and found that

the document was working well. Given the success in the pilot communities, implementation began throughout the state (Dunn et al., 1996). Following this study, the name of the form was changed from Medical Treatment Cover Sheet to Physician Orders for Life-Sustaining Treatment (POLST). The name was changed in order to distinguish the POLST from more traditional advance directives (Foreman, 2008). A second study was conducted in to determine the efficacy of the POLST in nursing homes throughout the State of Oregon. The study looked at nursing homes in urban, suburban, and rural environments. Study subjects were chosen from a pool of nursing home residents who had already chosen to sign a POLST form and whether they had indicated DNR and “transfer only if comfort measures fail.” Data was collected every two weeks for a period of 12 months. Study staff visited the site two months after completion of the study to review the charts for the last month of care for each subject. Charts were assessed for four factors: 1) orders for narcotics, 2) orders for limitation on life-extending treatments, 3) treatment interventions actually provided, and 4) verification that the POLST form was in the chart at the end of the study (Tolle, Tilden, Nelson, & Dunn, 1998). This study found that participants had high levels of comfort care and low rate of aggressive life-sustaining treatments. In addition, “the frequency of death outside of acute care, the low rate of hospital days and ICU care, the absence of CPR, and the high percentage of narcotic orders at the time of death all are unusual compared with national benchmarks reported by others” (Tolle et al., 1998). A major outcome found for participating residents with POLST forms was that the residents had a lower rate of hospitalization. The mean rate of hospitalization for the study population was 174 per 1,000 resident years, compared to a mean rate of 566 per 1,000 person years for residents in a similar facility in Monroe County, New York (Tolle et al., 1998). Study participants also had lower rates of death in a hospital. National surveys have found that most Americans would prefer to die in

their home or in a home-like setting. Only 5% of study participants died in the hospital, compared to national rates of about 20% (Tolle et al., 1998).

The POLST has been continually revisited and revised by the task force in order to enhance both the clarity and the utility of the form. Calls from treatment facilities and patient feedback have been incorporated into subsequent versions of the form. Revisions to the form were made in 1997, 1999, 2001 and 2008 (Foreman, 2008; Hickman et al., 2004). The Oregon task force is committed to updating the form every two years; however, all versions of the form remain valid (Foreman, 2008). In the 2001 version of the form, two changes were made to help increase the applicability of the form to the population using it. The first change was the inclusion of minors. In the section of the form that allows the provider to check off which person the form was discussed with, a new box was added for parent of minor. This change was made with input from community clinicians, various professions, community organization, and the school system (Foreman, 2008). The second change made in 2001 was the addition of nurse practitioners as acceptable signers of the form. The task force recognized that nurse practitioners provide much of the primary care services for Oregonians, especially those living in rural areas. In prior versions of the form, nurse practitioners were required to have a physician sign the orders. Along with the Oregon Board of Nurses, the task force determined that signing POLST forms was in the scope of a nurse practitioner and did not require a supervising physician. To help ensure that the change was properly instituted, the task force worked with EMS services to make certain that nurse practitioner orders would be accepted and respected (Foreman, 2008). The last update to the form was made in August 2008. Changes made to the most recent version are mostly in the form of section title and a few layout changes; however, the task force issued a report stating when the POLST is advised for individuals with disabilities (Foreman, 2008). In

this report, the task force reiterated that the POLST is for use with patients who are at the end-of-life, not patients with long-term disabilities who have not yet entered the last stages of life (CEHC, 2008).

In order for POLST to be completely effective in respecting the wishes of patients it must be able to be applied both in a health care facility and in the home. First responders need to be able to follow the orders. To protect First Responders, in 1999 the task force recommended that the Oregon Medical Board better define the scope of practice for EMTs/First Responders. The final language for the rule reads as follows: “An Oregon-certified First Responder of EMT, acting through standing orders, shall respect the patient’s wishes including life-sustaining treatments. Physician supervised First Responders and EMTs shall request and honor life-sustaining treatment orders executed by a physician, nurse practitioner or physician assistant if available. A patient with life-sustaining treatment orders always requires respect, comfort and hygienic care” (Foreman, 2008). This new wording allows First Responders and EMTs to carry out the wishes of individuals with POLST forms.

## **2.2 ADOPTION AND USE ACROSS THE UNITED STATES**

Since POLST was developed, many states have begun adopting a similar form. Currently 31 states have POLST-like form programs and seven have programs that are endorsed by the POLST Paradigm Task Force (OHSU, 2008). The POLST Paradigm is run out of the Center for Ethics in Health Care at the Oregon Health & Science University. The program aims to promote development, implementation, and evaluation of POLST in every state. Each state that has an operational POLST program has its own program description on the website (OHSU, 2008). The

task force for the POLST Paradigm is comprised of 14 health care professionals representing seven states that had implemented POLST before the year 2002 (OHSU, 2008). The POLST Paradigm website indicates three levels of programs: POLST Paradigm endorsed programs, developing programs, and no programs (OHSU, 2008).

In order to be a POLST Paradigm endorsed program, a program must meet 11 requirements: 1) the form must constitute a set of medical orders, 2) there must be ongoing training of health care professionals across the continuum, 3) use of the form is recommended to individuals with advanced chronic progressive illnesses that are likely to result in death within a year or to anyone wanted to define care preferences, 4) it is recommended that the form require either the signature of the patient or the patient's surrogate, 5) the form requires the signature of a physician, physician assistant, or nurse practitioner and the date of the signature, 6) the form is used to clarify a request for all or limited medical interventions, 7) the form includes explicit directions regarding resuscitation, 8) the form includes directions for medical interventions other than resuscitation, 9) the form is transferrable across medical settings, 10) the form is a uniform color within the state or region and is easily identifiable, and 11) there is a plan for evaluation of the form (OHSU, 2008). The National Quality Forum, a non-profit organization committed to developing a national health care quality and measurement reporting system, has recommended that the POLST for be implemented on a national scale (Hickman et al., 2008).

