

**PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT (POLST): HOW DO
NURSING FACILITIES IMPLEMENT THE POLST PROGRAM?**

by

Jason W. Manne

BS, State University of New York, 1975

JD, University of Pittsburgh, 1979

MHA/MBA, University of Pittsburgh, 2003

MA (Bioethics), University of Pittsburgh, 2007

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This dissertation was presented

by

Jason W. Manne

It was defended on

September 7, 2012

and approved by

Dissertation Advisor:
Steven M. Albert, PhD
Professor

Department of Behavioral and Community Health Sciences
Graduate School of Public Health
University of Pittsburgh

Committee Member:
Nicholas Castle, PhD
Professor, Department of Health Policy & Management
Graduate School of Public Health
University of Pittsburgh

Committee Member:
Howard B. Degenholtz, PhD
Associate Professor
Department of Health Policy & Management
University of Pittsburgh

Committee Member:
Scott Beach, PhD
Assistant Professor
Department of Behavioral and Community Health Sciences
Graduate School of Public Health
University of Pittsburgh

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Jason W. Manne, DrPH

University of Pittsburgh, 2012

The Physician Orders for Life-Sustaining Treatment (POLST) is a novel end of life advance planning tool. In form, the POLST is a medical order. However the document is completed before the onset of a medical crisis, and can be used by patients to direct medical treatment much like a living will. End-of-life care is an important public health concern, and it is hoped that the POLST will give individuals greater control over their medical care.

I surveyed 19 nursing homes using the POLST form in one Pennsylvania county to determine whether the POLST is being implemented in the way intended by its designers. The survey asked whether the POLST is presented to residents as required, recommended, or optional; whether the POLST is offered to all nursing home residents or only certain types of residents; whether the facility requires a patient or surrogate signature on the form; whether the facility updates the form at resident care conferences or upon a change in medical condition; whether the facility screens the POLST for errors and makes sure it is signed by an appropriate medical professional before it is put into the chart; and how much time it typically takes to complete a POLST for residents with and without a living will. The survey also asked whether facilities were complying with state law procedural requirements for end-of-life decision making when using the POLST.

The survey found that most nursing facilities reported that they present the form as being required, and they offer it to all residents regardless of medical condition. Approximately half of the facilities follow the recommendation of the National POLST Paradigm Task Force to obtain

a resident or surrogate signature on the POLST. Almost all respondents said they typically complete a POLST for a resident who does not have a living will in less than an hour. Most facilities update the form upon a change in medical condition and check the form for errors. Many of the surveyed nursing homes are not complying with procedural requirements of state law when using the POLST to implement decisions regarding end-of-life medical treatment.

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1.0 INTRODUCTION

Death cannot be defeated, but many of us would like to control how we die. Towards this end, American society has embraced the living will as a way for individuals to manage their dying process. Until fairly recently, most research had shown the living will to be largely ineffective (President's Council on Bioethics, 2005). The Physician Orders for Life-Sustaining Treatment or POLST was developed to address the perceived weaknesses of living wills, and to provide a more effective method for individuals to control the care they receive at the end of life.¹

The POLST was developed in Oregon and its use is rapidly spreading throughout the United States and internationally. As of this writing, POLST is known to be used in California, Colorado, Hawaii, Idaho, Louisiana, Montana, New York, North Carolina, Oregon, Pennsylvania, Tennessee, Utah, Washington, and West Virginia, as well as in parts of Wisconsin (Oregon Health and Science University, 2012). Programs are being developed in more than a dozen of other states, as well as in France, Spain, and Japan. Id. Some professional organizations have suggested that use of the POLST become standard practice nationwide (Cerminara & Bogin, 2008). Moves were made in Congress to incorporate the

¹ The POLST goes by other names including the MOLST (NY), POST (W.Va), MOST(North Carolina) and COLST (Vermont) (Sabatino & Karp, 2011, p v.)

POLST into Federal law as a part of the National health reform legislation. However, a proposal to include Medicare funding for POLST completion was “pulled from health care reform legislation in 2010 because of the frenzy it triggered” (Sabatino & Karp, 2011, p. 24). Former vice presidential candidate Sara Palin characterized the section of the bill containing the POLST provisions as establishing “death panels”.²

The POLST is a set of medical orders that directs the provision or withholding of specified life-sustaining medical treatments. In form, the POLST is similar to medical order sets that are routinely completed by doctors in hospitals and nursing homes to specify or limit life-sustaining treatments for patients who are near the end of their lives.^{3, 4} However, the POLST differs from a conventional critical care medical order set in that it is often signed by a physician before the onset of a medical crisis, and the instructions are based upon treatment preferences specified by the patient or a representative in advance. Moreover, unlike conventional end-of-life medical orders written in hospitals or nursing homes, a POLST may be kept at home by a patient and it is designed to be transferable between treatment settings.

Although it is in the form of a medical order, the POLST is similar to an instruction directive or living will because it contains treatment instructions provided by the patient to direct the provision or withholding of life-sustaining medical care in the event the patient

² The provision for the POLST was contained in section 1233 of H.R. 3200, an early version of the health reform legislation.

³ A medical order is an order of a specifically identified medical practitioner lawfully acting within the scope of his license for a specifically identified patient’s health care needs. See e.g. Kentucky Revised Statutes, 315.010 (2006).

⁴ A POLST order may be signed by a physician assistant or nurse practitioner where state licensing laws permit. However, for convenience, this paper shall refer to a POLST being signed by a “doctor” or “physician.”

becomes incapacitated or unable to communicate in the future.⁵ Indeed, the President’s Council on Bioethics has characterized the POLST as “novel form of instruction directive” (President’s Council on Bioethics, 2005, p. 76). However, the POLST differs from a living will by being immediately effective. Instruction directives generally do not become operative until there is a medical determination that a patient is terminally ill or permanently unconscious (Meisel & Cerminara, 2004).⁶ Additionally, most instruction directives are legal documents that are subject to formalities such as witnessing (Meisel & Cerminara, 2004). There are no such requirements for the POLST. One scholar has characterized the POLST as “a living will on steroids” (Hays, 2012). A table summarizing the similarities and differences between the POLST, critical care medical orders, and a living will appears below.

The POLST was created because conventional instruction directives often do not fulfill the goal of affecting the medical care that patients receive at the end of life (Ditto & Hawkins, 2005). The POLST was specifically designed to overcome the weaknesses perceived to be inherent in living wills that sometimes cause them to be ineffective. The POLST bridges the divide separating patient preferences from their implementing medical orders to order to increase instances when doctors and nurses follow a patient’s written end of life treatment instructions (Cerminara & Bogin, 2008).

⁵ In this paper, the terms “instruction directive” and “living will” are used interchangeably. The term “advance directive” includes living wills as well as proxy directives, where an individual authorizes another person to decide on medical treatment to be received by the individual in the event of incapacity or inability to communicate.

⁶ The POLST could also be analogized to a prehospital Do-Not-Resuscitate (DNR) medical order that is authorized by statute or regulation in almost all states to govern care provided by emergency medical services personnel. Indeed, in some states, the POLST can function as an out-of-hospital DNR form. However, the POLST contains more comprehensive instructions than does a typical prehospital DNR order and it is also intended for use in institutional settings. The literature on pre-hospital DNR forms is sparse.

Table 1 Similarities and differences between living wills, critical care order sets, and the POLST

	Living Will	Critical Care Orders	POLST
Purpose	Used by an individual to direct end-of-life care received by the individual	Used by a doctor to direct end-of-life care to be received by an individual	Used by an individual with a doctor's approval to control end-of-life care received by the individual
Content	Often used to request or reject certain types of life-sustaining treatment	Used to direct or reject certain types of life-sustaining treatment	Used to direct or reject certain types of life-sustaining treatment
When completed	Often completed when healthy and in advance of a medical crisis	Completed shortly before or during a medical crisis	Offered to individuals who may be expected to die within one year.
Legal status	Instructions to physicians and surrogates	Binding medical order	Binding medical order
When effective	Usually upon occurrence of a medical contingency that occurs in the future	Immediately	Immediately
Formalities	Individual's signature plus those of witnesses usually required to be effective	Must be signed by a physician	Must be signed by a physician. Patient signature optional unless required by law

2.0 NORMATIVE ASSUMPTIONS AND SCOPE OF THE DISSERTATION

In this section, I discuss the normative assumptions I applied in designing the research and writing this dissertation. I also explain some limits on the scope of this dissertation.

I am a lawyer by education and training. Ascertaining rules and applying them is what lawyers do. Once rules are clearly established by legislatures or courts, lawyers are usually not much concerned about whether they are right or wrong, but instead focus on whether the rules are being followed. Here, I ask whether the rules established for use of the POLST are being complied with by nursing homes in one Pennsylvania county. That was the primary focus of my research and is the main issue discussed in this dissertation.

This is a doctoral dissertation and therefore merely ascertaining whether rules are being followed is not enough. I must also address whether the rules need to be changed. However, any such discussion involves moral judgments about the value of human life, and how end-of-life decisions should be made. End-of-life decision-making involves some of the same issues surrounding the intrinsic value of human life that have caused the deep societal division over a woman's right to choose an abortion. It is not my intention to use this dissertation to argue the moral issues surrounding end-of-life decision making. Instead, in the paragraphs below, I set forth normative assumptions I applied in conducting my research and writing this dissertation.

First, I assume that it is both moral and acceptable for informed competent individuals to make voluntary decisions to refuse or withdraw life-sustaining treatment. This includes refusing or withdrawing such treatment in circumstances where it might be medically beneficial. In other words, an individual's right to exercise autonomy in making medical decisions is a moral imperative that generally overrides all other considerations. The POLST appears to be based upon this assumption. Some people consider the refusal of beneficial non-burdensome medical treatment to be the equivalent of suicide. They say that doctors who honor such refusals participate in euthanasia. I do not accept this position, and this dissertation does not question the primacy of individual autonomy in medical decision-making.

Second, I assume that only those decisions about life-sustaining treatments that are autonomously made are entitled to deference. Requiring an individual to accept or reject treatments in advance when they don't want to decide at all, steering patients to accept or reject treatments by presenting the treatment choices to favor what the provider thinks is best, or eliciting treatment preferences without making sure that the individual understands what he or she is accepting or rejecting, are all actions that undermine autonomy. The concept of autonomy in bioethics is nuanced, but it can be summarized as requiring that a treatment decision be intentional, made with substantial understanding, and made without controlling influences that determine the outcome (Beauchamp & Childress, 2001). Many of the procedures required or recommended by the POLST's designers appear intended to promote autonomous decision making. Most of the issues I raise in this dissertation relate to my belief that decisions to withhold or withdraw life-sustaining treatment reflected on a POLST form must be autonomously made in order to be morally valid.

Third, I assume that it is not morally objectionable for state legislatures to restrict or regulate the authority of surrogates to make decisions relative to life-sustaining treatments for incapacitated individuals. This means that spouses, life-partners, and children may sometimes be prohibited from making decisions to withdraw or withhold treatment, even though they know for certain what their loved one would want. Some people object to this governmental intrusion into highly personal family decision making. However, in this dissertation I do not question whether it is right for legislatures to impose such restrictions on surrogates. We live in a democracy and sometimes we have to accept decisions by legislators with which we disagree. The POLST's designers recognized that the form would be used in states with laws that restrict surrogate authority.

Finally, I assume that society should not devalue the lives of the elderly or disabled. A life is not worth less because it is being lived by a person near the end of their life or in a condition of profound disability. I contend that it is solely up to the individual or an authorized surrogate to determine when the benefits of continued medical treatment near the end of life outweigh the burdens. This position can be controversial because it necessarily implies that expensive medical procedures with only minimal potential to improve quality of life or to extend life must be paid for by government and health insurers. Opponents of the POLST suspect that the document is really intended to reduce end-of-life costs, and that the push to adopt the form may be "fiscally driven" (Brugger, Pavela, Toffler & Smith, 2012). However, in this dissertation I do not ask when society should deny end-of-life medical care desired by an individual, and I do not explore whether the POLST can save money.

3.0 BACKGROUND

3.1 THE PROBLEM OF UNWANTED TREATMENT NEAR DEATH⁷

“Over the past century, dying has become increasingly institutionalized. In the early 1900s, most people died at home, but by the middle of the 20th century, the majority of deaths in industrialized nations occurred in health care institutions” (Teno, Clarridge et al., 2004). By 1993, approximately 80% of all deaths that occurred in the United States occurred in an either a hospital or nursing home (Weitzen, Teno, Fennell, & Mor, 2003). Moreover, end-of-life care is increasingly provided using sophisticated life-sustaining technology. Approximately one fifth of all deaths in the United States -- more than half a million deaths per year -- follow intensive care unit therapy during the final hospitalization (Angus et al., 2004).

Technology has made the line between living and dying increasingly unclear. Most medical treatment holds the possibility of providing at least some benefit in almost every terminal illness (Callahan, 2000). Life-sustaining technology available in a modern ICU,

⁷ Chapter Three of this dissertation draws heavily from the writer’s masters in bioethics thesis entitled: A CRITICAL LOOK AT THE PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST): WHAT ARE ITS WEAKNESSES? The thesis is published online at: etd.library.pitt.edu/ETD/available/etd-11262007-200844/unrestricted/Manne-BIOETHICS-ETD1

such as mechanical ventilators and defibrillators, can often be employed by doctors to postpone a patient's inevitable death for days or weeks. A large study of over more than 6,000 ICU deaths by Prendergast, Claessens, and Luce (1998) found that nearly 70% of such deaths occurred after a decision to withhold or withdraw some form of life-sustaining treatment. A more recent study of the medical charts of 496 patients who died at a large academic medical center found that 82% died after explicit decisions with withhold or withdraw life-sustaining treatment (Walling et al. 2010). As observed by Chaiten and Arnold (2001), in many institutions, "more patients die in the ICU than anywhere else in the hospital, making the management of death a more common task for ICU staff than restoring health."

Even with the use of sedation and other palliative measures, death in an ICU can be uncomfortable at the least. Numerous studies have shown that ICU patients experience unpleasant symptoms such as pain, shortness of breath, and agitation, Nelson et al (2001) surveyed fifty cancer patients in an urban ICU who had the ability to self-report. Between 55% and 75% of the respondents reported experiencing pain, discomfort, anxiety, sleep disturbance, hunger and/or thirst that they rated as moderate or severe. One third of the respondents reported experiencing shortness of breath. Mularski, Heine, Osborne, Ganzini and Curtis (2005) surveyed 94 family members of individuals who died in an ICU. Pain was reported to be under control for the patient most or all of the time for only 47% of the decedents. A large study of the end-of-life decision making in hospitals found that more than one third of dying patients spent at least ten days in an ICU, and 46% received mechanical ventilation within three days of death (The SUPPORT Investigators, 1995). In this same study, "families reported that half of the patients who were able to communicate in their last

few days spent most of the time in moderate or severe pain.” The “available evidence leaves little doubt that that the prevalence of distressing symptoms among critically ill patients is substantial...” (Nelson & Danis, 2001).

Most people would prefer to die in at home or in a home-like setting rather than in an ICU. A systematic review of the literature on preferences for place of care and death among cancer patients by Higginson and Sen-Gupta (2000) found considerable variability among studies, but that home care was the most common preference. The fact that many people die in an ICU, rather than in their preferred alternative setting, creates both ethical and public health concerns. It is an ethical concern because American society generally accepts that we have an obligation to comply with competent individuals’ decisions about their own bodies. It is a public health concern because end-of-life care in an ICU causes significant suffering and is expensive. Jacobs and Nosworthy (1990) estimated that ICU care accounts for 20% of inpatient hospital costs in the United States. Zilberberg and Shorr (2012) say that \$4.6 billion could be saved in heart failure cases alone by eliminating the terminal hospitalization for that illness.

Providing a way for individuals to communicate their preferences for place of death in a way that will be honored may significantly reduce suffering at the end of life as well as our nation’s health care costs. For at least the past thirty years, society has sought an effective method of allowing patients to control the kind of medical care they receive at the end of life.⁸ Out of these efforts came first the living will and now the POLST.

⁸ California enacted the first law allowing patients to decide about life sustaining medical procedures in 1976. An early version of the living will was described in 1969 in an article by Luis Kutner in the *Indiana Law Journal*. (President's Council on Bioethics, 2005, p. 59)

3.2 PRECEDENT AUTONOMY AND LIVING WILLS

Some patients near the end of their lives are both competent to make medical decisions and able to communicate those decisions and doctors should comply with the expressed treatment preferences.⁹ However, many people lose the ability to either make medical decisions or communicate those decisions near the end of life. Both living wills and the POLST are premised on the belief that society should honor end-of-life treatment choices made by an individual in advance of a change in condition that causes the loss of decisional or communicative abilities. However, as an ethical question, it is far from clear that society should honor such choices made in advance.

In this section, I discuss the arguments for and against honoring end-of-life treatment instructions contained in documents such as living wills and the POLST. The arguments presented in this section were developed in the context of living wills.¹⁰

It is largely settled as a matter of law and public policy that competent individuals have a right to decide in advance what life-sustaining medical treatment they will receive when they become incapacitated. (President's Council on Bioethics, 2005, p. 60). The terms "living will" and "instruction directive" are often used to refer to a legal document containing such treatment instructions. The POLST is similar to an instruction directive, but it is in the form of a medical order. Although some POLST advocates have sought to characterize the

⁹ Whether physicians do in fact comply with the treatment preferences expressed by competent patients is another issue, and except as regards the POLST, that issue is beyond the scope of this thesis.

¹⁰ End-of-life treatment instructions can also be provided orally or in writing to a surrogate through a proxy directive often called a power of attorney for health care. The use of proxy directives is beyond the scope of this thesis.

document as expressing treatment preferences based upon what a patient wants “right now,” many of the medical orders contained in the POLST are only implemented upon a future change in medical condition.¹¹ Accordingly, many of the arguments made in the literature in favor and against instruction directives are equally applicable to the POLST.

Instruction directives are justified on both practical and moral grounds. From a practical standpoint, such directives can avoid the need for judicial intervention in medical decision making for incompetent patients, provide an assurance of civil and criminal immunity to providers when they carry out patient wishes to limit treatment, and reduce medical costs by limiting care that has little benefit (Meisel & Cerminara, 2004). Treatment preferences contained in such directives can also shift the emotional burden of deciding whether to limit treatment for a patient away from family members, thus reducing both the possibility of family conflict and the likelihood that family members will experience guilt, resentment, self-doubt and anxiety (Wicclair, 1993). The POLST provides similar benefits.

However, it is the moral argument in favor of directives like living wills and the POLST that usually has the most force in any discussion of end-of-life care. The practical considerations outlined above are important, but for most people they are not paramount. It is mostly because the instructions are believed to evidence the will of the patient, that we follow them. Society recognizes that individuals have a legal right to exercise “precedent autonomy,” and decide in advance what life-sustaining medical care they will receive in the future if they become unable to decide for themselves.

¹¹ An example of the “right now” characterization of the POLST can be found in the Fall 2007 issue of UPMC Health Journal where Dr. David Nace is quoted saying that “unlike a living will, the POLST form is a physician’s order that tells you what treatments this person wants based on how they are right now, not at some time in the future” (UPMC, 2007).

Ronald Dworkin's arguments supporting precedent autonomy are often cited in the bioethics literature as explaining why we follow instruction directives when individuals are not competent to decide for themselves. Dworkin (1994) argued that precedent autonomy has moral force because it is an extension of an integrity based view of autonomy that "encourages and protects people's general capacity to live their lives out of a distinctive sense of their own character, a sense of what is important to and for them" (p. 224). People have an interest in having their life "display a steady, self-defining commitment to a vision of character or achievement" and that their life as a whole be seen as an integral creative narrative (p. 205). The value of autonomy, according to Dworkin, "derives from the capacity it protects; the capacity to express one's own character—values, commitments, convictions, and critical as well as experiential interests—in the life one leads" (p. 224). Dworkin labeled the interests that people have in preserving a coherent narrative structure in their lives as "critical interests." It is our critical interests that "explain why many of us care how the final chapter of our lives turns out" (Dresser, 1995). Dworkin concluded that "a competent person's right to autonomy requires that his past decisions be respected even if they contradict the desires" he has at a later point when he is incapacitated (Dworkin, 1994, p. 228). In other words, to honor the narrative of a person's life, we must honor the individual's earlier choices (Dresser, 1995).

The concerns of Buchanan and Brock (1990) are often cited by those who oppose always giving moral priority to expressions of precedent autonomy found in instruction directives. There is always the practical issue of whether a person who signed an instruction directive was competent, adequately informed, and acted in a truly voluntary manner. Even if one accepts Dworkin's position on precedent autonomy, the treatment instructions

contained in an instruction directive will not be morally binding if the patient did not act autonomously because of lack of complete information or subtle coercion. This concern applies equally to the POLST.