**Table 1. List of State POLST Programs**

States with POLST Paradigm Endorsed Programs (n=7)	States with a Developing POLST Program (n=24)	States with No POLST Program (n=20)
California New York North Carolina Oregon Tennessee Washington West Virginia	Alaska Colorado Florida Georgia Hawaii Idaho Iowa Kansas Louisiana Maine Michigan Minnesota Missouri Montana Nebraska Nevada New Hampshire North Dakota Ohio Pennsylvania Texas Utah Wisconsin Wyoming	Alabama Arizona Arkansas Connecticut Delaware District of Columbia Illinois Indiana Kentucky Maryland Massachusetts Mississippi New Jersey New Mexico Oklahoma Rhode Island South Carolina South Dakota Vermont Virginia

The POLST Paradigm has recognized two major ways that states have gone about implementing the POLST form. States such as West Virginia, Tennessee, and Hawaii have used legislation in order to overcome legal barriers to POLST implementation. On the other hand, Oregon, Utah, and Washington used regulatory measures to overcome their barriers (OHSU, 2008).

### **2.2.1 POST in West Virginia**

West Virginia began using a POLST-like form in 2002, after seeing how successful the form had been in Oregon. They chose to name the form Physician orders for Scope of Treatment (POST) (Moss, 2008). The current program meets all 11 components required to be a POLST Paradigm Endorsed Program and the program is run in all counties within the state (Moss, 2008). As of 2008, the POLST form was being used in 85% of hospitals and hospice facilities within West Virginia and in 81% of nursing homes (Moss, 2008). Since implementation, the POST form has undergone a number of changes to create a form tailored to the needs of West Virginian practitioners and patients. The last time the form was revised was in 2006 (Moss, 2008).

West Virginia has been very conscious about ensuring that the POST is continually evaluated. During the first stages of implementation, chart reviews were done at nursing homes using the form to ensure adherence to patient's wishes (Moss, 2008). To better understand the usefulness of POST, West Virginia participated in a National Institutes of Health (NIH) funded study to look at the use of POST forms in nursing homes. Though not complete, the results so far have shown that the POST is associated with patient's end-of-life care wishes being respected (Moss, 2008).

In West Virginia, the POST form is bright pink in color (*Using the POST Form: Guidance for Healthcare Professionals*, 2007). While social workers, physician assistants, and nurse practitioners are able to help a patient complete the form and sign in the area designated for the preparer, only a licensed physician can sign and activate it (POST Task Force, 2007). Under the West Virginia Health Care Decisions Act in §16-30-13(d), POST forms must be reviewed whenever the patient is transferred between facilities (POST Task Force, 2007).

West Virginia has worked very hard to ensure that both the public and professional populations are aware of POST. For patients and families, videos, presentations, and brochures have been developed. Presentations are often done at senior centers and at consumer group meetings in order to ensure that those who most need the POST form are aware of its existence (Moss, 2008). Newsletters and newspapers have run articles presenting basic information on POST and instructing patients to consult their primary care provider for more information (Moss, 2008). In addition, professional education has been an important component of the POST program. A guidebook for providers was developed that details when and how the POST form should be used. Additionally, a video titled “The POST Form: A Better Way to Respect Patients’ Wishes” was developed (Moss, 2008). These educational materials help both physicians and patients understand the use of POST and develop the skills necessary to use it effectively.

Enabling the use of POST in West Virginia required legislative changes. In 2002, the “West Virginia Health Care Decisions Act” was passed (“West Virginia Health Care Decisions Act”, 2002). This Act specified the way advance directives for the State of West Virginia would need to be worded in order to be effective. In addition, §16-30-25 stated how the state would implement the new POST form:

(a) No later than the first day of July, two thousand three, the secretary of the department of health and human resources shall implement the statewide distribution of standardized physician orders for scope of treatment (POST) forms.

(b) Physician orders for scope of treatment forms shall be standardized forms used to reflect orders by a qualified physician for medical treatment of a person in accordance with that person's wishes or, if that person's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with that person's best interest.

The form shall be bright pink in color to facilitate recognition by emergency medical services personnel and other health care providers and shall be designed to provide for information regarding the care of the patient, including, but not limited to, the following:

- (1) The orders of a qualified physician regarding cardiopulmonary resuscitation, level of medical intervention in the event of a medical emergency, use of antibiotics and use of medically administered fluids and nutrition and the basis for the orders;
- (2) The signature of the qualified physician;
- (3) Whether the person has completed an advance directive or had a guardian, medical power of attorney representative or surrogate appointed;
- (4) The signature of the person or his or her guardian, medical power of attorney representative, or surrogate acknowledging agreement with the orders of the qualified physician; and
- (5) The date, location and outcome of any review of the physician orders for scope of treatment form.

(c) The physician orders for scope of treatment form shall be kept as the first page in a person's medical record in a health care facility unless otherwise specified in the health care facility's policies and procedures and shall be transferred with the person from one health care facility to another ("West Virginia Health Care Decisions Act", 2002).

These changes to the legislative code helped to initiate the full implementation of POST across the state and are an example of how a state was able to overcome barriers to implementation by using issuing legislations.

### **2.2.2 POST in Washington State**

The State of Washington began using the POLST form in 2000 and is now a POLST Paradigm Endorsed Program (Bender, 2005). POLST forms are used in home care settings, long-term care facilities, hospitals, hospice facilities, and emergency departments across the entire state (Bender, 2005). The POLST program in Washington came into being after the Regional Ethics Network of Eastern Washington (RENEW) held a community forum in 2000 to discuss advance directives. A physician from Oregon was in attendance and described Oregon's POLST program (Bender, 2005). Following this presentation members of RENEW and some Eastern Washington health care facilities reviewed the evidence available on the POLST and found that it was an improvement over the current advance directive programs available in Washington (Bender, 2005). These same agencies then received a grant from the Washington State Medical Association (WSMA) to do demonstration projects using POLST in two counties. After six months, WSMA and the Washington Department of Health (DOH) decided that the evidence was convincing enough for them to adopt POLST state-wide (Bender, 2005).

To facilitate the use of POLST in Washington, the advisory teams have created a number of training and educational sources. Videos are available to help providers learn how to effectively use the POLST. These videos were created by the WSMA and were provided to all nursing homes, hospitals, and EMS trainers in the state. In addition, the WSMA provides trainers to facilities who desire a greater more in-depth training (Bender, 2005). As public awareness was also important, video tapes and brochures were made available to the public to introduce them to the concept of POLST. A number of newspaper articles on the topic were also written, adding to the public's awareness of the form (Bender, 2005; Cooley, 2005; Osborn, 2005; Ostrom, 2005).

Unlike West Virginia, the adoption of POLST in Washington did not require legislative changes. Instead, the State was able to use regulatory methods to implement POLST. Prior to the initiation of POLST, the Department of Social and Health Services (DSHS) had interpreted the advance directive statute for the state in a way that prohibited surrogate decision makers from making decisions regarding DNR orders, even if the patient had had stated a preference (Bender, 2005). RENEW initiated several meetings with DSHS in order to convince them to reinterpret the statute in a way that made the POLST viable (Bender, 2005). One of the reasons for this flexibility was that the form contained both the physician's and the surrogate's signature (Bender, 2005). Regulatory changes also allowed the DOH to make changes regarding which forms were acceptable for use in the state, allowing them to designate the POLST over the original form without having to pass new legislation (Bender, 2005).

### **3.0 POLST IN OREGON: AN EXAMPLE**

Both West Virginia and Washington developed their programs after looking at the success of the POLST program in Oregon. The State of Oregon has worked extremely hard to improve end-of-life care for its residents. Since the mid-1980s the state has worked to educate citizens, practitioners, and facilities on advance care planning, end-of-life treatment procedures, and the process of dying (Tolle & Tilden, 2002). While Oregon is most famous for its Death with Dignity Act that allowed for physician-assisted suicide, the state has focused largely on other measures of providing comfort at the end-of-life (Tolle & Tilden, 2002).

The success of POLST in Oregon cannot be taken out of context. The state has enacted numerous measures surrounding end-of-life issues that have made it easier for the POLST to be successful. Using Tolle and Tilden's (2002) classifications, there are three changes in Oregon that allowed for the success of the POLST: (1) changes in public knowledge, (2) changes in rates of advance planning, and (3) changes in location of death and associated cost of inpatient care (Tolle & Tilden, 2002).

#### **3.1 CHANGE IN PUBLIC KNOWLEDGE**

Public knowledge of end-of-life options is important for improving rates of use. A group called Oregon Health Decisions has worked since the mid-1980s to improve Oregonians knowledge of

care options. The group conducts outreach activities, distributes advance directive information, conducts train-the-trainer programs, and conducts town meetings (Tolle & Tilden, 2002). In addition to these education activities, *The Oregonian*, a statewide newspaper, ran multiple articles describing how hospice works, who can benefit from it, and how to enroll (O'Keefe, 1997; O'Neil, 2005). Many local newspapers also ran stories on the POLST form, telling readers what the form is and how it can be used (Brown, 2005; Kettler, 2005). Media attention to end-of-life issues increased in 1994 and 1997 due to the passing of the physician-assisted suicide Death with Dignity Act. This much media attention surrounding issues of end-of-life served to facilitate conversation between family members and patients and providers and “increased the general sense of empowerment of the public in citizen’s right to serve as decision maker for him or herself and to authorize loved ones to make choices about end-of-life treatments” (Tolle & Tilden, 2002).

### **3.2 CHANGE IN RATES OF ADVANCE PLANNING**

The outreach and education measures taken by Oregon organizations have in fact had an effect on the rates of advance planning. The rates of advance directives and DNR orders in Oregon are extremely high (Tolle & Tilden, 2002). In 1993 a study found that 70% patients in nursing homes in Portland, Oregon, had DNR orders. Just three years later a second study found that 91% of nursing home residents in Oregon had written DNR orders (Tolle & Tilden, 2002). A study conducted in 1997-1998 using families of Oregonians who had recently passed away found that 67% of families reported that the decedent had some form of an advance directive. In

addition, 93% of families reported in the study felt that they knew what the decedent would have wanted with regard to life-sustaining treatment (Tolle & Tilden, 2002).

### **3.3 CHANGE IN LOCATION OF DEATH**

Location of death has also changed significantly over the years in Oregon. In 1980, half of all Oregonians died in an acute care hospital setting. In 1993 this figure dropped to 35%. In the same year the rate for the United States was 56%. As of 2002, Oregon continued to have the lowest rate of in-hospital death for any state (Tolle & Tilden, 2002; Tolle et al., 1998). This change in location of death has greatly reduced the cost for the last six months of life. In addition to having the lowest rate of in-hospital death, Oregon has the lowest rate of inpatient expenditures in the final six months of life for Medicare enrollees. The level of care has not been compromised as a result of these changes. Overall, studies have found that families of recently deceased Oregonians have found that overall families are pleased with the amount and quality of care that the patient received (Tolle & Tilden, 2002).

Implementation of the POLST did not occur overnight in Oregon. It took about a decade for the task force to go through the initial design stages to complete dissemination. The task force worked to ensure that all the proper stakeholders were at the table when the process began. Stakeholders included lawyers, physicians, nurses, EMTs, and other member of the medical community (Tolle & Tilden, 2002). The task force focused primarily on data collection up front. As discussed previously, focus groups were done with the original versions of the form to ensure that the language was appropriate and that the form could be easily understood (Dunn et al., 1996). In a second data collection stage, pilot studies were done to ensure that use of the form

would not keep patients from receiving needed care (Tolle et al., 1998). The data gained from the trials ensured that the task force had the necessary proof when they went to other entities, like the Oregon Board of Medical Examiners in order to revise the Scope of Practice for Emergency Medical Personnel (Tolle & Tilden, 2002).