Even if an instruction directive reflects the autonomous decision of a patient regarding future medical treatment, Buchanan and Brock (1990) point out that there are significant differences between a contemporaneous decision regarding medical treatment and one expressed in an instruction directive that may warrant giving the latter less moral weight. Therapeutic options and patient prognosis may change after an instruction directive is signed. The patient's actual medical condition may be different from the one he or she contemplated when the directive was signed. The patient's preferences for treatment may change in ways that were not anticipated by the patient when the directive was signed. Indeed, on this last point, the research literature appears to show the existence of what some have called a "disability paradox," where individuals who once held very negative beliefs about living a certain way decide that life is indeed worth living even in very burdensome circumstances (Hertogh, de Boer, Droes & Eefsting, 2007). It can also be argued that psychological changes in an incapacitated person can be so profound that earlier choices lack moral authority to control what happens in the present (Dresser, 1995; Buchanan & Brock, 1990).¹² Finally, informal safeguards that restrain imprudent or unreasonable contemporaneous choices, such as counter-arguments by family members, are not present when an instruction

¹² The argument that changes in the brain may result in a different "person" than the one who signed an advance directive is based upon the contention there is a psychological discontinuity between the person who signed the directive and the existing patient (Buchanan & Brock, 1990). This position asserts that damage to the brain resulting from conditions such as Alzheimer's disease may be so significant that the moral actor who issued an advance directive no longer exists and therefore an advance directive has no moral authority to direct the experiential interests of the individual who remains.

directive is applied. Although these arguments have been advanced in the context of living wills, they all apply with equal force to the POLST.

The weight we should give to precedent autonomy, and the respect we should give to the treatment preferences an incapacitated person previously expressed through an instruction directive, remains disputed in the bioethics community (Levine, 2006). Always honoring a patient's precedent autonomy is controversial because "when health care professionals honor advance directives that call for life-sustaining treatment to be forgone, patients die" (Wicclair, 1993, p. 45). Dresser (1994) contends that although "precedent autonomy clearly is important to many of the philosophers, legal academics, and policy makers writing on this subject," it does not appear to be very important to the public. She argues that people often prefer to have loving family members decide their medical treatment if they become incapacitated.

Moreover, honoring precedent autonomy expressed in the form of an instruction directive or POLST can sometimes lead to morally uncomfortable consequences. This is especially true where it appears that the patient's medical situation was not anticipated. An iatrogenic cardiac arrest is one example of an unanticipated medical situation where honoring patient instructions to withhold care is morally problematic for many doctors. Casarett, Stocking, and Siegler (1999) report that 69% of surveyed physicians in an urban community teaching hospital said they would refuse to honor a patient requested DNR order when the patient arrested due to physician error.

Another difficult situation is presented when an instruction directive or POLST requires the withdrawal or withholding of treatment for an incapacitated individual who appears to be in no discomfort. The example of the now pleasantly demented patient who

develops an easily treatable illness, but who previously signed an instruction directive refusing treatment, is cited as an example when applying precedent autonomy may be inappropriate (Buchanan & Brock, 1990, p. 108). This is the scenario presented by the patient named Margo in Andrew Firlik's 1991 commentary published in the Journal of the American Medical Association (Firlik, 1991). Dworkin (1994) used the example of Margo to illustrate his argument regarding critical interests. He contended that an instruction directive declining treatment previously signed Margo should be enforced because if we refuse to do what the patient wanted when she wanted when she was competent, "that would not be compassionate towards the whole person who tragically became demented" (p. 232).

The President's Council (2005) took a position contrary to that of Dworkin in cases involving dementia. The Council suggested decision makers should not overvalue precedent autonomy. Instead, the Council argued that we should focus on the present welfare of the patient in making treatment decisions. Illustrating the deep divide on the weight that should be given to precedent autonomy in such cases, one President's Council member wrote a stinging dissent stating that the "clear message from this report is, if you feel strongly about not living in a decerebrate state, you better kill yourself while you have control over your fate" (p. 229).

Empirically, it appears that patients and proxies do not give as much weight to precedent autonomy as many bioethicists would require. Fins et al (2005) surveyed 50 patient-proxy pairs and 52 individuals who had acted as proxies for someone else. They found that neither patients nor proxies generally viewed a deviation from the patient's instructions as a violation of the patient's right to autonomy. Rather, patients and proxies are heavily influenced by the likely prognosis, and the utility or futility of continued treatment.

Although the scope of precedent autonomy remains debatable as an ethical matter, it is essentially settled as a matter of law that competent individuals have a right to control future treatment when they become incapacitated (President's Council on Bioethics, 2005, p. 60). However, this right is not absolute and may be regulated by the state. In the Cruzan case,¹³ a majority of the United States Supreme Court upheld a Missouri statute requiring clear and convincing evidence of a patient's wishes before allowing a surrogate decision maker to terminate life-sustaining treatment. In the *Glucksberg*, decision¹⁴ the Supreme Court held that terminally ill individuals do not have a right to a commit suicide and it follows from that court decision that an advance directive requesting euthanasia need not be honored. Additionally, honoring precedent autonomy does not necessarily mean following the literal language of an instructive directive under all circumstances. In New Jersey, for example, the law allows a surrogate to override an instruction directive if there is reason to believe that it differs from what the patient would want under the circumstances.¹⁵

One significant area where the law often does not give effect to precedent autonomy is when an individual tries to revoke non-treatment instructions contained in an advance directive. Following the recommendation of National Conference of Commissioners on Uniform State laws in their proposed Uniform Rights of the Terminally Ill Act, many state statutes provide that an advance directive may be revoked by a patient without regard to his or her mental state (Meisel & Cerminara, 2004, ¶7.08(A)). In these jurisdictions, an incapacitated individual need only muster the ability to communicate a present desire for

¹³ *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 110 S.Ct. 2841 (1990).

¹⁴ *Washington v. Glucksberg*, 521 U.S. 702, 117 S.Ct. 2302 (1997).

¹⁵ N.J. Stat. § 26:2H-63(c)(2012)

treatment in order to overrule a prior directive to the contrary. As to why many states have such a rule, it may be that it just “generally seems wrong” to withhold treatment when “a patient, no matter how confused, asks that treatment be continued” (President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983, p. 152). Honoring precedent autonomy is not an absolute moral or legal imperative.

3.3 LIVING WILLS AND THEIR WEAKNESSES

Living wills are the principal legal device that individuals can use to formally communicate their end-of-life treatment preferences and exercise precedent autonomy. Until recently, most research suggested that living wills are not very effective in allowing individuals to control their end-of life care and the POLST was specifically designed to overcome barriers that were believed to thwart the effectiveness of living wills. Here, I summarize the research on living wills and discuss some of the perceived weaknesses of those documents

Most studies of advance directives do not differentiate between instruction directives and proxy directives, and many of the earlier studies found that advance directives had little effect on what happens in the hospital and ICU. For example, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) reviewed the care received by 618 patients with advance directives (i.e. proxy directives, instruction directives, and combined forms) and found that such directives “were irrelevant to decision-making” for end-of-life hospital care (Teno et al. 1994). Similarly, Kish Wallace, Martin,

Shaw, and Price (2001) examined the records of 135 matched pairs of critically ill cancer patients admitted to the ICU of a comprehensive cancer center with and without advance directives. They found that “there were no differences regarding the frequency with which life-supporting interventions were initiated with and without advance directives.” Ditto and Hawkins (2005) probably summarized the consensus view that existed only a few years ago when they said the “institutionalization of advance directives in American law and medical practice....stands in stark contrast to a growing body of research challenging their effectiveness in producing specific improvements in end-of-life medical care.”

Recent research has produced results more favorable to living wills. Teno, Gruneir, Schwartz, Nanda, and Wetle (2007) found that patients with an advance directive (i.e. a proxy directive or an instruction directive) were significantly less likely to die in an ICU and that such directives were “associated with less use of life-sustaining treatment, greater use of hospice and less likelihood of terminal hospitalization.” Degenholtz, Rhee and Arnold (2004) specifically studied instruction directives and found that they “are associated with a lower probability of in-hospital death for people older than 70 years of age, after adjustment for health status and other factors.” Silveira, Kim, and Langa (2010) reviewed data involving more than 3700 deaths in settings that included home, hospice, nursing home and hospital. The researchers found a strong agreement between treatment preferences stated in living wills and care received at the end of life. Nicholas, Langa, Iwashyna, and Weir (2011) reviewed end-of-life care received by 3302 decedents. They found that individuals with a treatment limiting advance directive were less likely to die in a hospital and more likely to use hospice. When the data was adjusted for demographic and socioeconomic factors, these effects persisted, but only in regions of the county that were characterized by higher levels of

end-of-life spending. Still, the recent research on the effectiveness of living wills is not all favorable. Halpern, Pastores, Chou, Chawla and Thaler (2011) found that neither a living will nor a health care proxy had an effect on clinical care in a cancer center. The best we can say today is living wills may be effective in some circumstances.

At an abstract level it is easy to understand why living wills might be ineffective. Instruction directives try to solve an unsolvable problem – that of directing specific medical care under unknown future circumstances. Living wills are typically drafted months or years in advance of a medical crisis. If the directive is drafted broadly, then it must be interpreted by doctors and the family, and the steps to be taken under it are often unclear. If the directive is drafted narrowly, then the range of circumstances to which it applies is likewise narrow or “its length and complexity would have to be increased” (President’s Commission, 1982, p. 157). Regardless of its breadth, instruction directives can only address “a limited range of medical situations that occur frequently enough to be of general concern to people” (p. 158).

Even if an instruction directive is sufficiently specific to provide meaningful direction for a patient’s particular medical condition, there are numerous procedural obstacles to its implementation. Ditto and Hawkins (2005) set forth a series of distinct hurdles that must be overcome before a patient’s wishes will be honored through a living will. First, the patient must complete the directive. This can be a significant obstacle. Resnick, Schuur, Heineman, Stone, and Weissman (2008) analyzed data from the 2004 National Nursing Home Survey and found only 20% of residents had living wills.

Assuming the patient completes a living will, there are the other barriers to compliance with patient treatment instructions identified by Ditto and Hawkins (2005). The wishes expressed in the directive must be authentic, which means that individuals are able to

imagine themselves in states of future illness and accurately predict what their preferences will be should they actually experience that state. Surrogates responsible for making decisions when a patient becomes unable to communicate must know of the existence of the living will so it can be retrieved and presented to the patient's physician. The physicians responsible for the patient's care must be able to interpret and apply what is written in the directive to the patient's current condition. Finally, both the patient's surrogate and the physician must be willing to comply with the directive in the context of the patient's current medical condition.

It is clear that instruction directives often do not cause doctors to implement end-of-life treatment preferences expressed by patients. As a result, many patients who want to control their care at the end of life are unable to do so. This had led to a search for other legal devices that a patient can use to provide binding instructions that will direct his or her end-of-life medical care. The POLST is one response to that search.¹⁶

3.4 THE POLST INNOVATION

In 1991, a multidisciplinary task force consisting of Oregon healthcare providers and organizations came together to address the problem of unwanted intensive medical

¹⁶ I do not discuss proxy directives in this section because such directives are not used to guide specific future medical treatments. Instead, an individual uses a proxy directive to designate someone else makes medical judgments on his behalf. (President's Council, 2005). By contrast, instruction directives, prehospital DNR forms, and the POLST all share the characteristic of containing specific treatment instructions to be applied in the future. Although hybrid documents combining instructions with a proxy directive are often used, a POLST does not contain a proxy directive and is not similar to such a device.

interventions and unwanted transfers to hospitals (Tolle & Tilden, 2002). The goal of the task force was to develop a way for patients to express their end-of-life treatment preferences through a form that would be respected by medical personnel across treatment settings (Tolle & Tilden, 2002). The result was a brightly colored POLST form that “converts patient and surrogate preferences for a variety of life-sustaining treatments into medical orders” (Hickman, Tolle, Brummel-Smith, & Carley, 2004). One purpose of the POLST form is to “prevent hospitalization during the dying process if the participant wants to receive comfort care at home” (Lee, Brummel-Smith, Meyer, Drew & London, 2000).

Initially, the POLST was suggested for use by a broad spectrum of the population and not just for persons near the end of life. Until late 2006, the official POLST.ORG web site said that any person with a “serious health condition” could consider using the form. However, the POLST’s designers have modified the recommended criteria regarding use of the form and, as of June 2012, the web site stated that the form “is most appropriate for seriously ill persons with life limiting or terminal, illnesses” (Oregon Health and Science University, 2012). The revised web site goes on to say that “to determine whether a POLST Paradigm form should be encouraged, clinicians should ask themselves, ‘Would I be surprised if this person died in the next year?’ If the answer is ‘No, I would not be surprised,’ then a POLST Paradigm form is appropriate.” The revised web site also now states that “[u]nless it is the patient’s preference, use of the POLST Paradigm form is not appropriate to limit treatment for persons with stable medical or functionally disabling problems who have many years of life expectancy.”

POLST task force members have described the document as “one example of a progressive AD [advance directive],” a category which includes do-not-hospitalize orders

and has a direct effect on treatment (Hickman, Hammes, Tolle & Moss, 2004). The President's Council (2005) calls the POLST a "novel form of instruction directive" (p. 76). It is difficult to classify the POLST because while it has many of the characteristics of an instruction directive, it cannot be classified as such due to the lack of required legal formalities applicable to living wills, such as being witnessed.

Instead, the POLST is legally a set of medical orders. A medical order can be defined as an order of a specifically identified medical practitioner lawfully acting within the scope of his or her license for a specifically identified patient's health care needs.¹⁷ As a medical order set, a POLST must be followed by nurses and other medical professionals unless countermanded. However, just as the POLST differs from a conventional living will, it also differs from the usual medical order set. Ordinarily, medical orders governing life-sustaining treatments can be written only by physicians who are credentialed and have privileges at the facility where the patient is currently receiving care. A POLST is intended to be transferable across treatment settings without regarding to institutional credentialing and privileging requirements.

The POLST form generally provides specific treatment instructions with respect to four items: (1) cardio-pulmonary resuscitation (CPR); (2) the level of medical intervention (ranging from comfort care at home to intensive hospital treatments); (3) antibiotic use; and (4) feeding tubes and IV fluids (long term or short term) (Lee, et al , 2000).¹⁸ However, using the POLST involves more than just a form. The designers of the POLST also crafted a

¹⁷ The definition is taken from Kentucky Revised Statutes, §315.010 (2007).

¹⁸ The antibiotics section no longer appears in the June 2011 version of the Oregon POLST form adopted by the National POLST Paradigm Task Force.

set of requirements and processes to govern how the form is used. These requirements and processes are referred to as the POLST Paradigm. Endorsed POLST programs are required to have a specified structure, meet certain program requirements, and use a form that meets stated specifications.

The structural, programmatic, and form content requirements for an endorsed POLST Paradigm program are set forth on the POLST.ORG web site. The National POLST Paradigm Task Force revises the requirements periodically, and the version discussed in this section has an effective date of April 26, 2012. The requirements have become progressively more detailed over time. Currently, there are four levels of POLST program development: (1) developing a POLST paradigm program; (2) endorsed POLST paradigm program; (3) mature endorsed regional POLST paradigm program; and (4) mature endorsed state POLST paradigm program. Each level has certain requirements associated with it. A complete list of the all the POLST program requirements is contained in Appendix “B” to the dissertation.

The minimum requirements for an operational POLST program are set forth under the Level Two requirements for an endorsed POLST paradigm program. The requirements as set forth on the POLST.ORG web site are:

1. The program has an effective statewide or regional coalition, and if there are two or more regional coalitions within a state, they are working on a coordinated strategy towards statewide implementation.
2. The program is identifying and building a research and quality assurance component.
3. There are identified champions who are active in the program implementation and education.

4. The POLST Paradigm Program is the preferred practice for the process of advance care planning and implementation across health care settings (e.g., emergency medical services, long-term care, hospital, and hospice) for persons with advanced illness and/or frailty whose clinicians would not be surprised if they died within the next year. The form is a set of current (in some states they may be accepted as standing) medical orders. The completion of a POLST Paradigm form should be based on the patient's goals for care to ensure that the patient receives the treatment he or she desires.

5. There is ongoing training of health care professionals across the continuum of care about the goals of the program, the creation and use of the form, and how to conduct a POLST conversation.

6. Mechanisms are in place to help assure that the orders are based on patient preferences. As allowed by statute and regulations, the National POLST Paradigm Task Force *strongly* recommends that all POLST Paradigm Programs require the signature of either the patient or the patient's legal representative (or witnessed verbal consent as allowed by and in accordance with state law) to make the form valid. The signature of the patient (or the patient's legal representative if the patient lacks decision-making capacity) provides evidence that patients or their legal representatives agree with the orders on the form. In this respect, the requirement that patients or their legal representatives review and sign the form provides a safeguard for patients that the orders on the form accurately convey their preferences. To increase accountability, it is especially important that programs being established without a governing state statute or regulation develop a process for POLST Paradigm form completion that documents, perhaps through a check box on the form, that review and approval of the form by the patient or the patient's legal agent has occurred.

7. Completion of the form and the decisions recorded on it should be voluntary and based on shared medical decision making.

8. There is a plan for ongoing evaluation of the program and its implementation. It is key for each program to be able to receive feedback with regard to how it is functioning.

9. There is an entity within the region or state that is willing to accept ownership for the program (e.g., hospital association, state department of health, hospice and palliative care association, university-affiliated ethics center, etc.) and has the resources to implement it.

10. The program shows evidence of attention to the core elements of sustainability of state POLST Paradigm Programs. (Oregon Health and Science University, 2012).

All POLST programs regardless of level must comply with the following requirements with regard to the form used:

1. The treatment being considered requires a medical order that needs a signature by a health care professional.

2. The medical order is based on the patient's goals of care and a person's preferences for treatment (e.g. as expressed in an oral statement or written advance directive). The treatment is a "comfort measure" or the order is an instruction regarding hospital transfer; or the medical order is a life-sustaining treatment that is being considered for use in a person with advanced progressive illness and/or frailty and has these characteristics: is frequently needed by health care professionals (e.g. EMS protocol, emergency department and ICU care, long term care or hospice); and/or is urgently needed by health care professionals (e.g. EMS protocol, emergency department and ICU care; long-term care or

hospice); and/or requires an informed consent process that is complex (e.g. tube feeding treatment); and/or is not effectively specified as “additional orders.”

3. Within the written medical order sections, which are preferably all on the front of the form, there is an explicit statement that comfort measures are always provided and the patient may require transfer to another setting of care (e.g. “Transfer if comfort needs cannot be met in current location”). In other words, the medical order sections of the form include language that affirms patients’ rights to be transferred to receive comfort care and are free of language that might restrict or negate patients’ access to comfort care. For example, forms shall not state in the comfort measures, “Do not transfer the patient” or “Avoid calling 911.” The medical order set should also state that food and fluids are always to be administered by mouth if medically feasible (e.g. offer food by mouth if feasible).

4. In addition to orders with regard to CPR, the POLST Paradigm form must indicate the level of medical intervention for the patient (exact wording for each level may vary from state to state) comfort measures; limited additional interventions; or full interventions. The level of intervention shall contain a description of the services to be provided and the site in which they will be provided. For example, a comfort measures order may indicate that the patient is not to be transferred unless comfort needs cannot be met in the person’s current setting. Treatments such as intubation and mechanical ventilation are to be included in the full interventions section. Patients who are already receiving long-term mechanical ventilation may indicate treatment limitations in the “Other Orders” space in the level of medical intervention section.

5. The form requires a valid clinician (physician, nurse practitioner or physician assistant depending upon state laws and regulations about signers) signature and a date of

signature. The medical orders shall be signed and dated and timed to clearly show the most current orders.

6. The form provides explicit direction about resuscitation (CPR) instructions or patient preferences if the patient is pulseless **and** apneic.

7. The form also includes directions about other types of intervention that the patient may or may not want. For example, decisions about transport, ICU care, artificial nutrition, etc. Space is provided for additional orders.

8. The form is uniquely identifiable and standardized within a state/region.

9. The form indicates with whom the orders were discussed or who provided informed consent.

10. The form indicates on the front page the name of the state or region.

11. The form may indicate that the program is an endorsed POLST Paradigm program.

12. Language in the forms should start with positive language. For example, the comfort measures description might read “Treat with dignity and respect. Keep clean, warm, and dry. Use medication by any route...” In the comfort measures section, the forms should avoid wording that starts with negative language and suggests that care and comfort of the patient are not paramount, e.g. “Do not intubate or transport...”

13. The NPPTF recommends that all medical orders be placed on the front page of the form (Oregon Health and Science University, 2012).

There are optional elements of the POLST paradigm as well. These optional elements include the role of surrogates in completing the form, whether the POLST form will replace a separate out-of-hospital DNR form, and whether a state will recognize forms

completed in other states. The color of the form is optional but the Task Force strongly recommends a bright easily seen color for the original document. For mature programs it is optional for physicians, nurse practitioners, and physician assistants working in practice settings including hospitals, nursing homes, private offices, and patient homes to offer the POLST to patients with serious or life-threatening illnesses.