### **3.4 MEASURES OF SUCCESS**

The success of the POLST in Oregon can be demonstrated in the fact that the state distributes roughly 7,250 forms each month and an average of 87,000 per year (Dunn, 2008). This is huge considering that the number of Oregonians who die each year is just over 30,000 (Tolle & Tilden, 2002). Many long-term care facilities have largely adopted the use of the POLST. The form is considered the standard of care in 96% of nursing facilities in the state. These facilities all have more than half of their patients using the form (Dunn, 2008). In addition, some hospitals mandate that patients released to long-term care facilities, other institutional setting, or home hospice complete the POLST (Tolle & Tilden, 2002).

The success of POLST lies in whether or not the form actually changes the way patients are cared for. A 2004 study of EMTs in Oregon helped to determine whether the form was in fact serving its purpose. Surveys were mailed to a random sample of EMTs working in the area surrounding Portland, Oregon. The results showed that 73% of EMTs had treated a patient with a POLST form. Respondents stated that the form changed the way they would treat a patient in nearly half of the cases when a POLST was present. More than 90% of respondents felt that the form was useful in deciding what to do in circumstances when the patient was in cardiopulmonary arrest and two-thirds felt that the form was useful in determining what

treatment to provide when the patient had a pulse and was breathing. Seventy-four percent of EMTs reported having some training on the form, an outcome that shows how much work has gone into educating providers (Schmidt et al., 2004).

### **3.5 FUTURE DIRECTIONS FOR POLST IN OREGON**

Oregon continues to try and make the POLST system more effective and convenient for its citizens. The newest venture is the Electronic POLST Registry. This system would allow patients with POLST forms to have them placed in an electronic registry. The registry would prove useful to EMTs under a variety of circumstances where the POLST form could not be immediately located. In the short film distributed by the OHSU Center for Ethics in Health Care, two women are gardening in their retirement community on a hot day. The first woman, who the viewer is told has significant medical problems, collapses. When the EMTs arrive they ask the friend if the unconscious woman has a POLST form. While the answer is yes, the form is back in the apartment complex, a building which is a considerable distance from the garden. The EMTs are able to call the registry, provide the patient's name, and receive all of the necessary information to treat the patient according to her wishes. The EMTs in the film reiterate the fact that without proper legal guidance, they are required to do everything they possibly can for a patient (Keiter & Toole, 2009).

This next step in Oregon's POLST journey is coming to fruition in summer 2009. At the beginning of the Oregon House of Representatives Legislative Session House Bill 2132 was introduced. This bill has two parts: (1) to facilitate the development of an Electronic POLST Registry and (2) establish an advisory committee for the Electronic POLST Registry. The first

portion of this goal is met through the following wording in the Act: “The Department of Human Services shall establish and operate a statewide registry for the collection and dissemination of physician orders for life-sustaining treatment to help ensure that medical treatment preferences for an individual nearing the end of the end of individual’s life are honored” (“POLST Registry (End-of-Life Care”, 2009). The second goal of the Act is to develop an advisory committee whose job is to oversee the process of creating such a registry. The Act states that “There is established the Oregon POLST Registry Advisory Committee to advise the Department of Human Services regarding the implementation, operation and evaluation of the POLST registry” (“POLST Registry (End-of-Life Care”, 2009). Oregon’s commitment to creating such a registry is reiterated in the final portion of the act that states that “This 2009 Act being necessary for the immediate preservation of the public peace, health and safety, an emergency is declared to exist, and this 2009 Act takes effect July 1, 2009” (“POLST Registry (End-of-Life Care”, 2009). A model of this registry currently exists in Clackamas County, one of the counties in the Greater Portland area (*Fact Sheet: End of Life Care*, 2009).

## **4.0 POLST IN PENNSYLVANIA**

Like many states, Pennsylvania heard about the success of POLST in other areas of the United States and decided to look into adopting a POLST-like form. Despite having used the form in the state for nine years, Pennsylvania has had limited success in fully implementing the form. They continue to be listed as a state with a developing POLST program on the POLST Paradigm website. Though there are many organizations working to create a better POLST program in Pennsylvania, there are a number of barriers to the Commonwealth being able to have a fully implemented, POLST Paradigm Endorsed program.

### **4.1 HISTORY OF POLST IN PENNSYLVANIA**

In the year 2000, Pennsylvania followed in the footsteps of Oregon and other states and developed its own POLST program. The program was begun by Dr. Judith Black at Highmark, an insurance company that serves 29 counties in Western Pennsylvania and 21 counties in Central Pennsylvania (Highmark, 2007). The program started under Highmark's Advance Care Planning/End-of-Life Initiative. Dr. Black had heard about the form being used in Oregon and knew that one nursing facility, Lutheran Affiliated Services-Passavant, was using the form. Highmark reviewed the records of those members who had been at this facility prior to death to see if there was any difference in the care that they received. Highmark discovered that patients

in this facility were more likely to have their end-of-life wishes respected and had fewer hospital admissions at the end-of-life (Marian Kemp, personal communication, March 31, 2009).

After reviewing this data, Advance Care Planning/End-of-Life Initiative immediately endorsed the use of POLST. In 2002, Highmark Inc. collaborated with Jewish Healthcare Foundation, not-for-profit charity that supports health care services and research to protect vulnerable populations (JHF, 2009), and began the use of POLST in more nursing facilities throughout Western Pennsylvania (Kemp, 2007). In 2004, a group of community leaders formed the Coalition for Quality at the End-of-Life (CQEL) in order to improve end-of-life care in Western Pennsylvania (Kemp, 2007). This group brings together the medical director, administrative director, and nursing directors from nursing homes to improve relationships between centers and help them better serve their residents (Marian Kemp, personal communication, March 31, 2009). In 2006, of the 14 groups that came together, almost all chose implementation of POLST as an important project that they wished to implement in their facilities (Marian Kemp, personal communication, March 31, 2009). Among the things the group has been charged with, they have the task of developing a plan to implement POLST throughout the region. The plan includes “a ‘POLST Repository’ for the providers and consumers to use for information, developing a ‘train the trainer’ model for education and enlisting the support of those who can facilitate the use of POLST in various settings” (Kemp, 2007). This is accomplished through the Document Treatment Preferences workgroup, one CQEL’s five workgroups (CRHC, 2009).

## 4.2 CURRENT USE OF POLST

Currently, the POLST form is being used in the following eight counties: Allegheny, Beaver, Butler, Lawrence, Lycoming, Mercer, Washington, and Westmoreland. Highmark is currently distributing roughly 2000 forms per month (Marian Kemp, personal communication, March 31, 2009). Despite this, the POLST form is not officially recognized by the Commonwealth of Pennsylvania. The out-of-hospital DNR order is the only document that EMS personnel are allowed to follow with regard to withholding CPR (Kemp, 2007). In response to Act 169 of 2006, the Commonwealth established a committee whose job it was to make recommendations to the Secretary of Health regarding the POLST form. After the committee looked at the form, they made recommendations to the Commonwealth that the form be adopted with a few changes. While no official announcement had been made in April 2009, unofficially the Commonwealth has decided to recommend that the POLST be adopted (Kemp, 2009). While mandating the use of POLST would provide faster benefits, recommendation will bring about greater recognition for the form and its uses.

In creating a POLST-like form for Pennsylvania, the committee working to develop a form for Pennsylvania made two changes. First, Pennsylvania requires that either the patient or the patient's surrogate sign the form (Kemp, 2009). On the original form, this signature is marked as optional. Second, in Section D, where the patient selects the level of artificially administered nutrition that they desire, an additional category of intravenous fluids was added (Kemp, 2009). Previously, the form had only included options pertaining to nutrition by food. Though the POLST form indication in the directions for health care providers that individuals who chooses "limited interventions" or "full treatment" should receive IV fluids, this may not be

clear to the patient completing the form or be what the patient intends. The additional category will help to ensure that all of a patient's desires for treatment are understood.

The Commonwealth of Pennsylvania has worked to increase awareness of the POLST form among medical professionals as well as health plans (Kemp, 2007). Thus far education campaigns have focused on professional education only. Brochures and videos are available to health care professionals interested in learning more about the POLST and how to talk about the subject of end-of-life care with patients (Kemp, 2007). Medical professionals can take a course for continuing education units through the University of Pittsburgh Health Sciences eLearning Environment Internet-Based Studies in Education and Research. The course is titled *Physician Orders for Life-Sustaining Treatment (POLST): Respecting Patient Choices Across the Continuum of Care* (Black, 2008).

In 2007, Pennsylvania Act 169 was passed. In addition to defining the terms of advance care planning in Pennsylvania, this legislation sought to define a number of terms related to end-of-life care. The term life-sustaining treatment was defined as "Any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the process of dying or to maintain the patient in a state of permanent unconsciousness". Act 169 also attempted to define the term terminal condition: "An incurable and irreversible medical condition in an advance state caused by injury, disease or physical illness which will, in the opinion of the attending physician, to reasonable degree of certainty, result in death regardless of the continued application of life-sustaining treatment". In addition, it defined end of life decision making for incompetent adult patients. Importantly for the enactment of POLST in Pennsylvania, the Act required the Commonwealth to form a committee whose mission is to "determine the

advisability of using a standardized form containing orders by qualified physicians that detail the scope of medical treatment for patients' life-sustaining wishes" (Hughes, 2007).

In 2009, a number of long-term care facilities, hospitals, and hospice programs were using the POLST form. As long-term care facilities have been at the forefront of implementing POLST, the greatest number of fully implemented programs can be found in this setting. The majority of these programs are found in Southwestern Pennsylvania, but are quickly spreading to other areas of the state (Kemp, 2009). The tables below list the long-term care facilities, hospitals, and hospice programs in the Commonwealth of Pennsylvania that are either using the POLST form or are in the process of implementing the POLST form. Programs listed as educational programs are using the POLST form and providing community education regarding its use.

**Table 2.** List of Long-Term Care Facilities in Pennsylvania with POLST Programs

Program Status	Institution
Fully Implemented Programs (n=36)	Altoona Center for Nursing Care Asbury Heights Baptist Homes of Pittsburgh Cedars of Monroeville Community LIFE (four locations) Concordia at Rebecca Concordia Lutheran Ministries Forbes Road Nursing and Rehab Friendship Ridge Friendship Village of South Hills Golden Living Center, Monroeville Grane, Providence Care Center, Beaver Harmar Village Care Center John J. Kane Regional Center, Glen Hazel John J. Kane Regional Center, Glen McKeesport John J. Kane Regional Center, Ross Township John J. Kane Regional Center, Scott LAS Passavant LAS St. Johns Lawson Nursing Home, Clairton Longwood at Oakmont Lutheran Community at Telford ManorCare Bethel Park ManorCare Greentree ManorCare Whitehall Presbyterian Senior Care Reformed Presbyterian Residence for Renal Care, Baum Boulevard, Pittsburgh Rochester Manor Shenango Presbyterian Senior Care St. Anne Home- Greensburg St. Paul’s Home Sycamore Creek The Heritage of Shadyside UPMC Canterbury Place UPMC Cranberry Place UPMC Horizon TCU UPMC Seneca Place Ursuline Senior Services Guardianship Program Valley View Home, Altoona Villa St. Joseph of Beaver Vincentian DeMarillac Vincentian Regency

**Table 2 Continued**

Fully Implemented Programs (continued)	Westwood Center for Nursing and Rehab Woodhaven Care Center Woodside Place
Educational Programs (n=4)	Beaver Elder Care Country Meadows Grane, Altoona Center for Nursing Care Townview Health and Rehabilitation Center
Implementation in Progress (n=10)	Garvey Manor, Hollidaysburg Golden Living Center, Hillview Golden Living Center, Mt. Lebanon ManorCare McMurray Mariner North Hills Mariner West Hills Rehabilitation and Nursing Center of Greater Pittsburgh, Greensburg Redstone Highlands Rittenhouse Pines ECF, Norristown Valley Care Masonic Home