A POLST does not replace conventional advance directives and may co-exist with them. However, the POLST is intended to be an operative legal document that directs medical care at the bedside when both forms co-exist. The POLST.ORG web states, “[t]raditional advance directives are recommended for all adults to appoint a surrogate and express values. When available, an advance directive should accompany a POLST Paradigm form as it helps identify [a] surrogate and may identify values but is not required for the orders to be valid” (Oregon Health and Science University, 2012).

The POLST form contains boxes for both withholding and providing the various forms of life-sustaining treatment covered by the form. Full treatment can be requested via a POLST. However, it appears that most people use the POLST to limit at medical care. Hickman et al. (2011) examined the POLST forms of 870 living and deceased residents in 90 nursing facilities across four states. They found that more than 85% of the forms contained DNR orders and more than 88% directed limited treatment or comfort care. Dr. Alvin Moss of the West Virginia Center for End of Life Care said some people have joked that the POLST should be called Physician Orders Against Life-Sustaining Treatment “because most of the time people are completing the form because there’s one or more life-sustaining treatments they don’t want” (Rotstein, 2007). A POLST is probably unnecessary for a

person who desires all medically indicated life-sustaining treatment, because full treatment is ordinarily the medical default position, even without a specific request from the patient.

In concept, the POLST should be more effective in translating patient treatment preferences into action in the ICU and elsewhere because it eliminates many of the barriers associated with completion and implementation of a living will. Two such barriers to completion of advance directives are the legalistic process required to complete them and confusion about the role of health care professionals in explaining them (Duke, Thompson, & Hastie, 2007). The POLST is simple to fill out and must be explained to the patient by a physician, nurse or other trained facility staff person. The POLST also overcomes the problem of treatment instructions contained in living wills not being included in the patient's medical record. The POLST paradigm requires that the form be a medical order set that is part of the patient's medical record.

The POLST is often described in the literature as being effective. For example, a comment by Farber, Shaw, Mero and Maloney (2006) in the *Annals of Internal Medicine* asserts that "research has demonstrated [the POLST's] effectiveness in helping patients have their preferences for end-of-life care honored, even when emergency medical services (EMS) are concerned." Bomba and Vermilyea (2006) likewise assert that "a decade of research in Oregon has proved that the POLST program more accurately conveys end-of-life preferences that are more likely to be followed by medical professionals than traditional advance directives alone." The President's Council (2005) similarly declared that the POLST "has shown high rates of compliance and effectiveness" (p. 76). The extent to which the published research actually supports these assertions will be discussed later in this dissertation.

3.5 RISKS WITH USING THE POLST

Few innovations come without at least a few disadvantages and the POLST is no exception. Like the living will, the POLST can cause the withholding or withdrawal of medical treatment in circumstances not anticipated or desired by the patient. The risk of such an unintended result may be enhanced with the POLST due to its status as a binding medical order.

Like the living will, the POLST is used to provide instructions for life-sustaining treatment to be provided in a future medical crisis. However, any attempt to control the delivery of medical care before it is needed is inherently problematic. There is “an inherent tension between ensuring that dying patients have a means of expressing their wishes about treatment termination before they are overcome by incompetence and ensuring that people do not make binding choices about treatment on the basis of hypothetical rather than real facts about their illness and dying process” (President’s Commission, 1983, p. 143). The fundamental problem is that while an individual can know his or her current condition, and even be confident that the end of life is only weeks or months away, the individual usually cannot know in advance the particulars of the situation that will pose an immediate threat of death. As observed by the President’s Council (2005):

There are, to begin with, simply too many possible future situations that the patient must try to imagine, each with its unique combination of burdens, benefits, and risks, making the notion of “informed consent” long in advance of treatment a highly questionable one. And those patients who are tempted to reject certain kinds of future medical intervention (on the ground that they

"wouldn't want to live like that") may not understand how short-term use of some of the same interventions could restore them to basic or even normal function. (p. 73)

Fagerlin and Schneider (2004) argue that instruction directives are primarily useful for people “whose medical situation is plain, whose crisis is imminent, whose preferences are specific, strong, and delineable, and who have special reasons to prescribe their care.”

The risk of an unintended result is of particular concern when the POLST is offered to relatively healthy people. Notwithstanding the difficulty in predicting future circumstances and desires, healthy people often sign living wills years in advance because the thought of living hooked up to machines is so distressing. However, the effectiveness of a living will is almost always subject to a catastrophic medical contingency. Moreover, family members or doctors will often choose to disregard instructions in a living will that seem inappropriate in a particular medical context. In contrast, a POLST is an immediately effective medical order with specific instructions printed on the form to “first follow these orders, then contact physician, NP, or PA.” There is less opportunity to reconsider what is written on the form and determine whether the instructions are appropriate to the particular circumstances.

Current criteria governing the POLST discourage its use for relatively healthy people but this was not always the case. Prior to Fall 2006, the POLST.ORG web site said that any person with a “serious health condition” could consider using the form. In a study of the POLST’s use in Oregon, Tolle and Tilden (2002) reported that “some hospitals now mandate the completion of a POLST form at discharge for patients transferred to long-term care facilities, other institutional settings, or home hospice” (p. 314)(emphasis added). The

POLST's designers appear to have recognized that the form was being offered to some people inappropriately and the POLST.ORG web site was revised in late 2006 to state that the form "is most appropriate for seriously ill persons with life limiting, also called terminal, illnesses." The revised web site also stated that "[u]nless it is the patient's preference, use of the POLST form is not appropriate to limit treatment for persons with stable medical or functionally disabling problems who have many years of life expectancy." This language continues on the current web site (Oregon Health and Science University, 2012).

Another weakness inherent in instruction directives that might be magnified with the POLST arises from the possibility that what is written on the form may not reflect authentic patient treatment preferences. If a patient lacks decisional capacity, if treatment options are not correctly explained, if a patient does not understand them fully, or if a patient is steered in a certain direction, then the patient treatment preferences indicated on a POLST form are not authentic because they are not truly reflective of an informed choice of treatments by the patient. The nature of living wills as legal documents tends to encourage thoughtful deliberation prior to execution. However, the POLST completion process may not be as deliberate. Although the individuals helping patients fill out a POLST are likely to be trained to explain life-sustaining treatments and answer questions -- something lawyers drafting living wills are not -- there is a risk that staff assisting patients with the form may be overburdened and hurried.

Another risk with the POLST is that the form may reflect the treatment preferences of medical staff rather than those of the patient. Doctors and other medical staff often have their own preferences for what care the patient should elect, and they may subtly influence how the POLST form is completed. Like other types of medical judgments, "decisions about

life-sustaining treatment can be dramatically affected by small changes in the way questions are framed” (Ditto & Hawkins, 2005). Fagerlin and Schneider (2004) observe that “an ocean of evidence affirms that answers are shaped by the way questions are asked. Preferences about treatment are influenced by factors like whether success or failure rates are used, the level of detail employed, and whether long-term or short-term consequences are explained first.” The President’s Commission (1982) similarly stated:

It is well known that the way information is presented can powerfully affect the recipient’s response to it. The tone of voice and other aspects of the practitioner’s manner of presentation can indicate whether a risk of a particular kind with a particular incidence should be considered serious. Information can be emphasized or played down without altering the content. And it can be framed in a way that affects the listener – for example, “this procedure succeeds most of the time” verses “this procedure has a 40 percent failure rate.” (p. 67).

Yet another risk that may be heightened with the POLST is the possibility that patients may be pressured into signing a POLST and expressing treatment preferences when they really have no such preferences. Use of a POLST is supposed to be completely voluntary but some providers have mandated its use in institutional settings. (Tolle & Tilden, 2002). Many people lack preferences regarding specific medical procedures and would rather leave end-of-life decisions to family members when the time comes. Others would simply prefer not to deal with the issue at all. The psychological assumptions behind advance directives were explored as part of the Advance Directives, Values Assessment, and Communication Enhancement (ADVANCE) project. One ADVANCE study surveyed 337

community dwelling patients with a mean age of nearly 73 years. “When interviewers asked patients how they wanted decisions made for them, most expressed a preference for having several people talk and then one person (presumably the surrogate decision maker) make the final decision alone” (Hawkins, Ditto, Danks, & Smucker, 2005). Very few of the patients wanted a document like the POLST that provides strict directions regarding treatment. As observed by the President’s Council (2005), some people are simply “content to delegate decisions to family members” and see documents like the POLST as “putting too much emphasis on self-determination rather than solidarity” or as “implying that disabled persons are better off untreated” (p. 72).

Finally there is the issue of treatment preferences that change after signing a POLST. A number of studies have found that preferences for life-sustaining treatment in response to hypothetical end-of-life scenarios are only moderately stable over time (Ditto & Hawkins 2005). Several studies suggest that overall, the proportion of people with stable preferences over a one or two year time period is around 75% (Ditto et al. 2003). Rosenfeld et al. (1996) examined the stability of preferences among seriously ill hospitalized patients over a period of two months. Using data from the SUPPORT project, the investigators examined treatment preferences for CPR versus DNR among more than 1500 patients. After two months, preference stability was 80%, with 135 patients (8.5%) changing to favor CPR. Ditto, Jacobson, Smucker, Danks, and Fagerlin (2006) also studied stability of preferences among elderly hospitalized patients. They found high rates of preference stability (93%) among people refusing CPR and artificial nutrition and hydration. However, preference stability was much lower for refusals of gall bladder surgery (82%) and antibiotics (75%).

There is also considerable variation within subgroups. Several studies suggest “declining health status is associated with a greater willingness to bear the burdens of therapy” (Fried et al. 2006). Danis, Garrett, Harris and Patrick (1994) found that while treatment preferences are extremely stable among relatively healthy people, patients who suffered an accident or who were hospitalized were more likely to change their choices to elect more treatment. If a patient’s medical condition is unstable, the patient’s treatment preferences may also be unstable (Ditto & Hawkins, 2005). In general, it seems that people are more prepared to accept treatment once they become sick than their prior statements would indicate (Callahan, 2000, p. 50). Many people who think they would never want to live with medical supports such as feeding tubes change their minds when the time comes. When questioned, individuals will often “express themselves positively on their quality of life, notwithstanding the fact that their actual existence strongly contrasts with formerly held standards: their affirmation of life seem almost ‘out of character’” (Hertogh, de Boer, Drees, & Eefsting, 2007). People with chronic illness and disability often emotionally adapt to their conditions and experience relatively high levels of mood and quality of life (Ubel, Lowenstein, Schwartz, & Smith, 2005).

Stability of treatment preferences has been examined in the nursing home setting but the results are inconclusive. McParland, Likourezos, Chichin, Castor and Paris (2003) elicited treatment preferences relative to CPR and medical nutrition and hydration from 65 residents. These individuals were interviewed at one and two years and 54 subjects participated in the second interview. They found increasing preference instability as follow up times lengthened with a trend towards increasing interventions. By contrast, Berger and

Majerovitz (1998) found nursing home resident treatment preferences to be stable over a six month period.

Rebecca Dresser wrote of the experiences that she and six other bioethicists faced when dealing with cancer. Illustrating the fact of changing preferences, she noted “we were a little surprised at the burdens we were willing to accept in exchange for a better chance of survival” (Dresser, 2011). There is certainly sufficient empirical evidence that changing treatment preferences over time can be a concern, and therefore it is important that written treatment instructions on a POLST be updated regularly to insure that they actually reflect a patient’s current desires. Instructions on the reverse of the form provide that it “should” be updated periodically, upon a transfer, or when there is a change in the patient’s health status, but there is no requirement in the POLST paradigm for a periodic review. Accordingly, there is a risk that the form may not reflect the patient’s present treatment preferences, even if it correctly reflected those preferences at the time of execution, as the result of changes in those preferences.

3.6 SUMMARY OF EXISTING RESEARCH ON THE POLST

3.6.1 Introduction to a review of the research

It is often reported in the literature that the POLST form is effective in translating patient preferences relative to end-of-life medical care into action. For example, a comment by Farber, Shaw, Mero, and Maloney (2006) in the *Annals of Internal Medicine* asserts that

“research has demonstrated [the POLST’s] effectiveness in helping patients have their preferences for end-of-life care honored, even when emergency medical services (EMS) are contacted.” Similarly, Bomba and Vermilyea (2006) assert that a “decade of research in Oregon has proved that the POLST program more accurately conveys end-of-life preferences that are more likely to be followed by medical professionals than traditional advance directives alone.” The President’s Counsel (2005) says that the POLST “has shown high rates of compliance and effectiveness” (76). A National Quality Forum consensus report says that “[c]ompared with other advance planning programs, POLST more accurately conveys end-of-life preferences and yields higher adherence by medical personnel” (National Quality Forum, 2006).

This section reviews the existing empirical research on the POLST. I identify those questions a research base supporting the POLST should answer. I then review the published studies that exist on the POLST at the time of this writing. I identify the research question addressed in each study and critique the study methodology of each pointing out weaknesses and limitations. I ask whether the study addresses the fundamental questions about the POLST that need to be answered before it is appropriate for society to institutionalize use of the form into end-of-life caregiving. Finally, I conclude that there is presently insufficient evidence to justify the POLST’s ongoing enthusiastic embrace by scholars, the medical community, and policymakers.

3.6.2 What the POLST research base should be able to show

The moral justification for using the POLST is based upon the form being an exercise of an individual's autonomy in controlling his or her end-of-life care so research showing that the form is a bona fide exercise of such autonomy is crucial. Studies should show us that when the POLST is completed in the way intended by its designers, the treatment selections written on the form accurately reflect the authentic preferences of a large majority of patients using the form across of a variety of probable end-of-life scenarios.

Research should also establish that doctors and nurses follow what is written on the POLST form. We also want to be confident that it is the POLST form, rather than some other intervention or factor, that is causing the compliance.

Since the POLST is intended to address shortcomings in living wills, and use of the form requires institutional changes in process and procedure that are not costless, we should want to see some studies showing that the POLST is more effective than living wills in translating written end-of-life treatment preferences into care at the bedside. Ideally, we would like to see a study that looks at whether compliance with written treatment instructions is significantly better with the POLST than with living wills.

We should want to see studies that show that the POLST works across treatment settings and among diverse populations. If the POLST is only effective in hospitals or nursing homes, or if its effectiveness is limited to certain racial, ethnic, or cultural groups, then its utility is limited.

Finally, research should also demonstrate that the POLST is being used by providers in the way intended by its designers. We need to have some assurance that when use of the

POLST is translated from theory into practice it does not become an instrument for implementing provider treatment preferences, rather than those of the patient. Even POLST advocates acknowledge that “with poor training, inadequate resources, and insufficient evaluation, the process can regrettably morph into another trampling of patient autonomy” (Bomba & Sabatino, 2009).

Research that is used to make public policy and serve as the basis of institutional change should not only address the above hypotheses, but should also be scientifically useful. This often means quantitative research that is carefully designed and implemented to have both internal and external validity. A study is internally valid if it is designed in such a way that one can be confident that the observed effects are due to the intervention being examined, rather than resulting from something else (Shortell & Richardson, 1978, p. 38). A study has good external validity if its results can be generalized to other situations. Hypothesis testing is commonly used in quantitative research as the basis of study design. Greenhalgh (2001) suggests that the hypothesis being tested should be clear in any quantitative research paper.

Here, I propose six hypotheses that should have ample evidentiary support before the POLST is adopted by medical institutions and policymakers. Of course, how much proof constitutes “ample evidentiary support” for the listed hypotheses is a value judgment. The important thing is to get data upon which such judgments can be made. The hypotheses - and some suggested ways of testing them or otherwise developing good supporting evidence - are as follows:

H1: The POLST accurately captures authentic patient treatment preferences when completed in the way intended by its designers. This hypothesis might be

tested by comparing the treatment preferences indicated on a sample of POLST forms with the preferences elicited shortly after POLST completion through use of a validated preference measuring instrument that includes multiple scenarios. An example of such an instrument is the Life Support Preferences Questionnaire or LSPQ (Beland & Froman, 1995). Kappa statistics showing a high degree of agreement between the POLST and the validating instruments might be used to provide evidentiary support for this hypothesis.

H2: The POLST form causes doctors and nurses to follow the written patient treatment instructions expressed on the form. This hypothesis might be tested by comparing the instructions on a sample of POLST forms with the actual end-of-life treatment received by individuals subsequent to the POLST being signed, and also by comparing the treatments received by individuals with a POLST with care received by individuals without a POLST. With respect to the latter inquiry, the null hypothesis should be that the POLST makes no difference in care. H2 might be adequately demonstrated by results showing a high degree of consistency between orders on the POLST and the care received, and also by results showing that completion of a POLST makes a statistically significant difference in the kind of care received by individuals when compared to situations when no POLST was completed.

H3: The POLST is effective in all treatment settings where it is recommended for use and across diverse populations. This hypothesis might be tested by conducting the studies recommended for H2 in a variety of treatment settings such as nursing homes, hospitals, hospice, and in the community.

H4: The POLST is more effective than a living will in securing end-of-life treatment consistent with a patient's written instructions. This hypothesis might be tested by comparing the consistency of care received with written treatment instructions for individuals who had a POLST versus those who had a living will. The null hypothesis would be that a POLST is no better than a living will in directing end-of-life medical treatment. H4 would be demonstrated by studies showing that a POLST makes a statistically significant difference in whether care conforms to treatment instructions when compared to a living will.

H5: The POLST does not harm patients by causing the withholding of treatment that is desired and should be provided. This hypothesis might be demonstrated by examining the end-of-life treatment received by individuals who had a POLST and looking at whether any medically appropriate life-sustaining treatments were withheld or withdrawn without specific authorization on the POLST form, or from the patient or a surrogate.

H6: The POLST is implemented in medical institutions in the way intended by its designers. Researchers might borrow the tools of evaluation and use a process evaluation to examine whether the POLST is actually be implemented in the field in the way intended by its designers. A process evaluation might include surveys of medical personnel who help individuals make selections on the POLST, and also involve the actual observation of POLST form completion.

In the next section, I review the POLST studies published prior to finalization of this dissertation in October 2012. I show that the existing research base is deficient in addressing

the six hypotheses identified above, and that most of the studies have significant methodological deficiencies that limit the ability to generalize from the results.

3.6.3 Summary of the POLST research studies

3.6.3.1 Before and after survey by Dunn et al. (1996)

Dunn et al. (1996) reported on a study of a predecessor document to the POLST called the Medical Treatment Coversheet (MTC) that was conducted in Oregon. The objective of the study was to describe the development, initial evaluation, and plans for implementation of the MTC form. The study includes the results of the initial evaluation and contains conclusions.

The study involved two stages. The first stage used focus groups and a committee of emergency physicians and paramedics to evaluate the form. The focus groups were composed of 28 physicians and 5 long-term care nurses who evaluated the form and suggested changes. In the second stage of the study, a group of 87 physicians, paramedics, and long-term care nurses were provided with a modified MTC form and three different clinical scenarios. They were asked what they would do both before and after exposure to the form. “Ideal” responses were determined by an expert panel. The authors do not explain how the 87 participants were selected.

The results of the survey showed that post-MTC decisions were more appropriate than pre-MTC decisions across all scenarios and clinician groups with one exception. Advanced EMS treatments were inappropriately withheld by 34% of all providers after MTC exposure. The authors attribute this problem to lack of education and training about the

document. Dunn et al. (1996) conclude that the MTC form is a “safe and effective instrument that would prevent unwarranted treatments and ensure that medically indicated treatments desired by the patient are provided.”

This study provides very limited evidence to support the six POLST hypotheses identified above. The form that was evaluated in the study was not a POLST form but a predecessor document called the MTC form. There was no attempt to evaluate whether the MTC form accurately reflected patient preferences. There was no attempt to test whether the MTC form was more effective than a living will.

The study explored whether physicians, nurses, and EMTs would change their behavior following exposure to the MTC form but the study has a number of weaknesses. The authors do not explain how they selected the study participants, so we have no assurance that the 87 participants were representative of medical providers in Oregon or elsewhere. The fact a survey design was used means that the responses reflect only what participants say they would do under a limited set of hypothetical facts and the responses may not predict real-world behavior in a variety of clinical contexts.

The authors’ conclusion that the MTC document ensures that medically indicated treatments desired by the patient are provided is unwarranted because there was no attempt to measure whether the MTC form accurately reflected patient preferences. Moreover, a substantial number (34%) of providers made decisions to inappropriately withhold life-sustaining treatments following exposure to the MTC.

3.6.3.2 Single cohort longitudinal study by Tolle, Tilden, Nelson and Dunn (1998)

The purpose of the study by Tolle, Tilden, Nelson and Dunn (1998) was to examine how frequently the DNR and comfort measures only orders on the POLST form were respected or ignored. The authors followed the care received by 180 residents of eight adult long-term care facilities in Oregon in which the POLST form had been in use for more than one year. One characteristic of all of these nursing homes was the very high percentage of residents having DNR orders. The mean number of patients in the selected nursing homes with DNR orders was 91%. Subjects for the study were selected based upon whether they had a POLST form in their medical record that indicated both DNR and that the patient should be transferred to a hospital only if comfort measures fail. Data for the study was obtained from patient records and other staff reports.

Of the 180 patients who were followed, 24 patients were hospitalized and 38 patients died. The hospitalizations were evaluated independently by two physicians to judge whether the transfers occurred as the result of failed comfort care. There was a 92% agreement between the raters on the reason for transfer. Raters disagreed on two cases but consensus was reached on those cases after consulting a third physician. The medical records for the 38 patients who died were reviewed to determine the care received in the month prior to death.

The study found that 85% of hospitalized patients were transferred because of failed comfort care and in 15% of the hospitalizations (n=4) the transfer was to extend life. Only two of the 38 deaths occurred in the hospital, with the deaths of the remaining patients occurring in the original nursing home. Family conferences were held shortly before death in 67% of cases.

The authors observe that the frequency of death outside of acute care in the POLST study population, including the low rate of hospital and ICU days, was much lower than national data reported in the literature. Tolle et al. concede that Oregon has very low rates of in-hospital death, but note that the rates in their study are lower than previously reported. They acknowledge that nursing homes in their study probably had a culture attuned to advance planning because they were among the first adopters of the POLST. They also acknowledge that Oregon may be different from the rest of the country in terms of racial demographics and the population's knowledge and education about end-of-life issues resulting from the debate in that state about legalizing assisted suicide.

This study provides no evidence on whether the POLST form accurately reflects authentic patient preferences. There was no attempt to test whether the POLST was more effective than a living will. The study seeks to generate evidence on the effectiveness of the POLST only with respect to the DNR and do-not-transfer orders on the form. The other medical orders on the POLST form were not examined. The form was only examined in the context of nursing homes. Hospital care and EMS services were not studied.

The design of this study makes it difficult to draw inferences that can be generalized from the results. The authors acknowledge that the nursing homes selected to participate in this study had extraordinarily high rates of DNR orders to start with, and were probably attuned to advance planning and end-of-life care. Oregon is also a unique environment as explained above. Medical staff in the studied facilities might have behaved similarly in the presence of conventional living wills. With respect to the patients who died, the presence of family conferences shortly before death in 67% of the cases is a confounding variable. We

cannot tell from the study if it was the POLST, or the family conferences, that guided medical action.

3.6.3.3 Retrospective chart review by Lee, Brummel-Smith, Meyer, Drew and London (2000)

Lee, Brummel-Smith, Meyer, Drew and London (2000) conducted a retrospective chart review for 54 patients who died during 1997 with a POLST form in their medical record at an Oregon site of the national Program of All-Inclusive Care for the Elderly (PACE). The objective of the study was to evaluate whether treatments received in the final two weeks of life were consistent with instructions documented in the POLST form.

PACE participants are eligible for long-term care paid by Medicaid, but most continue to live in the community. PACE participants receive comprehensive interdisciplinary care. The selected PACE site considered end-of-life planning a priority for all participants and a POLST is completed in most cases. POLST forms are completed based on patient preferences if the patient has decisional capacity. In other cases, surrogates are consulted. Family conferences are convened whenever a patient's health status changes but the POLST may not be updated before urgent decisions are needed.

Of the 57 patients who died in 1997, 98% had a POLST in their record. The results of the study showed that 50 patients (93%) of the study participants had forms specifying DNR and four patients (7%) requested CPR. Care was consistent with the POLST form in 91% of the cases. Three patients received CPR even though they specified DNR and two patients did not receive CPR even though they wanted it.

With respect to level of care, study participants varied in the level of care specified on the POLST form, with 24% requesting comfort measures, 33% requesting limited interventions, 33% requesting advanced interventions, and 9% requesting full treatment. Care was consistent with the POLST instructions in 46% of the cases. Care was less invasive in 33% of cases and more invasive in 20% of the cases.

For antibiotic administration, there were 28 patients for whom antibiotics were indicated. There was 86% compliance with POLST instructions relative to antibiotics, and in the remaining 14% of cases care was less invasive than requested. With respect to feeding tubes, 37 study participants were not eating sufficient calories to sustain life in the last two weeks of life. Of these patients, 34 had specified instructions regarding feeding tubes and care matched POLST form instructions in 32 (94%) of the cases.

For IV fluids, 41 participants stopped drinking adequate fluids by mouth in the two weeks prior to death. Three of these patients had not specified POLST instructions relative to IV fluids. For the remaining 38 patients, care complied with POLST instruction in 32 (84%) of cases. Five patients received more intensive IV therapy than requested and one patient received less.

Overall, the authors found that 39% of participants had POLST form instructions followed in all cases. Compliance rates with instructions on the POLST form were very high with respect to CPR (91%), antibiotics (86%), IV fluids (84%), and feeding tubes (94%). However, compliance with level of care instructions was only 46%. Lee et al. (2000) conclude that the POLST form “shows promise as a tool for promoting patients’ preferences” but caution that “there is substantial room for improvement in the level of medical intervention category...”

Like prior studies, this one by Lee et al. (2000) did not explore whether what was written on the POLST form accurately reflected patient treatment preferences. Also, like the prior studies, the one by Lee et al. does not compare compliance rates for the POLST form with those for living wills and, where applicable, prehospital DNR forms. This study also does not examine how the POLST form is used in hospitals.¹⁹

Unlike the prior studies, this one examines the effectiveness of all of the interventions listed on the POLST form. However, the presence of family conferences is a confounding factor that makes it impossible to determine whether it was the POLST form, or the family conferences, that animated provider behavior. It is also difficult to generalize from this study. The authors selected a study site that was highly attuned to end-of-life planning and it is possible that similar results might have been obtained by use of a conventional instruction directive or, where applicable, a prehospital DNR form. The PACE study site was a small closed care system and the authors acknowledge that providers in that setting might have been more comfortable relying upon POLST orders than might be the case in a more anonymous setting. As with the prior studies, this one was conducted in Oregon.

3.6.3.4 Telephone survey and onsite review by Hickman, Tolle, Brummel-Smith, and Carley (2004)

Hickman, Tolle et al. (2004) conducted a statewide telephone survey of Oregon nursing facilities between June and December 2002 followed by an onsite review of 429 medical

¹⁹ Six patients in this study by Lee et al. (2000) died in a hospital.

charts at seven nursing homes. The objective of the study was to assess statewide use of the POLST form, and explore patterns of orders documented on the POLST form for Oregon nursing facility residents aged 65 and older.

In the telephone survey, a research assistant requested permission to speak with the individual responsible for the completion of advance planning documents in each facility. Facility employees were asked a variety of questions about use of the POLST form in their facility. For the onsite reviews, a semi-random stratified sampling procedure was used to select seven Oregon nursing facilities that self-identified as using the POLST form for more than 50% of residents. The onsite reviews collected data including the presence or absence of a POLST form from each resident's chart, the location of the form, how the form was being used (i.e. to limit or request treatment) and typical problems in completing the form.

The telephone survey showed that 82% of surveyed Oregon nursing facilities used the POLST form for at least some of their patients. On average, these facilities reported that 86% of residents had completed POLST forms. The percentage of Oregon nursing facilities that reported use of the POLST form for more than half of their residents was 71%. A large majority (87%) of responding facilities also reported that they believe the POLST form reliably expresses resident wishes.

The onsite review showed that 71% of the POLST forms had patient or surrogate signatures and 89% contained information showing with whom the orders contained in the POLST form were discussed. Five percent of the forms were missing a physician or nurse practitioner signature. DNR orders were indicated on 88% of the POLST forms. Medical intervention limits were indicated on 89% of the forms. Antibiotic limits were indicated on 42% of POLST forms. Limits on artificial nutrition and hydration were indicated on 87% of

forms. Of the forms with DNR boxes checked, 77% indicated that more than the lowest level of care should be provided in at least one other treatment category. Of the POLST forms with the DNR boxes checked, 47% had less than the highest level of treatment indicated in at least one category of care.

This study contains data on the reported use of the POLST in Oregon nursing facilities, and shows how the POLST form was filled out in seven Oregon nursing homes. The study inquires into whether the POLST form reliably reflects patient preferences but only the opinions of surveyed facility staff were obtained on this issue. There is no reason to believe these opinions are reliable. The study did not examine whether physicians comply with instructions contained on the POLST form. The study did not examine whether the POLST is any more effective than an instruction directive in directing medical treatment. There was no attempt to study the use of the POLST in hospitals, in the community, or by persons under age 65.

3.6.3.5 Interviews and chart reviews by Meyers, Moore, McGrory, Sparr and Ahern (2004)

Meyers, Moore, McGrory, Sparr, and Ahern (2004) reviewed 21 medical charts and conducted 7 interviews to determine the extent to which POLST forms were being used in a two-county pilot area and whether POLST forms accurately reflected patient preferences. The authors also explored the experiences of nursing home staff, residents, and legal surrogates in using the form.

The authors invited 25 nursing homes that sent representatives to POLST training to participate in the study. Six facilities agreed to participate in the study, but since no POLST

forms were in use in two of the facilities only four nursing homes were ultimately involved. Twenty-one POLST forms were in use in the four nursing homes.

Project staff conducted medical chart reviews for each of the 21 residents with POLST forms. Project staff also interviewed two residents who had POLST forms along with the legal surrogates of five patients deemed incompetent. Nursing home contacts were also interviewed to gather information about training, policies, procedures and problems associated with the POLST form.

The study results showed that the two interviewed patients and the five interviewed surrogates expressed confidence that what was written on the POLST form accurately reflected their or their loved one's end-of-life wishes. The POLST was congruent with advance directives in all cases (n=12) where they existed. The chart review showed that medical care was congruent with POLST instructions in 19 (90.5%) of 21 cases. Compliance with informed consent procedures was documented in 16 (76%) of 21 cases. One chart indicated that the resident had changed her preference from DNR to resuscitate, but this was not reflected on the POLST. Several of the surrogates described the POLST as being presented in a way that made it seem mandated.

This study by Meyers et al. (2004) is the only published POLST study that attempts to measure whether what is written on the POLST form accurately reflects patient treatment preferences by asking patients or their surrogates directly. However, the tiny sample size (n=7) does not provide much useful evidence to support the hypothesis that the POLST accurately reflects patient treatment preferences.

This study also examined medical charts to determine whether the POLST is effective. However, the presence of congruent advance directives in 12 (57%) of 21 cases is

a confounding variable that makes it impossible to determine whether it was the POLST or the advance directive that animated provider behavior in these cases. The fact that the nursing homes self-selected for inclusion in the study limits the ability to generalize from the study results. The nursing facilities that agreed to participate with the study may have been committed to the POLST program. The small sample size (n=21) makes the results statistically meaningless even if sample selection issues are ignored.

The study did not seek to determine whether the POLST form was more effective than living wills or prehospital DNR forms. The study also did not examine whether the POLST was effective in hospitals, hospices, or when encountered by EMS personnel.

3.6.3.6 Written survey of Oregon EMTs by Schmidt, Hickman, Tolle, and Brooks (2004).

Schmidt, Hickman, Tolle and Brooks (2004) surveyed 1,048 randomly selected Oregon EMT providers and 572 (55%) individuals responded. In addition to collecting demographic information, the survey asked respondents about any education received about the POLST form, their experience with the form, and their opinions about the POLST program.

The study found that 74% of the surveyed EMT providers had been educated about the POLST program and 73% had treated at least one patient with a POLST form. Respondents reported that 87% of the POLST forms were filled out correctly and the POLST form changed the treatment plan for 45% of the patients. Many EMTs (25%) reported difficulty locating the form. In 10% of cases the form was not followed because it was overridden. This included nine cases where the patient overrode the form and 17 cases where a family member, caregiver, or individual holding a power of attorney countermanded it.

Most of the respondents (93%) agreed the form was useful when the patient had no pulse and was not breathing. Fewer (63%) agreed the form was useful when the patient had a pulse and was breathing. Seventy-eight EMT respondents (14%) thought the form did not reliably express patient wishes.

The study by Schmidt et al (2004) explores whether the POLST form accurately reflects patient preferences by asking EMTs, but there is no evidence that the opinions of EMTs on this issue are reliable. The study shows that many Oregon EMTs report that the POLST form influences their treatment decisions but this result may not be generalizable to other states because the Oregon regulations governing EMT scope of practice specifically require EMT providers to follow written physician or nurse practitioner orders regarding life-sustaining treatment. As with all surveys asking about past events, this survey might be subject to recall errors by participants. Given the Oregon regulations making non-compliance with a POLST a licensing violation, EMTs may have been unwilling to report non-compliance with POLST orders. The study does not provide any information as to whether the POLST form is any more effective at influencing EMS services than a living will or prehospital DNR form.

3.6.3.7 Analysis of legal barriers to POLST use by Hickman et al (2008).

Hickman, Sabatino, Moss and Nester (2008) surveyed individuals in all states and the District of Columbia state who were expected to understand relevant state end-of-life laws by virtue of their positions. They also conducted their own legal review of each state's law. The researchers then compiled two tables of actual and potential barriers to full implementation of POLST Paradigm programs in each jurisdiction. This study is limited to

a review of legal issues surrounding the POLST and does not provide any empirical evidence regarding its effectiveness in implementing patient end-of-life treatment preferences.

3.6.3.8 Telephone survey and chart review of POLST use in hospice by Hickman et al. (2009).

Hickman et al. (2009) conducted a telephone survey of all state recognized hospices in Oregon, West Virginia, and Wisconsin (n=133) and identified 71 hospice facilities using the POLST in those states. They also conducted a chart review of 383 medical charts of hospice patients who had died within the previous twelve months in a convenience sample of 15 POLST-using hospices in the three states. The researchers analyzed the treatment received by 275 of the patients who had a POLST form in the chart. The objectives of the study were to evaluate the use of the POLST form at the surveyed facilities, assess the attitudes of staff towards the POLST, collect data on the types of treatment options selected by hospice patients, and determine the effects of POLST forms on the use of life-sustaining medical treatments. The study was partially funded by a National Institute of Health (NIH) component.

The researchers found that most POLST-using facilities offered the form to all patients and that a majority had POLST forms for more than half of their patients. Problems relating to use of the form were reported by 51% of the facilities. The most common problems were difficulties understanding and explaining the form (28%) and logistical challenges in getting the required physician or NP signature (14%). An overwhelming number of survey participants (97%) reported that they believed the form was useful in

preventing unwanted resuscitations by emergency personnel and a similar number (96%) found the form useful in initiating end-of-life conversations.

The chart reviews also showed that patients with POLST forms were significantly more likely to have medical orders regarding life-sustaining treatments than individuals without such forms. Almost all (99%) of the POLST forms selected the DNR option. A large majority of patients (77%) selected some antibiotic use. Much smaller numbers elected treatment more intense than comfort care (20%). A small number (11%) selected use of artificial food or hydration. Six percent of the forms lacked the necessary physician or NP signature needed to make it valid.

The chart reviewed also showed that a DNR order on the POLST was almost always (99%) honored. However, three patients with orders for CPR did not receive it. Patients with comfort care orders on the POLST were significantly less likely to be hospitalized or to receive intravenous fluids, surgery, transfusions, or chemotherapy than patients with orders for limited or full treatment. Orders regarding antibiotics, however, were not predictive of whether such antibiotics were actually received. Use of feeding tubes was not analyzed due to data limitations. Treatment deviations from what was written on the POLST form were found in only 3% of the analyzed cases when deviations for comfort were excluded.

This research is the first in-depth exploration of use of the POLST in a hospice setting. Most of the data comes from Oregon even though hospices in three states participated in the research. The researchers do not break down the 71 surveyed facilities by state, but only 6% of Wisconsin's 68 hospice facilities use the POLST and that equates to four facilities. Similarly, 85% of West Virginia's 21 hospices use the POLST and this computes to 18 facilities. This leaves 49 of the 71 surveyed facilities as located in Oregon.

The researchers also identify 53% of the deceased patients with POLST forms as residing in Oregon hospice facilities. The researchers do not report if there is any geographic difference in how the POLST is perceived or used.

The chart reviews were performed at a convenience sample of 15 POLST programs in hospices and therefore it is impossible to determine whether the use and implementation of the form in these facilities is reflective of how it is used in hospices generally. We do not know what other end-of-life planning interventions were occurring in facilities that used the POLST, and whether any of these other interventions were closely associated with POLST use. The study did not explore whether treatment instructions listed on the POLST were authentic and consistent with resident preferences.

3.6.3.9 Chart review comparison of treatment of patients with and without a POLST in nursing homes by Hickman et al. (2010).

Hickman et al (2010) conducted a random sample review of 1711 medical charts drawn from 90 nursing facilities in West Virginia, Oregon, and Wisconsin. There were three objectives to the study. The first objective was to verify that residents with POLST forms are more likely to have orders reflecting life-sustaining treatment preferences than residents subject to traditional practices in nursing facilities. The second objective was to evaluate whether there were any differences between residents with POLST forms and those subject to traditional practices with respect to management of pain and shortness of death. The final objective was to compare the use of life-sustaining treatments for residents with POLST forms with that of residents subject to traditional practices.

A two-step stratified systematic random sampling plan was used in the first stage of nursing home selection, with nursing homes being stratified based upon POLST program use and urban versus rural location. Twenty charts were randomly selected from each nursing home with the goal of obtaining equal numbers of living and deceased residents, but the final sample included more living residents. There was intentional oversampling of non-white residents. Chart data was abstracted for sixty days prior to the date of collection for living residents, and for sixty days prior to the date of death for deceased individuals. Deceased residents had all died at the facility. The sample was split between approximately 48% POLST users and 52% non-users. The residents were evenly distributed among the three states.

The researchers analyzed the chart data for the presence of various orders for life-sustaining treatments, information about pain and shortness of breath and treatment for those symptoms, and the use of various life-sustaining treatments. The analysis of data related to symptoms and their management was limited to the last seven days of chart information. The remainder of the analysis considered the entire 60 day period excerpted in the chart review. Individuals who had POLST forms that were changed during the 60 day period were excluded from the analysis of use of life sustaining treatments.

The researchers confirmed that residents using POLST forms were more likely than non-users to have standing orders governing one or more types of life-sustaining treatment (100% vs. 87%). When CPR was excluded from the analysis, the difference was dramatic. With respect to the level of medical intervention the POLST users had medical orders in 97.4% of the cases while non-users had orders only 13.9% of the time. For antibiotic use the difference was 95.7% versus 3.2%. For feeding tubes the difference was 92.3% versus 6.7%.

The researchers also found no difference between POLST users and non-users with respect to symptom assessment or management.

With respect to use of life-sustaining treatments, the study found that individuals with comfort care orders on their POLST were 59% less likely to receive life-sustaining treatments than residents with traditional DNR orders and 71% less likely than residents with traditional full code orders. No difference was found with respect to interventions given to residents with POLST full treatment orders and traditional full code orders. The presence of orders on POLST forms relative to antibiotic use was found to have no effect on treatment.

This study was funded by a NIH component and is the first research on the POLST using a large random sample size drawn from diverse jurisdictions. It shows that in one type of facility -- nursing homes -- treatment generally follows the instructions on POLST forms, except as regards antibiotics. However, some caution is appropriate in reaching this conclusion since the authors eliminated individuals whose POLST form changed within the study period from portions of the analysis. Residents with a changed POLST form are the ones most likely to be in an unstable or rapidly changing condition, which may prompt treatment decisions not consistent with instructions previously provided on the forms. The study provides some reassurance that POLST users do not receive less symptom assessment and management by virtue of having the form. This finding is an important addition to the research base. The study's finding that individuals who have a POLST generally have more life-sustaining treatment orders in the chart than individuals using traditional practices is not surprising given the nature of the form as a medical order set. The study does not examine whether the presence or absence of such orders was appropriate given each resident's medical condition.

3.6.3.10 Comparative, retrospective, observational study of advance care plans in La Crosse County, Wisconsin by Hammes, Rooney, and Gundrum (2010).

This paper reports on the second wave of the La Cross Advance Directives Study. The researchers reviewed 400 charts of adults who died at 12 health care organizations in La Crosse County, Wisconsin during the period September 1, 2007 through March 31, 2008. This community has used the Respecting Choices system for end-of-life care since 1993 and the POLST program since 1997. The study does not focus on the POLST, but it is included here because contains some new data on the form not previously reported in the literature. Specifically, the study finds that the average age of a POLST form in the study population was 4.3 months versus 3.8 years for an advance directive.

3.6.3.11 Chart review examining the consistency between treatments provided to nursing home residents and POLST orders by Hickman et al. (2011).

This is a second study based upon analysis of data from the NIH-funded study discussed in §3.6.3.9 above. The study objective was to determine if treatments provided to nursing facility residents were consistent with orders on the POLST form. The researchers found they were.

With respect to resuscitation orders, the researchers found that where a POLST form contained a DNR order, there was no instance of resuscitation. The overwhelming majority of cases (85.7%) had DNR orders. However, in the small number of cases where the POLST contained a valid “full code” order and the patient required resuscitation, those instructions were often not followed. The researchers identified seven cases with valid “full code” orders

on the POLST where resuscitation could have been attempted. Treatment was not provided in six of them.

The researchers found high levels of compliance (>90%) with POLST orders with respect to intensity of care and antibiotic use. However compliance with feeding tube instructions was only 64%. Overall compliance with treatment orders on the POLST was 94%.