**Table 3.** List of Hospitals in Pennsylvania with POLST Programs

Program Status	Institution
Fully Implemented Programs (n=12)	St. Clair Hospital UPMC Presbyterian UPMC Shadyside UPMC St. Margaret UPMC McKeesport Heritage Health System, Sewickley Heritage Health System, Beaver Lewistown Hospital Montgomery Hospital Medical Center, Norristown Susquehanna Health System Divine Providence , Williamsport Divine Providence, Muncy Valley
Implementation in Process (n=3)	Summit Health System, Waynesboro Summit Health System, Chambersburg Uniontown Hospital

**Table 4.** List of Hospice Programs in Pennsylvania with POLST Programs

Program Status	Institution
Fully Implemented Programs (n=5)	Grane Hospice Family Hospice and Palliative Care- Inpatient Units Heartland Hospice (ManorCare) Montgomery Hospital Home Care and Hospice Divine Providence Hospices
Educational Programs (n=2)	Bethany Hospice Harmony Hospice
Implementation in Process (n=1)	Vitas Hospice

### **4.3 BARRIERS TO FULL IMPLEMENTATION**

The progress that has been made in Pennsylvania with regard to POLST is amazing, especially considering that there have not been any legislative or regulatory changes made. Despite the progress made, there are a number of barriers to the Commonwealth being able to fully implement the POLST form. Barriers to implementation include organizational management, acceptance of physicians and facilities, lack of evaluation, current laws, and the inability of the forms to be signed by physicians assistants and nurse practitioners. Pennsylvania currently meets most of the criteria to become a POLST Paradigm Endorsed Program; however, in order to become endorsed Pennsylvania needs to meet four more requirements: 1) the form needs to constitute a set of medical orders that must be followed by both EMS in the field and professionals in the emergency room, 2) a plan for ongoing training for medical personnel needs to be developed, 3) the form needs to be transferrable across settings, including when using

home care, and 4) a plan for ongoing evaluation of the form needs to be developed (Kemp, 2007).

A major barrier to full implementation has come from the management of the POLST program. Currently, the POLST is being managed by Highmark. While Highmark has been involved in POLST since it began in the state, they struggle to be able to continue running the program (Kemp, personal communication, March 31, 2009). Highmark does not have the staff to have someone working on POLST full time. Instead, staff members who have other jobs are asked to be involved in distributing POLST forms and facilitating efforts around the state (Kemp, personal communication, March 31, 2009). In addition to staffing concerns, the fact that Highmark is a health plan keeps them from being able to do public education campaigns: “We’re a health plan and we have to be very careful that we are not perceived as attempting to limit care” (Kemp, personal communication, March 31, 2009). Public education campaigns have been an integral part of public acceptance of the form in West Virginia, Washington, and Oregon, and could play an integral role in the acceptance of POLST in Pennsylvania, provided that the right source is providing the education.

While POLST has been gaining the acceptance of physicians and medical directors, it has been especially difficult explaining that if a patient has an advance directive the physician cannot simply transfer the data from the advance directive onto the POLST form. A necessary component of the POLST form is that the provider has a conversation with the patient regarding each area on the form (Kemp, personal communication, March 31, 2009). Education programs play a major role in ensuring that physicians fully understand how to use the POLST form. This education also helps to convince individuals and facilities that POLST is a worthwhile program

that should be initiated. Initiatives have been especially successful when a physician at the facility accepts and champions the POLST (Kemp, personal communication, March 31, 2009).

Another barrier that Pennsylvania has faced relates to the evaluation of POLST programs. Past the initial evaluation done by Highmark, no studies have been done in Pennsylvania to show that the POLST is a useful instrument (Kemp, personal communication, March 31, 2009). Currently no funding has been provided for any group or agency to do a formal evaluation (Kemp, personal communication, March 31, 2009). Looking at how well the wishes of an individual are respected if they have completed a POLST compared to those who have not completed one would help to convince other facilities and the Commonwealth that the use of such a form would be beneficial.

State laws also interfere with full implementation of POLST in Pennsylvania. A review of state laws found that a number of states have barriers to fully implementing the use of POLST. Of the eight barriers addressed, Pennsylvania was found to have three, significantly less than many other states. The three barriers for Pennsylvania were lack of default surrogate provisions, detailed statutory out-of-hospital DNR forms or identifiers, and medical preconditions for out-of-hospital DNR (Hickman et al., 2008). Having a detailed statutory out-of-hospital DNR form or identifier was found to be the most problematic in the use of POLST, since these forms apply even in the home. These barriers are often found in the necessity for a person to be in the end-of-life stages or have a terminal condition, terms which are not uniformly defined (Hickman et al., 2008).

Unlike in Oregon, nurse practitioners and physicians assistants are unable to sign a POLST form; only a physician may authorize its use (Black, 2008). So far, this has not proven to be a barrier to the implementation of POLST. In practice, social workers are involved in filling

out the majority of completed POLST forms in the Commonwealth, though nursing staff, nurse practitioners, and physician assistants also complete the forms. These completed forms are then given to the attending physician for final approval (Kemp, 2009).

## **5.0 RECOMMENDATIONS FOR PENNSYLVANIA**

While Pennsylvania has begun to institute POLST in some communities around the Commonwealth, there is still much to be done in order to fully implement the form in the fashion that it is meant to be used. Based on a review of successful programs in other states, there are a number of actions Pennsylvania could take that facilitate greater implementation of the form across the Commonwealth.