This study shows that where a POLST form directs the withdrawal or limitation of life sustaining treatment in a nursing facility, those instructions are generally followed. However, some caution is appropriate in accepting this result. As noted previously, individuals whose POLST changed within the study period were excluded from the analysis and therefore the results may not be applicable to individuals with unstable or rapidly changing conditions.

3.6.3.12 Survey of emergency medical services professionals experience with advance directives and the MOLST by Sam et al. (2011).

Two hundred and thirty emergency medical services professionals and volunteers from New York City and Long Island filled out a survey of their attitudes and practices regarding advance directives and New York's version of the POLST. The New York form is the "Medical Orders for Life Sustaining Treatment" or MOLST.

Seventy-nine percent of respondents were aware of the MOLST and 68% said they would be comfortable honoring a MOLST. Nearly three quarters (72%) were unaware that a photocopy was a legal document and a majority (54%) did not know the form was pink.

Approximately half (52%) of the respondents had received training on the document. Seventy-one percent had never encountered a MOLST in the field. More experienced respondents were significantly more likely to be comfortable honoring the MOLST than those with six years of experience or less.

This study was published in the form of a letter to the editor. Although the sample is not random and the research was limited to one part of New York, it adds to the literature. This is only the second published study regarding how the POLST form is used by emergency services personnel. The researchers conclude that there is “a significant dearth of knowledge” regarding the form among emergency services personnel and it recommends more training on the form.

3.6.3.13 Survey of knowledge and attitudes of health care workers regarding the MOLST by Vo et al. (2011).

Vo et al. distributed anonymous survey forms regarding New York’s version of the POLST to staff in six nursing homes affiliated with the North Shore LIJ Health System located in New Hyde Park, New York. Three nursing homes with low MOLST use and three with high use were selected based on proximity to the researchers’ offices. One hundred sixty nine surveys were returned reflecting a response rate of 35%. The goal of the research was to compare knowledge and attitudes of health care workers regarding the MOLST based upon the prevalence of use of the form in the facility.

Respondents from low prevalence facilities were generally older than those from high using facilities. Twice as many respondents (77.4% vs. 37.2%) from high MOLST-using nursing homes agreed that all nursing home residents should have the form. Also, 46.8% of

respondents in high use facilities agreed that residents with MOLST form had better pain management compared to 11.8% in low use facilities. Twice as many respondents from low use facilities felt the length and detail of the form made it difficult to complete. Only 19.6% of respondents in low use facilities knew the MOLST did not need to be pink to be valid as compared to 51.4% of respondents from the high use group. Large numbers of both groups knew that a MOLST had to be signed by a physician to be valid but more than 10% of both groups did not.

This study provides some new data regarding the attitudes of health care workers regarding the POLST. It also highlights the need for continuing education and training of staff regarding the POLST since substantial numbers of respondents did not know crucial information about the form. However the research design does not permit any generalization from the findings.

3.6.3.14 AARP report by Sabatino and Karp (2011)

Sabatino and Karp conducted open ended telephone interviews of 47 key informants involved in POLST development in 12 states. Five additional interviews were conducted in one state that attempted but failed to implement a POLST program. The authors also reviewed legislation and regulations regarding the POLST for the 12 states. A one day multi-disciplinary expert roundtable reviewed the work. This work resulted in a 55 page report detailing legislative and regulatory developments regarding the POLST, identification of issues surrounding implementation of the POLST, and recommendations.

The report includes observations by the respondents about barriers and issues that posed challenges to POLST implementation. This non-peer reviewed study is included in the

literature review because it contains some survey data, and reading the report is required by the National POLST Paradigm Task Force for a program to qualify as a Level I POLST program. It contains some information on difficulties that the respondents perceived in implementing the POLST in the way intended by its designers.

3.6.3.15 Retrospective Chart Review by Hammes, Rooney, Gundrum, Hickman and Hager (2012)

This is a second study based upon data from the La Cross Advance Directives Study discussed in paragraph 3.6.3.10 above. The objectives of the study were to determine: (1) the demographics of individuals with a POLST form as compared to those who only had a health care power of attorney; (2) the variety of orders that exist on the POLST form at the time of death; (3) the overall relationship between POLST orders and the use of medical treatment; (4) the rate of discrepancy between POLST orders and treatments provided; and (5) who is consenting to the decisions when the POLST form is completed.

The study found that 67% of decedents had a POLST form either alone or in combination with a health care power of attorney. POLST users were older, more likely to die in long term care, and almost always (97%) had chronic or terminal illnesses. There were 35 unique combinations of orders used by the decedents. Orders for comfort care were almost always followed with only two patients being hospitalized for reasons other than comfort.

The researchers found that five patients requested aggressive treatment but were not resuscitated. However, they determined based upon chart review that the goals of care had shifted for all of these patients and new medical orders were written without the POLST

being changed. The researchers also found that instructions regarding antibiotic use were usually followed but that POLST orders were overridden in 20 cases. Consent for the instructions on the POLST form was provided by a patient or surrogate in 94% of the cases. The decedent supplied sole consent in 37% of the cases and the surrogate provided sole consent in 41%. Multiple individuals provided consent in 23% of cases.

This study provides information about how the POLST form is filled out by health care providers in one county in Wisconsin where the providers are engaged with end-of-life issues as the result of a community-wide advance planning initiative. The researchers acknowledge that due to the simultaneous operation of the Respecting Choices program in the county it cannot be determined whether the form has any effect on treatment. The study fills a gap in the literature by providing data on the identity of persons consenting to completion of the POLST form for patients.

3.6.3.16 Survey of self-reported practices and options of North Carolina nursing home professionals using the MOST form by Caprio, Rollins, and Roberts (2012)

Caprio, Rollins, and Roberts (2012) asked 11 health care professionals drawn from two North Carolina nursing homes about how the North Carolina version of the POLST form was used in their facilities. The North Carolina form is called “Medical Orders for Scope of Treatment” or MOST.

Nearly all of the respondents indicated that it was appropriate for a nurse practitioner to discuss and complete the MOST form. One half supported having social workers introduce the form. All of the respondents were aware of the annual review requirements but only three of the 11 respondents knew all of the criteria that trigger a MOST review. Nearly

all of the respondents believed that the MOST form has the potential to improve communication of treatment preferences between patients and physicians or physicians and families.

This small study inquired into how the North Carolina version of the POLST was used in two nursing homes. It does not address any of the unresolved questions about the POLST nor does it add much to the existing literature. The results cannot be generalized.

3.6.3.17 Survey of the dissemination of POLST use in California nursing homes by Wenger et al. (2012).

Wenger et al surveyed 546 nursing homes in California to gather information on the extent of POLST form usage in such facilities during 2010. They estimated that 54% of state nursing home residents had a POLST. They also found that staff in 82% of responding nursing homes had received POLST education, and estimated that 43% of staff had been educated. Fifty-nine percent of the reporting facilities said they had a formal policy on handling the POLST. Two thirds of nursing homes had admitted a resident with a POLST and 15% of newly admitted residents had a POLST. Eighty-one percent of nursing homes had completed a POLST form with a resident. More than one third of nursing homes reported difficulty involving physicians with POLST form completion, and having doctors sign the form. Twenty-one percent of facilities reported that they had difficulty interpreting a POLST to make treatment decisions and more than one quarter reported that family had disagreed with POLST content.

This study of over 500 nursing homes provides useful new information on how the POLST form is being implemented in a large and diverse state. It addresses POLST implementation issues such as staff education, problems encountered in interpreting the POLST form, and the difficulty of involving physicians in POLST completion.

3.6.3.18 Analysis of preferences for treatment stated on POLST forms contained in the Oregon POLST registry by Fromme, Zive, Schmidt, Olszewski, and Tolle (2012).

The researchers looked at the treatment preferences of individuals indicated on more than 25,000 POLST forms contained in the Oregon POLST registry. Doctors in Oregon are required to send completed POLST form to a state administered registry unless the patient opts out. The registry is accessible to emergency personnel and hospitals 24-hours a day. The research compared the forms of individuals having the DNR box checked with those who elected resuscitation.

The overwhelming majority of forms (72.1%) contained a DNR instruction. Of these forms, 49.6% also had orders for comfort care only. The remainder of the POLST forms requested either limited treatment or full treatment. For individuals who desired resuscitation, 75.7% had medical orders for full treatment. Only 2.7% had orders for comfort care and 21.6% had orders for limited interventions.

This research confirms prior findings that many people with a DNR order desire other life-sustaining treatments. It is a population review, so there are no issues arising out of sampling procedure. The main limitation of the research is that it was limited to Oregon, which may have a different end-of-life culture than other areas of the country.

3.6.4 Conclusions about the POLST Research

As shown in the table appearing below, with the possible exception of the two NIH-funded studies, all of the published POLST research studies discussed above suffer from serious methodological weaknesses when measured against the standards of “good” quantitative research, where considerations of internal and external validity are highly valued. In terms of the six POLST research hypotheses identified in section 3.1 above (i.e H1 through H6), there is not a single hypothesis that can be said to have solid evidentiary support backed by multiple well designed studies from which generalization is appropriate. For H3, the column lists the setting where a POLST hypothesis was examined, if any.

Table 2 POLST Hypotheses and Supporting Studies

Study	H1: POLST captures authentic preferences	H2: POLST affects treatment received	H3: POLST works in multiple settings	H4: POLST is better than a living will	H5: POLST does not harm patients	H6: POLST correctly used in institutions
Dunn et al (1999)		X	Multiple			
Tolle et al (1998)		X	Nursing Homes			
Lee et al (2000)		X	PACE			
Hickman et al (2004)	X		Nursing Homes			X
Meyers et al (2004)	X	X	Nursing Homes			X
Schmdt et al (2004)	X	X	EMTs			
Hickman et al (2008)						
Hickman et al (2009)		X	Hospice			X
Hickman et al (2010)		X	Nursing Homes		X	X
Hammes et al (2010)						
Hammes et al (2012)		X	Multiple		X	
Hickman et al (2011)		X	Nursing Homes		X	
Sam et al (2011)						
Vo et al. (2011)						
Caprio et al (2012)			Nursing Homes			X
Fromme et al (2012)						
Wenger et al (2012)						X

There is only scant research to support H1 which supposes that the POLST captures authentic patient treatment preferences as opposed to, for example, the preferences of the provider representatives assisting with the form. Hickman et al. (2004) and Schmidt et al. (2004) put this question to medical providers without providing any evidence that the providers actually knew what the patients wanted. Meyers et al. (2004) asked this question of seven patients or their surrogates. This is not convincing data that the POLST is capturing authentic patient treatment preferences.

Six published papers report on the effectiveness of the POLST form based upon chart reviews and thus address H2. Two of the published papers were based on the large NIH funded study of POLST which was well designed and had a large sample size. These are the papers by Hickman et al (2010) and Hickman et al (2011). However, the NIH study was limited to nursing homes and a crucial segment of POLST users – patients with unstable medical conditions – was omitted from the study. Additionally, while the sample was drawn from three diverse states, it cannot be said that these three jurisdictions are necessarily representative of the entire United States. The NIH funded hospice study by Hickman et al. (2009) suffers from the same limitation. The remaining studies on POLST effectiveness do not qualify as good quantitative studies from which generalization is appropriate. Tolle, Tilden, Nelson and Dunn (1998) selected nursing homes in Oregon that had high DNR rates and used family conferences. Lee, Brummel-Smith, Meyers, Drew, and London (2000) similarly used a study site that was committed to good end-of-life care and also used family conferences. Meyers, Moore, McGrory, Sparr, and Ahern (2004) had 19 of 25 nursing homes refuse to participate in their study, and ended up reviewing only 21 medical charts.

There are no chart reviews showing the POLST is effective in hospital settings or when encountered by emergency services personnel on the street. According H3 is also not completely addressed.

No published study examines H4 and compares the effectiveness of the POLST against living wills head to head in the same facility. One cannot simply rely upon existing research that shows that advance directives are sometimes ineffective, and then assume that the POLST must be necessarily better. If the effectiveness of living wills was studied in provider settings committed to end-of-life care similar to those where the POLST was examined, it might very well be found that doctors would follow living will instructions with equal alacrity.

In terms of harm to patients (H5), the three studies by Hickman et al (2010), Hickman et al. (2011) and Hammes et al. (2012) all looked at whether the POLST might harm patients by causing the withholding of treatment that should be provided. The studies provide some reassurance that the POLST is not being used as a signal to deny treatment that should be provided. However, the study by Hammes et al. (2011) was limited to providers who were committed to advance planning in one Wisconsin county, and the two studies Hickman et al. were limited to nursing home patients. Accordingly, H5 is only incompletely addressed by the research.

A number of studies have looked at whether the POLST is actually being implemented in medical institutions in the way intended by its designers per H6. However, most of the existing research focuses on whether required or optional signatures are on the POLST form, and whether the form indicates with whom the medical orders have been discussed. However, if filling out the POLST is not optional with the resident, or if the

treatment choices are being elicited from relatives who have not been designated by the resident, then the POLST may not represent an exercise of autonomous decision making.

Finally, it should not be ignored that most of the existing studies were conducted by past or present members of the National POLST Paradigm Task force. This includes the large studies funded by the NIH. The possibility that allegiance bias to particular theories might affect the outcomes of research has been extensively reported upon in the psychological literature and has some empirical support (Leykin & DeRubeis, 2009). If one disregards all the research that might be unintentionally biased based upon the researchers' allegiance to advancing adoption of the POLST, then what we know about the form is very little indeed.

3.7 RESEARCH AIM AND METHODOLOGY

Callahan (1989) warned of a “klutz factor,” referring to what happens to movements and practices “when they are taken out of the hands of the first pioneers, who act carefully and thoughtfully after due deliberation, and are put the hands of very large numbers of people who may not approach them with the same care.” This concern has not escaped some members of the National POLST Paradigm Task Force. Two members have cautioned that if institutions using the POLST do not take steps to insure that the form is used as intended, it can “morph into another trampling of patient autonomy” (Bomba & Sabatino, 2009).

The aim of the research reported in this dissertation is to follow up on the concern that the POLST is being used in medical institutions in a way that is different from the way

the form is intended for use by its designers. The research addresses hypothesis six (H6) outlined above. The research is exploratory in nature.

Most of the studies touching on POLST implementation ask whether the appropriate signatures were include on the completed POLST forms and/or whether there was an indication on the forms with whom the orders were discussed. Hickman et al. (2004) conducted a chart review of 355 POLST forms in seven nursing homes and looked at whether the forms contained the required physician or nurse practitioner signature, the optional resident or surrogate signature, and a specification with whom the orders were discussed. Hickman et al. (2009) looked for the presence or absence of the same signatures and specification in a hospice setting. Hickman et al. (2010) included a check for resident or surrogate signatures as part of their study comparing treatments of nursing facility residents with or without a POLST.

There has been less research focusing on the procedures used by medical facilities to obtain completion of the form. Myers, Moore, McGrory, Ocn, and Ahern (2004) asked two residents and five surrogates how the POLST form was introduced to them. They also asked staff at four nursing homes about training, informed consent procedures, and institutional policies regarding the POLST form. Caprio, Robbins, and Roberts (2012) asked twelve health professionals in two North Carolina nursing homes about the timing for completion of the POLST and who helps with its completion. They also asked about the procedure for introducing the form to residents and whether the respondents were aware of review requirements. Sabatino and Karp (2011) asked knowledgeable informants to about how the form was being used in 12 states, but did not study any particular treatment setting. The

California survey by Wenger et al. (2012) included questions about staff education and difficulties encountered when completing a POLST.

The research conducted for this dissertation asked about signatures and other procedural matters, but also inquired about whether the POLST was presented to individuals as required, recommended or optional, who was offered the form, and whether there was compliance with State law requirements regarding surrogate authority to make treatment selections. No previous study has looked at these issues. Nursing homes were selected as focus of the research because the POLST is widely used in that setting and, since much of the existing research deals with nursing home use, the research results can be viewed in the context of the literature rather than standing alone. H6 was selected as the focus of the research because the results could be scientifically meaningful in the context of the existing literature. Additionally, an investigation of POLST procedures in nursing homes via a survey of facility personnel is a manageable project for a doctoral dissertation. I considered focusing upon H1 and the authenticity of resident preferences since research on this issue is urgently needed. However, the complexity of that project made it infeasible for me.

Data collection was conducted in Allegheny County, Pennsylvania and was limited to nursing homes participating in the POLST program. Allegheny County was selected for convenience of the researcher, but also because the county has many characteristics that make it a good site for an exploratory inquiry into how the POLST is being used. The county has a program for nursing homes that has been in operation since 2000. This program was also developed under the general guidance of a National POLST Paradigm Task Force member located in Pittsburgh, and therefore the purpose and method of the POLST paradigm

were often communicated to participating facilities by a person directly involved with its development.

Nursing homes using the POLST in the county were identified through a listing obtained from the member of the National POLST Paradigm Task Force located in Pittsburgh. That Task Force member partnered with a major health insurer and the University of Pittsburgh Institute on Aging to promote use of the form in nursing homes, hospitals, hospices, and retirement communities. Twenty-four nursing facilities were identified as using the POLST form for their residents.

The researcher developed a survey form covering a number of aspects of POLST use in nursing homes, including questions asking about compliance with the required and recommended safeguards for use identified by the National POLST Paradigm Task Force. The survey was designed for face-to-face administration with a respondent designated by the nursing facility. Survey questions relating to procedural safeguards were all in the multiple choice format covering all possible choices including “other” or “uncertain” responses. The survey script read to respondents encouraged them to provide additional information if the suggested responses did not adequately capture the facility’s practices. A copy of the survey form is an appendix to this dissertation.

A draft of the survey form and accompanying instructions was submitted for expert review to three current or past members of the National POLST Paradigm Task Force. Comments from these individuals were incorporated into the survey form. The survey was pre-tested at three Allegheny County nursing homes and revised again in response to issues revealed during the testing phase. The final survey form was submitted to the Institutional Review Board of the University of Pittsburgh and was approved.

Introductory letters were sent to all of the identified POLST participating nursing facilities in Allegheny County. These letters were followed up by a telephone call to each facility seeking the names of the individuals responsible for the POLST program at the facility. The identified individuals always included either a social services staff member or the director of nursing. Face to face interviews were successfully conducted at 19 of the 24 facilities by the researcher.

The interviews took about thirty minutes each and were conducted over a four month period beginning in April 2010. Survey respondents were assured confidentiality during the introductory script reading. The survey form did not identify either the facility or the respondent by name. The response rate was 79%. The results of the survey were coded onto an Excel spreadsheet at the close of the field work, and were tabulated by hand. Three articles were developed using the data. These articles follow. As of December 2012, article one is being considered for journal publication in a revised form. The two other articles may be submitted for publication at a future date.

**4.0 ARTICLE ONE – THE PHYSICIAN ORDERS FOR LIFE SUSTAINING
TREATMENT (POLST): ACTUAL VERSUS INTENDED USE IN A NURSING
HOME SETTING**

4.1 ABSTRACT

The Physician Orders for Life Sustaining Treatment (POLST) is a new end-of-life planning tool being adopted in many jurisdictions throughout the United States. However, there is little research on how it is being administered to residents in nursing homes. This article examines whether nursing facilities using the POLST are administering the form in the way intended by its designers.

A face to face survey of self-identified staff familiar with POLST use at 19 nursing facilities in Allegheny County, Pennsylvania was conducted between April and August 2010. The survey asked whether nursing facilities present the POLST form to residents as a required, recommended, or optional document; whether the POLST is offered to all residents or only certain types of residents; whether the facility requires a patient or surrogate signature on the form; whether the facility updates the form at resident care conferences or upon a change in medical condition; whether the facility screens the POLST for errors and makes sure it is signed by an appropriate medical professional before it is put into the chart; and

how much time it typically takes to complete a POLST for residents with and without a living will.

I found that most nursing facilities present the POLST form to residents as being required, and they offer it to all residents regardless of medical condition. Approximately half of the facilities follow the recommendation to obtain a resident or surrogate signature on the POLST. Almost all respondents say they typically complete a POLST for a resident who does not have a living will in less than an hour. Most facilities update the form upon a change in medical condition and check the form for errors before putting it in the resident's medical chart. I conclude that additional training on use of the POLST is needed because many nursing facilities did not comply with procedures required or recommended by the National POLST Paradigm Task Force.

4.2 INTRODUCTION

Death cannot be defeated, but many of us would like to control how we die. Towards this end, society has embraced the living will as a way for individuals to manage their dying process. Unfortunately, research shows the living will to be often ineffective (Ditto & Hawkins, 2005). What has recently arrived on the scene as another device for patients to control their end-of-life medical care is the Physician Orders for Life-Sustaining Treatment or POLST.

The POLST is a set of medical orders that directs the provision or withholding of specified life-sustaining medical treatments. The POLST is similar to critical care medical

order sets that are routinely completed by doctors in hospitals and nursing homes to specify or limit life-sustaining care for patients who are near the end of their lives. However, the POLST differs from conventional critical care orders in that it is often signed by a physician, physician assistant, or nurse practitioner before the onset of a medical crisis, and the instructions are based upon treatment preferences specified by the patient or a representative in advance. This aspect of the POLST makes it similar to a living will. The POLST can be used to request full treatment, but it is most often used to prevent transfers to intensive care and to limit life-sustaining procedures such as cardiopulmonary respiration and mechanical ventilation (Hickman et al. 2010). Additional orders relating to antibiotics, tube feeding, and overall intensity of care are also included. A novel feature of the POLST is its intended portability between treatment settings without regard to institutional credentialing and privileging requirements. POLST forms can differ slightly from state to state, but most closely follow the model of the Oregon form. Sample POLST forms can be viewed on the POLST.ORG web site.

A growing body of research shows that there is a high degree of compliance with the treatment instructions contained in the POLST by medical personnel (Hickman et al. 2010). Use of the POLST is spreading rapidly throughout the Nation. More than 20 states have active or developing POLST programs (Oregon Health and Science University, 2012). Congress came close to nationalizing use of the POLST during the enactment of health reform. However, the advance care planning section that incorporated the POLST did not appear in the bill that was ultimately enacted into law (O'Reilly, 2009).

If there is a problem with the POLST, it may be that it is too effective (President's Council on Bioethics, 2005). Treatment limitations contained in the POLST may be

implemented by doctors, nurses, and emergency medical personnel in circumstances not anticipated by the patient. To prevent this from happening, procedural safeguards for use of the form have been specified by the National POLST Paradigm Task Force on its web site (Oregon Health and Science University, 2012). These safeguards require that use of the form be completely voluntary, and that only certain categories of patients be offered the POLST. The form should not be used to limit the treatment of persons with stable medical conditions, or who are disabled and have many years of life expectancy. Additionally, the Task Force strongly recommends that medical providers obtain the signature of a patient or surrogate on the form to insure that orders on the form are in agreement with the patient's treatment preferences. Training materials issued by the Task Force also recommend that the form be updated whenever there is a change in the patient's medical condition.

There is no published research investigating whether medical facilities using the POLST form comply with the required and recommended procedural safeguards. This research begins the exploration of that issue in the nursing home setting.

4.3 METHODS

The research was conducted in Allegheny County, Pennsylvania. This county is located in western Pennsylvania and includes the city of Pittsburgh. It has a POLST program for nursing homes that has been in operation since 2000. Nursing homes using the POLST in the county were identified through a listing obtained from a member of the National POLST Paradigm Task Force located in Pittsburgh. That Task Force member partnered with a major

health insurer and the University of Pittsburgh Institute on Aging to promote use of the form in nursing homes, hospitals, hospices, and retirement communities. Twenty-four facilities were identified as using the POLST form for their residents.

A survey form was developed covering a number of aspects of POLST use in nursing homes, including questions asking about compliance with the required and recommended safeguards identified by the National POLST Paradigm Task Force. The survey was designed to be administered in a face-to-face interview with a respondent designated by the nursing facility. The survey questions relating to procedural safeguards were all in the multiple choice format covering all possible choices including “other” or “uncertain” responses. The survey instructions encouraged respondents to provide additional information if the suggested responses did not adequately capture the facility’s practices.

One question asked: “Does the facility offer the POLST to all residents in all units of the facility. In other words is it offered to everybody?” A second question asked respondents to characterize how they presented the POLST to residents. It asked: “We would like you to characterize how the facility presents the POLST form to the resident. You could characterize the way the facility presents the POLST form to residents as being required, recommended, optional, or you could use another description. How would you describe it?”

Other questions on the survey form asked if respondents personally assisted residents and surrogates with making selections on a POLST form and, if so, inquired how much time it typically took them to complete a POLST form for a resident and whether the form was completed in one session or multiple sessions. Questions also asked if facilities screened POLST forms for errors and the presence of a signature by a physician or other appropriate

health professional. No questions were asked about portability because Pennsylvania has not enacted a law permitting this aspect of the POLST paradigm.

A draft of the survey form and instructions was submitted for expert review to three current or past members of the National POLST Paradigm Task Force. Comments from these individuals were incorporated into the survey form. The survey was pre-tested at three Allegheny County nursing homes and revised again in response to issues revealed during the testing phase. The final survey form was submitted to the Institutional Review Board of the University of Pittsburgh and approved.

Introductory letters were sent to facility administrators at all of the identified POLST participating nursing facilities in Allegheny County. These letters were followed up by a telephone call to each facility seeking the names of the individuals responsible for the POLST program at the facility. The identified individuals always included either a social services staff member or the director of nursing. Face to face interviews were successfully conducted at 19 of the 24 facilities by the researcher. The remaining facilities did not respond to repeated telephone calls seeking to set up interviews. Table 3 shows the characteristics of the surveyed facilities as compared to all Allegheny County nursing facilities. All facilities said they used the Oregon POLST form.

The interviews took about thirty minutes each and were conducted over a four month period beginning in April 2010. Survey respondents were assured confidentiality during the introductory script reading. The survey form did not identify either the facility or the respondent by name. The response rate was 79%. The results of the survey were coded onto an Excel spreadsheet at the close of the field work, and were tabulated by hand.

4.4 RESULTS

Table 4 shows the results of the survey on questions relating to nursing home compliance with POLST procedural safeguards. Nearly three fifths (58%) of the 19 responding nursing homes said they presented the POLST form to residents as being required by the facility. Almost a third of the homes (32%) said they presented the POLST as a recommended document. Only two facilities said they presented the POLST form to residents as optional. All but one of the 11 facilities that said they presented the form as required also reported a POLST completion rate exceeding 80%, which was the upper limit provided by the survey questionnaire. However, respondents at seven of these 11 facilities also volunteered that the completion rate was at or near 100%. The one facility that said it presented the form as required and did not also report a completion rate above 80% said this was due to the fact that POLST completion was only required of new residents and was optional with existing residents.

More than 80% of the surveyed nursing homes said they offer the POLST to all of their residents regardless of medical condition. Only three facilities said they offer the POLST selectively based on the resident's medical condition. All of the surveyed nursing facilities reported that they had short-term rehabilitation units.

Nearly half the facilities (47%) said they require a patient or surrogate signature on the POLST. An equal number of facilities said they do not. The respondent at one nursing home was uncertain as to the facility's practice relative to signatures. Almost all of the facilities (89%) said they updated the POLST upon a change in the resident's medical

condition. More than two thirds (68%) of the facilities said the POLST was reviewed at the resident's comprehensive care planning conference.

Table 5 summarizes the data relative to error checking and the presence of the required signature of an individual authorized to write medical orders. Almost 80% of the facilities reported that they screen the POLST form for errors such as multiple boxes checked in the same section. More than two-thirds of the facilities reported that they make sure an authorized health professional signs the POLST before it is put into the resident's chart as part of the medical orders. Two of the facilities that reported putting unsigned POLST forms in the chart said the forms would be flagged for the doctor to sign.

The time respondents reported it typically takes to complete a POLST for a resident is shown in Table 6. More than half of the respondents (53%) said it typically took less than ten minutes to complete a POLST for a resident with a living will. A much larger percentage (95%) of respondents reported that it took them less than an hour to fill out a POLST for a person with a living will. When a resident lacks a living will, most respondents said it took longer to complete the POLST. Only 21% of the respondents said that they could typically complete a POLST for such a resident in less than ten minutes. Twenty-six percent of respondents said they typically require ten to 20 minutes to complete the form when there is no living will and 37% of respondents said they typically require 20 minutes to an hour. Only two respondents said it typically takes many hours to complete a POLST for a resident without a living will. Nearly three quarters (74%) of respondents said they typically completed the POLST in a single session with the resident.

4.5 DISCUSSION

This study sought to determine if nursing homes using the POLST in one Pennsylvania county complied with procedural safeguards required or recommended by the National POLST Paradigm Task Force. These safeguards provide that use of the form by residents be completely voluntary, that the form generally be restricted to individuals who have a likelihood of dying within one year, and that a resident or surrogate signature appears on the form. The safeguards help ensure that the POLST form is appropriately used, and is a bona fide exercise of resident autonomy. We found that many nursing homes did not fully comply with the safeguards.

An important question addressed by the survey was whether use of the POLST form is completely voluntary with the resident. The survey addressed this issue by asking how the facility presented the form to residents. The survey did not ask whether completion of a POLST form was actually mandated as a condition of remaining in the facility because both state nursing home licensing regulations, and the Federal Patient Self-Determination Act, prohibit a facility from conditioning care on the signing of a POLST.²⁰ It is therefore unlikely that any facility would have such a policy. Additionally, the survey asked if completion of the POLST was “optional with the resident,” instead of “voluntary”, because the concept of voluntariness has a nuanced meaning in the context of informed consent (Beauchamp & Childress, 2001, pp. 93 - 94). All respondents appeared to understand what was being asked, and the results suggest that the POLST is often presented in a way that

²⁰ The state nursing home licensing regulation at 28 Pa.Code §201.29(f)(2012) limits a facility’s authority to discharge a resident to medical reasons or non-payment. The Patient Self-Determination Act, 42 U.S.C. §1396a(w)(2012), prohibits conditioning care upon the signing of an advance directive.

leads residents and surrogates to believe that completion of the form is mandatory, even though a resident cannot legally be forced to have the form. Sabatino and Karp (2011) also found this to be an issue in nursing homes (18).

The survey also inquired into whether the POLST form is offered to all residents in all units of the facility. Offering a POLST to individuals who may be expected to live for several years is discouraged under the POLST paradigm. A substantial body of literature shows that treatment preferences are only moderately stable over time (Fried, O’Leary, Van Ness & Fraenkel, 2007). Sometimes people change their minds when their medical condition changes, and they decide to accept burdensome medical interventions that they previously thought were unacceptable (Danis, Garrett, Harris & Patrick, 1994). Medical treatment preferences are also sensitive to context and treatment preferences change when individuals are asked to make decisions within the contexts of different medical scenarios (Winter, Parks, & Diamond, 2010). When a POLST is offered to everyone in the facility – including relatively healthy patients in short-term post-hospital rehabilitation units – there is a potential for some residents to reject interventions that appear unattractive to them now, but which would be both beneficial and acceptable in a medical crisis. The POLST is supposed to reflect the “here and now” treatment goals of individuals (Sabatino & Karp, 2011). However, asking nursing facility residents who are not near the end of life whether they would want tube feeding or mechanical ventilation without supplying a plausible and relevant medical context for those questions can be a meaningless exercise.

Approximately half of the surveyed nursing homes do not require a resident or surrogate signature on the POLST. A signature by the person providing treatment instructions on the POLST is “strongly recommended” by the National POLST Paradigm

Task Force because it “provides evidence that the patients or their legal representatives agree with the orders on the form” and “provides a safeguard for patients that the orders on the form accurately convey their preferences” (Oregon Health and Science University, 2012). Without a resident or surrogate signature, there is no assurance that the resident’s treatment preferences have been correctly translated into POLST medical orders.

Almost 90% of the surveyed facilities said they update the POLST upon a resident’s change in condition. Nearly 80% of the facilities reported that they review the POLST at the resident’s comprehensive care planning conference. Such conferences are usually held at least quarterly to comply with Federal Medicare and Medicaid regulations. These percentages show that most surveyed nursing homes are making sure that the medical orders on the POLST are reasonably current. However, when one considers that the POLST contains life or death medical orders, even a 90% compliance rate may be too low.

Approximately one fifth of the facilities reported that they do not screen POLST forms for errors like multiple boxes checked in the same section, and nearly one third of the facilities said they do not check for an authorized signature before putting the POLST form in the medical chart. Errors in POLST forms can lead to unwanted treatment or unintended death. Facilities should be routinely screening POLST forms before they are put into the medical chart.

It is difficult to evaluate whether sufficient time is being spent filling out the POLST form. It may be expected that the POLST completion process will go quickly with residents who already have a living will. These individuals have given significant thought to their end-of-life care. Accordingly, it is not necessarily surprising that most respondents say they typically take less than ten minutes to complete a POLST for residents with a living will.

However, the responses from facilities relative to persons without a living will may suggest that facility personnel are not spending enough time on advance planning with residents. Forty-seven (47%) percent of respondents said that they typically completed a POLST for such residents in less than 20 minutes. Eight four (84%) percent of respondents said it typically took less than an hour to complete a POLST for residents without a living will. Nearly three-quarters (74%) of respondents said they typically completed the POLST with a resident in a single session.

Good advance care planning takes time and recognizes that the issues involved with end-of-life care are complex and emotionally difficult (Parks & Winter, 2009). It is recommended that such planning be done in stages, with a focus on goals of treatment rather than upon a list of medical procedures to be accepted or rejected (Harle, 2008). One reason the POLST has been embraced by the provider community is because the form provides unambiguous end-of-life treatment instructions in a format that medical personnel can implement automatically. However, the form's moral legitimacy is founded upon the principle of individual autonomy, and this means that facilities must take the time necessary to insure that what is on the form reflects well thought out decisions regarding end-of-life treatment.

4.6 LIMITATIONS

This research surveyed 19 nursing facilities using the POLST in one county in Western Pennsylvania. The results may not generalize to other geographic locations or types of

facilities. Also, the data reported in this study was provided by the respondents based upon their own recall. The data were not validated by direct observation or chart review. The survey did not specifically inquire whether the POLST form was offered to residents receiving short-term rehabilitation services. Respondents may have interpreted the questions differently in light of their own facility practices. Finally, the county's POLST program coordinator says that the POLST form currently in use requires a resident or surrogate signature, and that extensive provider education has occurred since the time of the survey.

4.7 CONCLUSION

This small exploratory study is the first research specifically probing how nursing homes use the POLST form. The research suggests that the POLST might not be implemented in clinical settings in the way intended by the form's designers. Almost all of the surveyed Allegheny County nursing homes reported that they violate one or more procedural safeguards established by the National POLST Paradigm Task Force to prevent misuse. Not all nursing homes say they screen POLST forms for errors or update them regularly. The amount of time facilities report they spend filling out the form for residents without a living will raises questions about whether residents have given sufficient consideration to the end-of-life treatment decisions reflected in the POLST form.

Existing research has shown that the POLST is effective in securing compliance with written end-of-life treatment instructions. As a result, the POLST has the potential to improve the quality of end-of-life care. However, it is crucial that facilities using the form

make continuing efforts relative to quality control and training to insure that the POLST is properly used. Additional research is needed to determine if completed POLST forms accurately reflect the authentic treatment preferences of the individuals using the document.

4.8 TABLES

Table 3 Comparison of surveyed POLST nursing facilities with all nursing facilities in Allegheny County, Pennsylvania
(n=19)

Nursing Facility Characteristic	Surveyed POLST participating facilities	All Allegheny County facilities
Ownership		
For profit	7 (37%)	32 (48%)
Non-profit	8 (42%)	29 (44%)
Governmental	4 (21%)	5 (8%)
Size		
<100 beds	4 (21%)	25 (38%)
100-199 beds	10 (53%)	31 (47%)
200+ beds	5 (26%)	10 (15%)

Table 4 Nursing home compliance with POLST safeguards

n=19

How is the POLST presented to residents?	# facilities	% facilities
Required	11	58%
Recommended	6	32%
Optional	2	11%
Is the POLST offered to all residents in all units?		
Yes	16	84%
No	3	16%
Is a resident or surrogate signature required?		
Yes	9	47%
No	9	47%
Uncertain	1	5%
When is the POLST reviewed or updated?		
Upon a change in medical condition	17	89%
At the resident care conference	13	68%

(Percentages may not add up to 100% due to rounding)

Table 5 Screening for Errors

Type of error review	# of facilities	% of facilities
Facility checks the POLST for errors, like multiple boxes checked in the same section of the form.	15	79%
Facility checks the POLST for a signature by a doctor or other appropriate health professional before it is put into resident's chart	13	68%

Table 6 Time it takes to complete a POLST form

(n=19)

Time with a living will?	# respondents	% respondents
< 10 minutes	10	53%
10-20 minutes	5	26%
20 minutes – 1 hour	3	16%
Many hours	0	0%
Uncertain	1	5%
Time without a living will?		
< 10 minutes	4	21%
10-20 minutes	5	26%
20 minutes – 1 hour	7	37%
Many hours	1	5%
Uncertain	2	11%
One session or multiple?		
One session	14	74%
Multiple sessions	5	26%

**5.0 ARTICLE TWO – DO ALLEGHENY COUNTY NURSING HOMES USING
THE POLST COMPLY WITH THE REQUIREMENTS OF PENNSYLVANIA’S
END-OF-LIFE STATUTE APPLICABLE TO THE FORM?**

5.1 ABSTRACT

The Physician Orders for Life Sustaining Treatment (POLST) is a novel end-of-life advance planning tool that is rapidly gaining acceptance in many states. The POLST form contains medical orders for end-of-life care that are written in advance of a medical crisis. Research has shown the POLST to be effective in translating written end-of-life treatment instructions into action at the bedside. The form is often completed by surrogates of incapacitated individuals, but many state laws governing end-of-life decision making by surrogates do not easily accommodate the POLST. This article looks at whether nursing homes using the POLST in one urban Pennsylvania county comply with that state’s law regarding surrogate authority to make medical decisions regarding life sustaining medical treatments. We found that many did not.

5.2 INTRODUCTION

The Physician Orders for Life-Sustaining Treatment (POLST) is a novel end-of-life advance planning tool that is rapidly gaining acceptance for use in hospitals, hospices, nursing homes, and other settings as a supplement to living wills. “The POLST has taken root in about a quarter of the states and is under development in the majority of the others.” (Sabatino & Karp, 2011, vii). Congress came close to nationalizing use of the POLST during the enactment of health reform.²¹ A growing body of research shows that there is a high degree of compliance with the treatment instructions contained in the POLST by medical personnel (Hickman et al. 2011). The POLST appears effective at translating patient treatment instructions into bedside medical practice at the end of life.

The POLST is a set of medical orders signed by a physician that directs the provision or withholding of specified life-sustaining medical treatments. The form is similar to critical care medical order sets that are routinely completed by doctors in hospitals and nursing homes to specify or limit life-sustaining care for individuals who are near the end of their lives. However, the POLST differs from conventional critical care orders in that it is often signed by a physician before the onset of a medical crisis, and the instructions are based upon treatment preferences of the patient specified in advance. In this way, the POLST is similar to a living will. The POLST contains medical orders relative to resuscitation status, intensity

²¹ The provision regarding the POLST was part of the controversial advance planning section that was stripped out of the health reform bill on final passage. For a summary of the controversy, see O'Reilly, K. ‘End-of-life care provision stirs angst in health reform debate’ *Amednews.com* at:

<http://www.ama-assn.org/amednews/2009/08/24/prsa0824.htm> (last visited December 11, 2012).

of treatment, antibiotic use, and provision of artificial nutrition. The POLST also contains a signature box for the patient or a surrogate (Oregon Health and Science University, 2012)

The National POLST Paradigm Task Force establishes guidelines for use of the POLST form that are published on the POLST.ORG web site. Those guidelines contemplate that family members or other surrogates will provide instructions for completion of the form if the individual lacks decision making capacity. However, there is no specific guideline for surrogate completion since states have varying laws regarding surrogates and end-of-life decision making.

Hickman et al. (2008) surveyed state laws that might impact upon adoption of the POLST throughout the United States. They identified twenty three states that limit the authority of surrogates to decline life-sustaining medical treatments. They concluded that some legal restrictions might make use of the POLST more cumbersome and complex in a particular jurisdiction, but only a few are absolutely incompatible with the program. For Pennsylvania, the only POLST barrier identified as applicable to an institutional setting is a pregnancy limitation.

Pennsylvania is a state with both an active POLST program and a law limiting surrogate authority to decline life-sustaining medical treatments. The state law divides surrogates into two classes – “agents” holding a health care power of attorney and “representatives” who are designated less formally or who exercise authority by virtue of their relationship with their principal as specified in the statute. Agents are formal surrogates and they possess full power to make all decisions for their principal, but unless a written health care power of attorney provides otherwise, their authority to make medical decisions does not arise unless the individual is determined incompetent to make medical decisions by

a doctor.²² Representatives are designated less formally, or by default through a statutorily defined hierarchy of relatives and friends.²³ Representatives have the same authority as agents with one crucial difference. Representatives cannot decline life-sustaining medical treatment unless the individual is determined to be in an end-stage condition or is permanently unconscious.²⁴ State law requires a certification in the medical record by the attending physician that the individual is in an end stage condition or is permanently unconscious before a health care representative can decline life sustaining treatments.²⁵

Pennsylvania has no law specifically addressing the POLST. However, when the state's end-of-life statute was enacted, the health department was directed to study the POLST.²⁶ In 2010, an official Pennsylvania POLST form was adopted by the state department of health.

There is no published research investigating whether medical facilities using the POLST form comply with the requirements of state law regarding surrogate decision making. The complexity of Pennsylvania's end-of-life statute makes it a good site to explore whether facilities using the POLST have successfully managed to use the form while simultaneously complying with state law restrictions on surrogate decision making.