One of the first moves that Pennsylvania needs to make in order to better implement the POLST is to launch an educational campaign for both the general public and health care professionals. One reason why the POLST was so successful in Oregon is that the public was already discussing issues of advance directives and end-of-life care. Additionally, the educational measures undertaken by West Virginia have also shown to be effective in increasing the use of POLST forms. These discussions make discussing life-sustaining treatment with family, friends, and providers more productive. In addition, communication campaigns would push individuals to begin requesting the use of the form when they are diagnosed with a terminal condition. In addition, targeting the general public would also target providers, who are also members of the community. These campaigns should not only focus POLST, but on other issues of palliative and end-of-life care including hospice, advance directives, and DNRs. Increased use of end-of-life resources, like hospice care, will help patients to access the needed assistance in obtaining and filling out POLST. Since Highmark is unable to undertake this task in a productive

way, another agency would need to take over this task. The Department of Health is the obvious government agency to take on such a task. Another option would be through CQEL or the University of Pittsburgh Institute to Enhance Palliative Care. Either of these groups would be able to launch a successful campaign without appearing to restrict care for patients.

Second, the Commonwealth of Pennsylvania needs to work to develop more demonstration projects that are closely monitored and evaluated. If changes are to be made to policies that are a barrier to full implementation, researchers will need to be able to present concrete proof that the program actually works. While data from studies done in Oregon and other states is in fact compelling, it is necessary for lawmakers to see the effect that POLST can have in Pennsylvania. Like Oregon, the Commonwealth needs to be able to convince the accrediting body for the EMS service that POLST should be an order capable of being followed by EMTs in the field. Compelling evidence that POLST forms indicate the preferences of patients in Pennsylvania and that these preferences are properly carried out when the patient has a POLST is necessary to convince lawmakers and organizations that it is worth changing policy in order to fully implement the form. A prospective study looking at whether individuals with POLST forms are more likely to have their end-of-life wishes honored would help to prove that the form is a useful tool for Pennsylvania's population.

The most important policy change that needs to be made in order to make the POLST a useful instrument in the commonwealth is allowing EMTs to follow the orders on the form. Currently, EMTs in Pennsylvania are allowed to follow out-of-hospital DNR orders, but not DNR orders on the POLST. As the POLST is signed by a physician who has discussed the orders with the patient, it should be a valid order that can be used in the field during an emergency situation. The POLST form needs to be applicable across all environments of care so that the

transfer of the patient does not interfere with the continuum of care. Other states have implemented procedures that allow EMTs to use POLST in the field and Pennsylvania should follow in their footsteps. Changing the scope of the job, like Oregon, keeps EMTs from being held responsible for denying any treatment in the field when a POLST is present.

## 6.0 CONCLUSION

Quality care at the end-of-life is extremely important for Pennsylvania. The Commonwealth's increasing older population means that a greater number of individuals will be demanding access to good palliative and end-of-life care in the coming years. A first step to providing this care is ensuring that both the patient and the provider know what the patient's care preferences are. After examining the literature surrounding POLST, it is clear that it is an effective tool for recording these preferences. The portability and simplicity of the form make it ideal for ensuring that conversations between patients and providers take place regarding preferences for life-sustaining treatments. Studies have shown that patients with POLST forms are more likely to have their end-of-life wishes respected. In addition, these patients are more likely to be allowed to die outside a hospital setting, an indicator that has been found to be extremely important to individuals. Finally, as many patients transfer between care settings during the last few months of life, the POLST provides a way to ensure continuity of care. As the POLST form is a simple, non-technical, and inexpensive device, Pennsylvania should adopt a POLST-like form for use across the Commonwealth. This form would help to ensure that Pennsylvanians receive quality palliative and end-of-life care, independent of the type of facility they are in.

The knowledge that the POLST form could help many Pennsylvanian's receive quality end-of-life care is not unknown to the State. The fact that a committee was charged with examining the possibility of introducing a POLST-like form on a statewide level shows that the

Commonwealth is not only interested in such a measure, but also committed to ensuring that such a program becomes standard practice across the state. Despite this knowledge, implementation of the form has faced many barriers. Among these are lack of acceptance by facilities and providers, lack of public knowledge, inability of EMS personnel to follow POLST orders in the field, and laws that are in effect limiting the use of advance directives. While these barriers pose significant difficulties for the implementation of the POLST, there are a number of ways that the Commonwealth can work to overcome these barriers and ease acceptance of the POLST. I propose three recommendations to facilitate large scale implementation of POLST in Pennsylvania: 1) create a public and professional education program that is accessible and understandable, 2) conduct demonstration projects to prove that the POLST is effective with a Pennsylvania population, and 3) create new statutes that allow EMS providers to act upon POLST forms in the field without fear of legal action. Doing these three things will help to ensure that Pennsylvania has greater success in creating a statewide program that meets the requirements to be a POLST Paradigm Endorsed Program.

**APPENDIX A**

**OREGON POLST FORM**

# Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician, NP, or PA. These medical orders are based on the person's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section.

Last Name/ First/ Middle Initial

Address

City / State / Zip

Date of Birth (mm/dd/yyyy)

Last 4 SSN

Gender

M  F

## A CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

Attempt Resuscitation/CPR  Do Not Attempt Resuscitation/DNR (Allow Natural Death)

When not in cardiopulmonary arrest, follow orders in B, C and D.

## B 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, 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 cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). **Transfer** to hospital if indicated. Avoid intensive care.

**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: \_\_\_\_\_

## C ANTIBIOTICS

No antibiotics. Use other measures to relieve symptoms.  
 Determine use or limitation of antibiotics when infection occurs.  
 Use antibiotics if medically indicated.

Additional Orders: \_\_\_\_\_

## D ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food by mouth if feasible.

No artificial nutrition by tube.  
 Defined trial period of artificial nutrition by tube.  
 Long-term artificial nutrition by tube.

Additional Orders: \_\_\_\_\_

## E REASON FOR ORDERS AND SIGNATURES

My signature below indicates to the best of my knowledge that these orders are consistent with the person's current medical condition and preferences as indicated by the **discussion with**:

Patient  Health Care Representative  Parent of Minor  
 Court-Appointed Guardian  Other \_\_\_\_\_

Print Primary Care Professional Name

Office Use Only

Print Signing Physician / NP / PA Name and Phone Number

( )

Physician / NP / PA Signature (mandatory)

Date

**SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED**

**Information for Person Named on this Form**

This form records your preferences for life-sustaining treatment in your **current** state of health. It can be reviewed and updated by your health care professional at any time if your preferences change. If you are unable to make your own health care decisions, the orders should reflect your preferences as best understood by your surrogate.

**Signature of Person or Surrogate**

Signature	Name (print)	Relationship (write "self" if patient)
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**Contact Information**

Surrogate (optional)	Relationship	Phone Number	Address	
Health Care Professional Preparing Form (optional)	Preparer Title		Phone Number	Date Prepared
PA's Supervising Physician			Phone Number	

**Directions for Health Care Professionals**

**Completing POLST**

- Should reflect person's current preferences. Encourage completion of an advance directive.
- POLST must be signed by a physician/NP/PA to be valid. Verbal orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.
- Use of original form is encouraged. Photocopies and FAXes are legal and valid.

**Using POLST**

Section A:

- No defibrillator (including AEDs) should be used on a person who has chosen "Do Not Attempt Resuscitation."

Section B:

- 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).
- IV medication to enhance comfort may be appropriate for a person who has chosen "Comfort Measures Only."
- Treatment of dehydration is a measure which prolongs life. A person who desires IV fluids should indicate "Limited Additional Interventions" or "Full Treatment."

Section D:

- Oral fluids and nutrition must always be offered if medically feasible.
- A person with capacity, or the surrogate of a person without capacity, can void the form and request alternative treatment.

**Reviewing POLST**

This POLST should be reviewed periodically and if:

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

Draw line through sections A through E and write "VOID" in large letters if POLST is replaced or becomes invalid.

The POLST program was developed by the Oregon POLST Task Force and is housed at OHSU's Center for Ethics in Health Care. For permission to use the copyrighted form contact the Center. Information on the POLST program is available online at [www.polst.org](http://www.polst.org) or at [polst@ohsu.edu](mailto:polst@ohsu.edu).

**SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED**

**APPENDIX B**

**PENNSYLVANIA POLST FORM**

# Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician or NP. This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Last Name
First Name/ Middle Initial
Date of Birth

<b>A</b>	<p><b>CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.</b></p> <p><input type="checkbox"/> Resuscitate/CPR                      <input type="checkbox"/> Do Not Attempt Resuscitation (DNR/no CPR)</p> <p>When not in cardiopulmonary arrest, follow orders in <b>B, C</b> and <b>D</b>.</p>
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<b>B</b>	<p><b>MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.</b></p> <p><input type="checkbox"/> <b>Comfort Measures Only</b> Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <b>Do not transfer to hospital for life-sustaining treatment. Transfer if comfort needs cannot be met in current location.</b></p> <p><input type="checkbox"/> <b>Limited Additional Interventions</b> Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. <b>Transfer to hospital if indicated. Avoid intensive care.</b></p> <p><input type="checkbox"/> <b>Full Treatment</b> Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. <b>Transfer to hospital if indicated. Includes intensive care.</b></p> <p>Additional Orders: _____</p>
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<b>C</b>	<p><b>ANTIBIOTICS</b></p> <p><input type="checkbox"/> No antibiotics. Use other measures to relieve symptoms.</p> <p><input type="checkbox"/> Determine use or limitation of antibiotics when infection occurs.</p> <p><input type="checkbox"/> Use antibiotics if life can be prolonged.</p> <p>Additional Orders: _____</p>
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<b>D</b>	<p><b>ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food by mouth if feasible.</b></p> <p><input type="checkbox"/> No artificial nutrition by tube.</p> <p><input type="checkbox"/> Defined trial period of artificial nutrition by tube.</p> <p><input type="checkbox"/> Long-term artificial nutrition by tube.</p> <p>Additional Orders: _____</p>
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<b>SUMMARY OF MEDICAL CONDITION AND SIGNATURES</b>		
<p><b>Discussed with:</b></p> <p><input type="checkbox"/> Patient</p> <p><input type="checkbox"/> Parent of Minor</p> <p><input type="checkbox"/> Health Care Representative</p> <p><input type="checkbox"/> Court-Appointed Guardian</p> <p><input type="checkbox"/> Other: _____</p>	<p><b>Summary of Medical Condition</b></p>     	
<p><b>Print Physician/ Nurse Practitioner Name</b></p>	<p>MD/DO/NP Phone Number</p>	<p>Office Use Only</p>
<p><b>Physician/ NP Signature (mandatory)</b></p>	<p>Date</p>	

**SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED**

## HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

### Signature of Person, Parent of Minor, or Guardian/Health Care Representative

Significant thought has been given to life-sustaining treatment. Preferences have been expressed to a physician and/or health care professional(s). This document reflects those treatment preferences. (If signed by surrogate, preferences expressed must reflect patient's wishes as best understood by surrogate.)

Signature (optional)	Name (print)	Relationship (write "self" if patient)
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### Contact Information

Surrogate (optional)	Relationship	Phone Number	
Health Care Professional Preparing Form (optional)	Preparer Title	Phone Number	Date Prepared

## Directions for Health Care Professionals

### Completing POLST

Must be completed by a health care professional based on patient preferences and medical indications.

POLST must be signed by a physician or nurse practitioner to be valid. Verbal orders are acceptable with follow-up signature by physician or nurse practitioner in accordance with facility/community policy.

Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid.

### Using POLST

Any incomplete section of POLST implies full treatment for that section.

No defibrillator (including AEDs) should 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).

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

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

A person with capacity, or the surrogate of a person without capacity, can request alternative treatment.

### Reviewing POLST

This POLST should be reviewed periodically and if:

- (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.

Draw line through sections A through E and write "VOID" in large letters if POLST is replaced or becomes invalid.

## The Oregon POLST Task Force

The POLST program was developed by the Oregon POLST Task Force. The POLST program is administratively housed at Oregon Health & Science University's Center for Ethics in Health Care. Research about the safety and effectiveness of the POLST program is available online at <[www.polst.org](http://www.polst.org)> or by contacting the Task Force at <[polst@ohsu.edu](mailto:polst@ohsu.edu)>.

**SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED**

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