²² 20 Pa.C.S. §5454 (2012).

²³ 20 Pa.C.S. §5461 (2012).

²⁴ 20 Pa.C.S. §5461(e) (2012).

²⁵ 20 Pa.C.S. §5462 (2012).

²⁶ 20 Pa.C.S. §5488 (2012).

5.3 METHODS

Allegheny County, Pennsylvania was selected as the research site. This county is located in western Pennsylvania, and it includes the city of Pittsburgh. Nursing homes using the POLST in the county were identified through a listing obtained from a member of the National POLST Paradigm Task Force located in Pittsburgh. That Task Force member partnered with a major health insurer and the University of Pittsburgh Institute on Aging to promote use of the form in nursing homes, hospitals, hospices, and retirement communities. The POLST program has been in operation in Allegheny County since 2000.

A survey form was developed covering a number of aspects of POLST use in nursing homes, including several questions asking about surrogate completion. The intended respondents for the survey were the individuals responsible for the POLST program at each nursing facility. The survey form asked if there are circumstances when the facility allows surrogates to make treatment selections on the POLST. If the respondent answered this question in the affirmative, the survey went on to inquire whether surrogates are allowed to make decisions even when the resident is able to do so and, if so, it elicited the circumstances when this was permitted. The survey form also inquired if facilities permitted health care agents holding a written power of attorney to limit certain kind of medical care on the POLST and whether they permitted family members or other representatives not holding a power of attorney to do so. Finally, the survey asked if facilities required a written certification of the resident's medical condition before allowing a representative not holding a power of attorney to limit treatment and, if so, what kind of medical determination was required.

A draft of the survey form and instructions was submitted for expert review to three current or past members of the National POLST Paradigm Task Force. Comments from these individuals were incorporated into the survey form. The survey was pre-tested at three Allegheny County nursing homes and revised again in response to issues revealed during the testing phase. The final survey form was submitted to the Institutional Review Board of the University of Pittsburgh and approved.

Twenty-four facilities were identified as using the POLST form for their residents based on a listing supplied by the local member of the National POLST Paradigm Task Force. Introductory letters were sent to all of the identified POLST participating nursing facilities in Allegheny County. These letters were followed up by a telephone call to each facility seeking the names of the individuals responsible for the POLST program at the facility. The identified individuals always included either a social services staff member or the director of nursing. Face to face interviews were successful conducted at 19 of the 24 facilities by the researcher. Table seven shows the characteristics of the surveyed facilities as compared to all Allegheny County nursing facilities.

The interviews were conducted over a four month period beginning in April 2010. Survey respondents were assured confidentiality during the introductory script reading. The survey form did not identify either the facility or the respondent by name. The response rate was 79%. The results of the survey were coded onto an Excel spreadsheet at the close of the field work, and were tabulated by hand.

5.4 RESULTS

Tables eight and nine show how many facilities allow a family member or health care representative (i.e. – a surrogate not holding a power of attorney) to make selections on the POLST to limit life-sustaining treatment, and whether a certification of end-stage condition or permanent unconsciousness is required. All but one facility (95%) allow family members and other representatives to make such selections on the POLST form. Three facilities explicitly require an end-stage medical certification before allowing a representative to make such selections. The overwhelming majority of facilities (78%) do not require any medical certification before allowing a family member or representative to direct limited treatment on a POLST. In one of these facilities the respondent said a medical certification is recommended.

Sixteen (84%) of the nursing facilities allow surrogate completion of the POLST, even if the resident is physically and mentally able to make the decisions. Three of these facilities require that the resident be present or aware of the process. Three facilities reported that they do not allow a surrogate to complete the POLST for a competent resident. Of the sixteen facilities allowing surrogates to make treatment selections on a POLST, 75% will allow the surrogate to provide treatment instructions if the competent resident says he or she wants the surrogate to make the decisions.

5.5 DISCUSSION

The overwhelming majority of surveyed Allegheny County nursing homes allow a family member or other representative not holding a health care power of attorney to provide instructions on a POLST to withhold of life-sustaining medical treatment without a medical certification that the resident is in an end-stage condition or is permanently unconscious. This practice is inconsistent with Pennsylvania law.

Pennsylvania's end-of-life statute has been described by Pennsylvania's Supreme Court as reflecting a "careful legislative effort to balance various rights and interests in the sensitive area of personal medical care provided to one who is not competent to assert his or her own rights."²⁷ The Legislature gave paramount weight to the value of personal autonomy in medical decision making, but only when that autonomy is exercised directly by the individual or by an agent formally appointed under a written health care power of attorney. The Legislature was more restrictive when dealing with the decisions of informal surrogates. Since surrogates incorrectly predict the end-of-life preferences of their principals approximately one-third of the time, it may be reasonable to be more circumspect about decisions to limit life-sustaining treatments that are made by informal surrogates (Shalowitz, Garret-Mayer & Wendler, 2006).

Moreover, in the case of health care representatives, we are dealing with surrogates often designated by default. Where a health care agent has not been appointed, Pennsylvania's law provides for a hierarchy of default representatives with priority given to

²⁷ *In re D.L.H.*, 2 A.3d 505 (Pa. 2010)

the spouse and certain adult children. However, the statute does not take into account the complexities of family relationships and it is possible that the default scheme will result in the appointment of a health representative who is unaware of the resident's treatment preferences. This is yet another reason the Legislature may have limited the authority of health care representatives to withhold or withdraw life-sustaining treatment when an individual is neither end-stage nor permanently unconscious.

The fact that the surveyed facilities do not require the end stage medical certification before allowing health care representatives to direct completion of the POLST should not be interpreted as implying that the form is being used to routinely withhold treatment inappropriately. Given the nature of the nursing home setting, it is possible or even likely that most individuals with POLST forms limiting treatment are in fact in an end-stage condition.

This study also found that three quarters of the facilities allow competent residents to designate surrogates to make decisions for them. This is also potentially inconsistent with Pennsylvania's end-of-life statute. Health care agents do not possess authority until the resident is incompetent, unless there is a specific provision to the contrary in the power of attorney document. Likewise, health care representatives can only make decisions for incompetent residents. However, any facility non-compliance as regards competent residents is easily remedied. Nursing facilities only need to make sure that competent residents ratify decisions made by their surrogates, and this can be evidenced by having them sign the POLST form as recommended by the National POLST Paradigm Task Force.

5.6 LIMITATIONS

This research involved a survey of 19 nursing facilities using the POLST in one county in Western Pennsylvania. The results may not generalize to other geographic locations or types of facilities. Also, the data reported in this study was provided by the respondents based upon their own recall. The data were not validated by direct observation or chart review.

5.7 CONCLUSION

The POLST is a new end-of-life tool that appears to be effective in allowing individuals to control their end-of-life medical care. However, many nursing facilities using the POLST in Allegheny County, Pennsylvania may not be following procedures required by Pennsylvania's end-of-life statute. Nursing facilities need to develop and enforce internal procedures that will allow use of the POLST form consistent with the requirements of state law.

5.8 TABLES

Table 7 Comparison of surveyed POLST nursing facilities with all nursing facilities in Allegheny County, Pennsylvania

Nursing Facility Characteristic	Surveyed POLST participating facilities	All Allegheny County facilities
Ownership		
For profit	7 (37%)	32 (48%)
Non-profit	8 (42%)	29 (44%)
Governmental	4 (21%)	5 (8%)
Size		
<100 beds	4 (21%)	25 (38%)
100-199 beds	10 (53%)	31 (47%)
200+ beds	5 (26%)	10 (15%)

Table 8 Can a health care representative (non-POA) limit treatment on a POLST?

(n=19)

Non-POA surrogate can limit treatment on a POLST form?	# facilities	% facilities
Yes	18	95%
No	1	5%

Table 9 Does the facility require an end-stage medical certification for POLST limiting treatment?

(n=18)

Is an end-stage certification required for a non-POA to limit treatment on the POLST form?	# facilities	% facilities
Yes	4	22%
No	14	78%

6.0 ARTICLE THREE - THE PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST): HOW DO NURSING HOME STAFF IMPLEMENT THE POLST PARADIGM IN ALLEGHENY COUNTY, PENNSYLVANIA?

6.1 ABSTRACT

The Physician Orders for Life-Sustaining Treatment (POLST) is a novel end-of-life advance planning tool that is rapidly gaining acceptance in many states. The POLST form contains medical orders for end-of-life care that are written in advance of a medical crisis. Research has shown the POLST to be effective in translating written end-of-life treatment instructions into action at the bedside and the form is often used in nursing homes.

There is no research reporting how nursing facility staff go about completing the POLST form with residents. This article explores which staff classifications are involved with POLST form completion and how the form is used in the end-of-life planning process. We found that social workers were the facility staff most likely to be working with residents to complete the POLST form. We also found that facility staff often use the document to structure an end-of-life conversation rather than as a device to record decisions previously made.

6.2 INTRODUCTION

The Physician Orders for Life Sustaining Treatment (POLST) is a novel end-of-life advance planning tool that is rapidly gaining acceptance for use in hospitals, hospices, nursing homes, and other clinical settings as a supplement to living wills. More than 20 states have active or developing POLST programs and a growing body of research shows that there is a high degree of compliance with the treatment instructions contained in the POLST by medical personnel (Hickman et al., 2011).

The POLST is a set of medical orders signed by a physician that directs the provision or withholding of specified life-sustaining medical treatments. The form is similar to critical care medical order sets that are routinely completed by doctors in hospitals and nursing homes to specify or limit life-sustaining care for individuals who are near the end of their lives. However, the POLST differs from conventional critical care orders in that it is often signed by a physician before the onset of a medical crisis, and the instructions are based upon treatment preferences of the patient specified in advance. In this way, the POLST is similar to a living will. The POLST contains medical orders relative to resuscitation status, intensity of treatment, antibiotic use, and provision of artificial nutrition. The POLST also contains a signature box for the patient or a surrogate (Oregon Health and Science University, 2012).

One clinical setting in which the POLST is widely used is in nursing homes. The 2004 National Nursing Home Survey found that more than 13% of nursing homes nationwide reported using the POLST (Renick, Foster & Hickman, 2009). This means that more than 2,000 nursing homes were using the POLST at a time when the program was barely out of its infancy. Since that time legislation authorizing the form has been approved

in numerous jurisdictions, including the two largest states of New York and California. The number of nursing homes using the POLST is probably now in the many thousands.

There is no published research reporting on how nursing home facility staff implement the POLST program in their facilities. This paper begins the exploration of that issue.

6.3 METHODS

Allegheny County, Pennsylvania was selected as the research site. This county is located in western Pennsylvania, and it includes the city of Pittsburgh. The POLST program has been in operation in the county since 2000. Nursing homes using the POLST in the county were identified through a listing obtained from a member of the National POLST Paradigm Task Force located in Pittsburgh. That Task Force member partnered with a major health insurer and the University of Pittsburgh Institute on Aging to promote use of the form in nursing homes, hospitals, hospices, and retirement communities.

A survey form was developed covering a number of aspects of POLST use in nursing homes, including several questions asking respondents about how their facility administered the POLST program. The intended respondents for the survey were the individuals responsible for the POLST program at each nursing facility. All respondents indicated that they had personal experience assisting residents and their surrogates with completion of the form.

The survey asked respondents to identify by position those staff members who sometimes help with filling out the POLST form, and also to identify the one staff position most likely to be involved with making the treatment selections on the form. The survey also asked respondents to describe how they used the form in the end-of-life planning process, and how its use had changed end-of-life planning at the facility.

A draft of the survey form and instructions was submitted for expert review to three current or past members of the National POLST Paradigm Task Force. Comments from these individuals were incorporated into the survey form. The survey was pre-tested at three Allegheny County nursing homes and revised again in response to issues revealed during the testing phase. The final survey form was submitted to the Institutional Review Board of the University of Pittsburgh and approved.

Twenty-four facilities were identified as using the POLST form for their residents based on a listing supplied by the local member of the National POLST Paradigm Task Force. Introductory letters were sent to all of the identified POLST participating nursing facilities in Allegheny County. These letters were followed up by a telephone call to each facility seeking the names of the individuals responsible for the POLST program at the facility. The identified individuals always included either a social services staff member or the director of nursing. Face to face interviews were successful conducted at 19 of the 24 facilities by the researcher. Table 10 shows the characteristics of the surveyed facilities as compared to all Allegheny County nursing facilities. Nearly three-quarters of the facilities (74%) had regularly used the POLST form for more than one year.

The interviews were conducted over a four month period beginning in April 2010. Survey respondents were assured confidentiality during the introductory script reading. The

survey form did not identify either the facility or the respondent by name. The response rate was 79%. The results of the survey were coded onto an Excel spreadsheet at the close of the field work, and were tabulated by hand.

6.4 RESULTS

Table 11 shows that a wide variety of nursing facility staff are involved in helping residents or their representatives fill out a POLST form. Doctors, nurses, social workers, nurse practitioners, and admission staff were all often mentioned as sometimes being involved with POLST completion. However, social workers appear to dominate the POLST completion process as being the facility staff classification most likely to be involved with POLST completion (table 12).

Facility respondents were asked to explain how the POLST was used in the end-of-life planning process. They were told that the POLST form can be used to plan for end-of-life care in different ways. They were given the example of first having a discussion of resident values and treatment goals and then using the POLST at the end of these discussions to record the decisions that were made. They were also given the example of using the POLST form at the beginning of the end-of-life conversation to structure the conversation by going through the various treatment options. Respondents were told that there may be other ways of using the POLST form and then asked in an open ended question to explain how their facility typically used the POLST in end-of-life planning.

Table 13 shows that respondents at a majority of facilities (58%) mentioned they use the POLST to structure the end-of-life conversation. Only one respondent said their facility used the POLST at the conclusion of the end-of-life conversation. Respondents at two facilities (11%) said they do not view the form as an end-of-life planning tool. Five of the nursing facility respondents (26%) answered the open ended question in a way that was not susceptible to categorization.

Respondents were asked how they felt the POLST had changed the way their nursing facility approached end-of-life issues with residents. This was also an open ended question with no suggested response. The results are summarized in Table 14. The most common response mentioned that the POLST improved dialog, discussion, or communication. Eight respondents (42%) included a statement to this effect in their response. Five respondents (26%) mentioned that the POLST made staff more comfortable, aware, or confident in dealing with end-of-life issues. Three respondents (16%) said that the POLST protected resident rights or wishes. Two respondents (11%) said the form promoted greater physician awareness or participation in the end-of-life planning process. Six respondents (32%) indicated that the POLST had not changed the way their nursing facility approached end-of-life issues.

6.5 DISCUSSION

Done correctly, advance care planning requires a shared understanding of the goals of care based on where a particular patient is in a disease trajectory (Beach & Morrison, 2002).

Physicians, patients, and family members must all reach a shared understanding of treatment goals. Patients determine the goals of their care, whereas clinicians are the experts in determining which procedures, if any, are likely to achieve those goals (Truog, 2011). Medical orders implementing patient goals should be the final step in the advance planning process.

This survey suggests that completion of the POLST in most surveyed nursing homes is unlikely to be the conclusion of a comprehensive advance planning process with residents. Only one of 19 facilities reported that the POLST was used to record treatment decisions that were made after a discussion of resident values and treatment goals. The majority of the surveyed facilities (58%) used the POLST to structure the end-of-life conversation. However, approaching the patient with a list of life-sustaining measures to accept or reject, before discussing goals of care and prognosis, “puts the cart before the horse” (Messinger-Rapport, B., Baum, E., and Smith M., 2009).

This survey also highlights the important role that supporting staff at nursing homes play in selecting what specific end-of-life medical procedures a resident will receive. In more than half of the nursing facilities, the person most likely to be helping the resident or representative check the boxes designating future use of these interventions is a member of the admissions staff or a social worker. Even though a physician or other person authorized to write medical orders must sign the POLST form, it is legitimate to ask whether individuals who are neither doctors nor nurses have the kind of training and knowledge needed to recommend the use or prohibition of specific medical procedures to individuals and their doctors. “We do not advance people’s autonomy by giving effect to choices that originate in insufficient or mistaken information” (Dresser, 1995).

The facilities that participated in the survey generally reported a positive impact from using the POLST. More than 40% of respondents said that the form promoted more dialogue with residents or family members about end-of-life issues. Other comments included that the form made staff more comfortable, confident, or aware when dealing with end-of-life issues and that the form protected or promoted resident rights. However, six facilities (31%) said that the use of the form did not change the way they approached end-of-life issues with residents.

6.6 LIMITATIONS

This research involved a survey of 19 nursing facilities using the POLST in one county in Western Pennsylvania. The results may not generalize to other geographic locations or types of facilities. Also, the data reported in this study was provided by the respondents based upon their own recall. The data were not validated by direct observation or chart review.

6.7 CONCLUSION

This exploratory survey of 19 nursing homes using the POLST in one urban Pennsylvania county found that many types of facility staff assist residents and their representatives in making end-of-life treatment selection on the POLST form. Social workers were identified as the most likely staff person to help residents and their representatives make treatment selections on the POLST form, but in some facilities a member of the admissions staff, a

doctor, or a nurse provides that assistance. A majority of the nursing homes use the POLST to structure the end-of-life conversation, rather than as a way to record the decisions made during a prior conversation involving patient values and treatment goals. Respondents generally had favorable views of the POLST's impact on the way their nursing home approached end-of-life issues.

6.8 TABLES

Table 10 Comparison of surveyed POLST nursing facilities with all nursing facilities in Allegheny County, Pennsylvania

Nursing Facility Characteristic	Surveyed POLST participating facilities	All Allegheny County facilities
Ownership		
For profit	7 (37%)	32 (48%)
Non-profit	8 (42%)	29 (44%)
Governmental	4 (21%)	5 (8%)
Size		
<100 beds	4 (21%)	25 (38%)
100-199 beds	10 (53%)	31 (47%)
200+ beds	5 (26%)	10 (15%)

Table 11 Which facility staff are sometimes involved with helping residents or their representatives make treatment selections on the POLST form?

(n=19)*

Staff Classification	# facilities	% facilities
Admissions staff	3	16%
Social work staff	18	95%
Nurses	15	79%
Nurse Practitioners or Physician Assistants	13	68%
Physicians	16	84%

* Percentages exceed 100% because multiple selections are permitted

Table 12 Which facility staff person is most-likely to be the one helping a resident or representative make treatment selections on the POLST form ?

(n=18)*

Staff Classification	# facilities	% facilities
Admissions staff	2	11%
Social work	8	44%
Nurses	4	22%
Nurse Practitioner or Physician Assistant	0	0%
Physician	4	22%

* One facility was excluded from the count because the respondent did not identify a single classification as most likely to help with filling out the POLST. That respondent identified both doctors and nurses in response to the question. Percentages do not add up to 100% due to rounding.

Table 13 How is the POLST used in the end-of-life planning process?

(n-19) *

* Percentages do not add to 100% due to rounding

	# facilities	% facilities
At the end of the conversation about end-of-life care to record the decisions made.	1	5%
To structure the conversation about end-of-life care by going through the form	11	58%
Not used as an end-of-life planning tool	2	11%
Other or uncertain	5	26%

Table 14 How has the POLST changed the way your facility approaches end-of-life issues with residents?

(n = 19)*

	# facilities	% facilities
There is more dialogue, discussion or communication about end-of-life issues	8	42%
Staff is more comfortable, confident or aware with respect to end-of-life issues	5	26%
More physician awareness or participation	2	11%
There is more protection of resident rights or wishes	3	16%
Has not changed things.	6	32%

* - Percentages exceed 100% because multiple selections were permitted

7.0 DISCUSSION AND CONCLUSION

7.1 GENERAL DISCUSSION AND RECOMMENDATIONS

This research found that many Allegheny County nursing facilities are not using the POLST in the way intended by the form’s designers, or in a way consistent with Pennsylvania’s end-of-life statute. This section discusses the major findings from the research and makes recommendations

7.1.1 Presentation of the form as required

The National POLST Paradigm Task states on its web site that “the use of a POLST Paradigm form is **always voluntary**” (Oregon Health and Science University, 2012)(emphasis in original). However, a majority of the surveyed nursing homes in Allegheny County (58%) presented the POLST to residents and surrogates as a required form. This practice is not unique to Allegheny County. A 2010 report issued by a California advocacy group also finds that nursing home residents are frequently told that the POLST is mandatory (California Advocates for Nursing Home Reform, 2010). Similarly, Tolle and Tilden (2002) reported a decade ago that “some hospitals now mandate the completion of a POLST form at discharge for patients transferred to long-term care facilities, other

institutional settings, or home hospice.” Sabatino and Karp (2011) also found this to be an issue in nursing homes.

The survey conducted for this dissertation did not ask respondents why their facilities presented the POLST form to residents as required. However, it is easy to understand why nursing homes might want a mandatory POLST process. Physicians are generally not present on a round-the-clock basis in nursing homes, and therefore clinical staff both want and need direction on whether to provide life-sustaining treatment to individual residents who arrest and stop breathing. A properly completed POLST provides such direction and can substitute for a code status form. Moreover, since refusing a POLST form is tantamount to requesting full treatment, why not require the resident to explicitly make that election on the form? It is also probably easier to obtain end-of-life decisions from residents and families when they are told that filling out the POLST form is mandatory. Quality control is also made easier since if a POLST is not in the resident’s medical record then the omission is always an error.

These practical considerations do not justify telling residents that completing the form is required. Completion of the POLST form cannot be mandated consistent with Federal and State law as discussed above. Moreover, the moral justification underlying the POLST is the right to individual autonomy, and a coerced decision cannot be an autonomous one. People have a right to refuse to make a decision on end-of-life treatments until medical circumstances do not permit further indecision. The fact that refusing a POLST may cause a facility to provide full treatment if the resident or a surrogate cannot make a decision in a crisis is a consequence that a resident may choose to accept. Moreover, making the POLST mandatory in nursing homes may lead to other undesirable consequences. Staff helping with

the POLST may find it is necessary to steer indecisive residents to certain choices just to get the form completed and done with. Physicians may believe they are obligated to fill out and sign a POLST unilaterally, since the absence of the form in the patient's chart will be tagged as an error. Critics of the form are already concerned that the POLST creates a situation where "it is more convenient and legal for a physician not to engage the health care proxy/surrogate in a discussion of the patient's wishes and circumstances" (Tully & Honkamen, 2009).

The National POLST Paradigm Task Force correctly prohibits mandatory POLST completion. The surveyed nursing homes that present the form as being required are not using the form in the way intended by its designers.

7.1.2 Offered to all residents.

Most of the surveyed nursing homes (84%) say they offer the POLST to all residents in all units of the facility. Since all of the surveyed facilities have short-stay rehabilitation units, this implies that the POLST is likely being offered to relatively healthy individuals with long life expectancies. While it is quite possible that most forms for short stay residents had full care orders, the POLST is not intended for use by such individuals.

Whether the POLST form should be routinely offered to all long-stay nursing facility residents is a closer question. It can be argued that nearly all long-stay nursing home patients will ultimately die while living at the facility and therefore all such residents should have end-of-life medical orders in place via a POLST. However, some long stay residents have a

life expectancy of many years. It may be premature to offer medical orders regarding life-sustaining treatments to these individuals.

A substantial minority of nursing home residents live in the facilities for a considerable period of time. Kelly et al (2010) looked at the average and median lengths of stay for long stay residents who died while living in a nursing home between 1992 and 2006. They found that while the median length of stay was only five months, the average stay was much longer at 13.7 months. In other words, even though most long stay residents died within a few months after admission, a sizeable percentage of individuals lived much longer and thus skewed the average length of stay upwards. Indeed, the 75th percentile of the length of stay reported by Kelly et al. for long stay patients was 20 months, and a few patients lived in the nursing home for more than five years. The existence of a substantial number of longer-lived nursing home residents was also reported in the 2004 National Nursing Home Survey. That survey found the average length of stay in a facility as of the date of the survey to be 835 days, and the median to be 463 days (Jones, Dwyer, Bercovitz, & Strahan, 2009). However, that study's sampling design tended to overestimate longer stay residents. Similar data exists for nursing home residents with dementia. Mitchell et al. (2009) followed 323 nursing home residents with advance dementia for 18 months and found that the median length of stay was three years. It should also be noted that these residents also had a high six-month rate of mortality (25%), and many underwent burdensome interventions in the last three months of life.

The National POLST Paradigm Task Forces says on its web site that the general screening test for use of the form is to ask "would I be surprised if this person died in the next year" (Oregon Health and Science University, 2012). The Task Force also says that

“unless it is the patient’s preference, use of the POLST Paradigm form to limit treatment is not appropriate for persons with stable medical or functionally disabling problems who have many years of life expectancy” (Oregon Health and Science University, 2012). This implies that the appropriateness of offering a POLST should be evaluated on a case by case basis. However, the National POLST Paradigm Task Force leaves the door open to offering the form universally when it includes the words “unless it is the patient’s preference” before the prohibition on offering the POLST to individuals with many years of life expectancy. How can you determine the patient’s preference for a POLST without first offering one? Similarly, the Task Force allows offering the form to persons with “serious or life-threatening illnesses” in the optional component of the POLST paradigm for mature regional and state programs. A serious illness is not necessarily one that curtails life expectancy so this language would also seem to permit providers to offer the POLST very broadly. A training video posted on the POLST.ORG web site illustrates the Task Force’s straddling of both sides of this issue. Early in the video, a healthy elder is shown taking out skis and the voice-over says that most 65-year olds are too healthy to have a POLST. Later on a speaker says that institutions can have a policy of offering the POLST to everyone (Oregon Health and Science University, 2012).

The possibility that the POLST can be used as an instrument of voluntary euthanasia is a matter of concern to critics of the form. Brugger (2011) complains that the POLST allows some individuals, “especially those with an exaggerated conception of autonomy and a repugnance for some disability or limitation” to engage in self-killing. The Catholic Bishops of Wisconsin similarly state that the POLST oversimplifies end-of-life decision making and poses a “real risk that an indication may be made on it to withhold a treatment

that, in particular circumstances, might be an act of euthanasia” (Wisconsin Catholic Conference, 2012). The “would you be surprised” test and other language discouraging use of the POLST for individuals with many years of life expectancy may be intended to address this concern. However, the Task Force has refused to completely shut the door on the POLST being offered to individuals with many years of life expectancy.

It cannot be said that Allegheny County nursing homes who offer the POLST to all residents of the facility are in violation of the POLST paradigm. However, offering the form to relatively healthy individuals is inappropriate.

7.1.3 Signature requirements

Nearly half (47%) of the surveyed facilities do not require a resident or surrogate signature on a POLST form. This is not a violation of the POLST paradigm because the Task Force only requires a physician signature on the form. Nonetheless, it is good idea to require a resident or surrogate counter-signature. Nursing homes that do not have such a requirement should reconsider the issue.

The National POLST Paradigm Task Force provides the following explanation of its position on whether a resident or surrogate signature should be required:

National POLST Paradigm Task Force *strongly* recommends that all POLST Paradigm Programs require the signature of either the patient or the patient’s legal representative (or witnessed verbal consent as allowed by and in accordance with state law) to make the form valid. The signature of the patient

(or the patient's legal representative if the patient lacks decision-making capacity) provides evidence that patients or their legal representatives agree with the orders on the form. In this respect, the requirement that patients or their legal representatives review and sign the form provides a safeguard for patients that the orders on the form accurately convey their preferences. To increase accountability, it is especially important that programs being established without a governing state statute or regulation develop a process for POLST Paradigm form completion that documents, perhaps through a check box on the form, that review and approval of the form by the patient or the patient's legal agent has occurred.

(Oregon Health and Science University, 2012).

The above passage provides an explanation of why a patient or surrogate signature should be required on the POLST form, but no reason for making such a signature optional. The reason probably relates to the form's status as a binding medical order, since patients and surrogates do not ordinarily countersign medical orders. The POLST is intended for use in various settings including the hospital. In an intensive care unit, for example, getting a patient or surrogate signature on a POLST form while the patient is in the midst of a crisis might be impractical or inappropriate.

Critics have complained that "technically, the [POLST] form makes it more convenient and legal" for a physician not to have end-of-life discussions (Tully & Honkaen, 2009). Brugger, Pavela, Toffler, and Smith (2012) express concern that the failure to obtain signatures may evidence a lack of fully informed consent. So, as with the prior issue of offering the POLST to individuals not near the end of life, the Task Force has adopted a

position that addresses criticism, but does not absolutely close the door on a practice that some fear is being abused.

There seems to be no good reason for not requiring a patient or surrogate signature on a POLST that is obtained in a nursing home. These patients are -- by definition -- not in the midst of a medical crisis, and the purpose of the form is to plan for future contingencies. The setting is more relaxed and the reasons for requiring a signature set forth by the National POLST Paradigm Task Force are persuasive. Most states require a patient's signature on the POLST form to confirm consent (Sabatino & Karp, 2011, p. 11).

Nursing homes that do not currently require a resident or surrogate signature on the POLST form should reconsider their policy.

7.1.4 Updating the POLST

Respondents from nearly 90% of the surveyed Allegheny County nursing homes said the POLST is updated upon a change in resident condition, and nearly 80% said the form is reviewed at the resident's care conference. These results suggest that the nursing homes are making a good effort to insure that the medical orders on the POLST are current. However, all POLST forms should be updated regularly or upon a change in resident condition. The POLST has been described by advocates as reflecting "the patient's *here-and-now* goals for medical decisions that could confront the patient in the immediate future" (Bomba & Sabatino, 2009). Given that a substantial number of patients change their treatment preferences over time, stale forms create the risk of "ordering inappropriate or outdated measures" (Brugger, Pavela, Toffler & Smith, 2012).

The need for a frequent review and updating of the forms is discussed in POLST educational materials. However, there is no formal requirement that approved programs have procedures in place to insure updating of the form upon a change in medical condition or the expiration of a period of time. The National POLST Paradigm Task Force should consider adding such a requirement.

7.1.5 Error checking

Approximately one fifth of the surveyed facilities do not screen POLST forms for errors like multiple boxes checked in the same section. Respondents in nearly one third of the surveyed nursing homes also reported that there is no check for an authorized signature before the POLST form is put into the medical chart. Nursing homes need to take steps to correct these problems.

Errors in a POLST form can cause confusion in a medical crisis and may result in the resident receiving treatment contrary to his or her desires. Missing physician signatures can also cause confusion because the form is not yet a binding medical order, and the nursing staff may be justifiably uncertain as to whether the form can legally be followed. Some facilities had a practice of putting POLST forms into the chart with a flag for a needed a physician signature. However, an unsigned POLST will likely create uncertainty even if it is flagged.

Nursing homes should have quality control measures in place to routinely review POLST forms for errors and unsigned POLST forms should not be put into the medical chart.

7.1.6 End-stage certification

Pennsylvania law restricts the authority of informal surrogates to instruct physicians to withdraw or withholding life-sustaining treatments. Spouses and children lacking a formal health care power of attorney are prohibited from providing instructions which limit treatment of an individual unless there is a prior medical certification by a physician that the individual is in an end-stage medical condition or is permanently unconscious. The research conducted for this dissertation found that nearly 80% of the surveyed Allegheny County nursing homes are not obtaining the necessary medical certification before allowing informal surrogates to make treatment selections on a POLST form.

This problem can be solved changing the POLST form used by Pennsylvania nursing homes to incorporate the needed medical certification. The Pennsylvania Department of Health recently approved a POLST form that contains the following physician certification:

By signing this form, I acknowledge that this request regarding resuscitative measures is consistent with the known desires of, and in the best interest of, the individual who is the subject of the form.

A possible change in that form might add the following bolded language:

By signing this form, I acknowledge that this request regarding resuscitative measures is consistent with the known desires of, and in the best interest of, the individual who is the subject of the form. **If directions to limit treatment were obtained from a health care representative not holding a health care power of attorney, I also certify that the individual is in an end stage medical condition or is permanently unconscious.**

The suggested change in the Pennsylvania POLST form does not address the underlying issue of nursing homes allowing informal surrogates to provide treatment instructions that the law does not allow. However, it does signal to physicians that they must examine the

severity of the resident's medical condition before signing a POLST. Presumably physicians will question the authority of a surrogate to direct limited treatment when the resident is not in an end-stage condition nor permanently unconscious. That is what the law intends.

7.1.7 Embedding in a comprehensive EOL planning process

Some nursing home residents arrive at the facility having already completed a living will and completing a POLST for these individuals is a matter of verifying the continuing validity of the instructions and converting them into a binding medical order via the POLST form. More than half of the respondents said that it typically took less than ten minutes to complete a POLST for such individuals, and this result is not unexpected.

However many nursing home residents arrive at the facility without having gone through the process of completing an instruction directive. Nearly half of the survey respondents said it typically takes less than 20 minutes to complete a POLST for such individuals. Is meaningful advance care planning being conducted with the POLST in such a short period of time? We just don't know.

7.2 PUBLIC HEALTH SIGNIFICANCE

The Centers for Disease Control identifies end-of-life planning as an emerging public health priority (CDC, 2012). End-of-life care has many of the characteristics of a public health issue including universality, association with a substantial burden of suffering, and a

significant societal financial impact (Rao, Anderson & Smith, 2002). The POLST was created to improve end-of-life care and make it more consistent with the desires of individuals. This research has public health significance because it contributes to the literature relating to the POLST and its use in end-of-life planning.

7.3 CONCLUSION

7.3.1 How should the POLST be used in end-of-life planning

In preceding sections, I expressed my concerns about how the POLST is used in end-of-life planning, and questioned whether existing research adequately supports such use. In addition, the research reported in this dissertation highlights the need for ongoing evaluations of POLST programs to insure they are operated in compliance with standards established by the National POLST Paradigm Task Force. In this section, I discuss the role the POLST should play in end-of-life planning in nursing homes.

The POLST has a place in end-of-life planning for nursing home residents because research shows that doctors will follow its instructions and some people want a document like the POLST. However, the form's role should be much more restricted than that currently urged by the National POLST Paradigm Task Force and POLST advocates. The form's main drawback is that may be "*too effective, too easy to act on quickly...*" (President's Council on Bioethics, 2005, p. 76). The POLST suffers from many of the same limitations that make living wills problematic. Accordingly, its use should generally be

limited to persons “whose medical situation is plain, whose crisis is imminent, whose preferences are specific strong and delineable, and who have special reasons to prescribe their care.” (Fagerlin and Scheider, 2004). The only exception to this criterion might be individuals who feel so strongly about not having a particular medical procedure that they want a POLST form even though they are fully aware of its risks. In the time line of advance care planning, the POLST should come into play in the later stages of illness (Sabatino & Karp, 2011, p. 4).

People whose end-of-life path is less clear should be encouraged to complete a proxy directive, along with a statement of end-of-life treatment preferences to guide the designated surrogate. Such a form maximizes the possibility that end-of-life treatment preferences will be honored, while protecting the individual from having treatment inappropriately withdrawn in unanticipated circumstances. An example of such a form is the combined Health Care Power of Attorney and Living Will jointly approved by the Allegheny County Medical Society and Allegheny County Bar Association.²⁸ When the individual’s end-of-life trajectory becomes clearer, and a POLST form becomes appropriate, the surrogate will then have the information needed to complete one if the individual cannot communicate.

“The key underlying premise behind the validity and efficacy of POLST is meaningful discussion between patients (or surrogates) and clinicians, resulting in informed decisions notated on the POLST form” and therefore the form “is not a standalone intervention. It has to be understood as an integral part of the spectrum of good chronic and palliative care management” (Sabatino & Karp, 2011, p. 21). Accordingly, nursing home

²⁸ That form is available at: <http://www.acms.org/lw/index.html>

staff involved with helping residents and surrogates complete the form need to be taught how to conduct an advance planning conversation, not just a “POLST conversation.” The problem with focusing training just on the POLST conversation is that it may encourage a checklist approach to filling out the form. Messenger-Rapport, Baum, and Smith (2009) say that “approaching the patient with a list of life-sustaining measures to accept or reject, before discussing goals of care and prognosis, puts the cart before the horse.” Checklists can lead to “illogical combinations of interventions that lack any medical rationale” and create only the illusion of patient autonomy (Trough, 2001). Brugger, Pavela, Toffler, and Smith (2012) claim that POLST orders “exacerbate already existing problems with living wills by utilizing the simplistic check-box format.” This criticism has some merit.

Good advance care planning should use an approach that emphasizes communication rather than form completion. “This approach shifts the emphasis from the completion of legal forms to an ongoing process of *advance care planning*. Advance care planning involves an iterative process of communication over time among the individual, the health care provider, the proxy, and others who may participate in the health care decision-making process to discern the individual’s priorities, values, and goals of care” (Sabatino & Karp, 2011, p. 2). A patient or surrogate should first decide upon the treatment goals with the doctor, and only then determine what specific treatments are appropriate to meet those goals (Lynn & Goldstein, 2003). The POLST rests on the premise that “patients or their surrogates understand their current medical circumstances and options and that the orders agreed to on POLST accurately reflect their goals of care” (Sabatino & Karp, 2011, p. 22). However, the process of making sure this occurs is not simple. Rather it “is a complex multifaceted intervention, requiring a high level of skill in educating patients and their surrogates,

counseling them on their options, and working through the POLST form in an understandable way, both initially and whenever the orders require review” (22).

Finally, when it is time to have a conversation about filling out the POLST, that conversation should include a discussion of differing plausible scenarios requiring the various treatments listed on the form rather than just one scenario. The doctor signing a POLST for a resident should be sure that the resident’s treatment preferences do not change depending upon the scenario that is presented. Asking an individual whether he or she wants to accept or reject interventions such as tube feeding or mechanical ventilation is not meaningful when presented only in a way that prompts a negative response. If a nursing home resident’s selections of treatments depend upon the facts, then a POLST is not probably appropriate for that resident.

An example of a POLST training video that illustrates this problem is provided by the University of California Health System Center for Healthy Aging (U.C. Davis, 2012). The video entitled “Having the POLST Conversation” shows a physician having an office conversation with an elderly patient. The doctor asks the patient to pretend she has a stroke that results in her inability to eat or communicate. The doctor adds color to the scenario by saying that food placed into the patient’s mouth causes choking or gagging or may just sit there and dribble out. He says that a neurologist feels the condition is permanent, but a feeding tube can be put in to extend life. Not surprisingly, the patient rejects the feeding tube and the doctor checks the POLST form accordingly. However, the patient is never asked about short term use of a feeding tube, even though the POLST form contains an option for a defined period of use.

The POLST is a useful addition to the variety of end-of-life planning tools that currently exist, but it is not a panacea. POLST advocates are over-marketing the form and promoting its use in situations where it is not appropriate. A somewhat disturbing example of over-marketing is found in New Jersey's recently enacted POLST legislation. That state's law says a POLST "is recommended for use by patients who have a life expectancy of less than **five years**...."²⁹ Why would we possibly have a public policy of encouraging individuals with five years of life ahead of them to authorize currently effective medical orders regarding resuscitation, tube feeding, and mechanical ventilation? It makes no sense.

7.3.2 Going forward with the POLST research

Many important questions about the POLST form remain unanswered. In this dissertation I identified six distinct hypotheses that should be proven before the POLST can be accepted as an improvement over existing ways of communicating end-of-life treatment preferences to medical providers. I demonstrated that only one of the six POLST hypotheses that I identified – that the POLST causes doctors and nurses to follow written patient instructions expressed on the form -- has substantial empirical support. However, three of the six POLST hypotheses I identified stand out from the others as being more urgently in need of research because relate to the form's potential to do harm by causing death under circumstances not intended by the individual. These should be research priorities.

First, we need to know that the POLST does not harm patients by causing the withholding of treatment that is desired and should be provided. Three studies have looked

²⁹ N.J. Stat. § 26:2H-131 (2012)

at that issue in various settings, but given the stakes – life and death – we need more research to be reassured that the form is not causing harm.

We also need to know that the POLST is being implemented in medical institutions in the way intended by its designers. The research I conducted shows that there are significant problems of implementation of the POLST paradigm in one county’s nursing homes, even though the program in that county was established under the guidance of a member of the National POLST Paradigm Task Force. If similar problems exist in other settings and locations, it is a cause for significant concern. Of course there should be an ongoing program of evaluation for every POLST program, but program evaluations are not typically published. It is important to have solid base of published research on this issue too.

Finally, we need research validating that the POLST is capturing the authentic treatment preferences of individuals. This is perhaps the most important issue of all. If it turns out that many people change their mind when different plausible end-of-life scenarios are presented, or if many individuals say that what is on the POLST form is not what they really want in terms of end-of-life care, then what is written on the form is not a meaningful exercise of medical decision making. “The validity of POLST depends on the voluntary informed consent of patients or their surrogates” (Sabatino & Karp, 2011, p. 11). If the POLST does not accurately reflect what individuals really want, the moral justification for using the form collapses.

There is a rush by policymakers and institutional decision makers to embrace the POLST as an improvement in advance care planning. In the opinion of this writer, that action is premature.

APPENDIX A—OREGON POLST FORM – JUNE 2007 VERSION

HIPIAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, **then** contact physician, NP, or PA. 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

A	CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse <u>and</u> is not breathing . <input type="checkbox"/> Attempt Resuscitation/CPR <input type="checkbox"/> Do Not Attempt Resuscitation/DNR (<u>A</u> llow <u>N</u> atural <u>D</u> eath) When not in cardiopulmonary arrest, follow orders in B, C and D.
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B	MEDICAL INTERVENTIONS: Person has pulse <u>and/or</u> is breathing . <input type="checkbox"/> 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. <i>Do not transfer to hospital for life-sustaining treatment. Transfer if comfort needs cannot be met in current location.</i> <input type="checkbox"/> 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. <i>Transfer to hospital if indicated. Avoid intensive care.</i> <input type="checkbox"/> Full Treatment Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. <i>Transfer to hospital if indicated. Includes intensive care.</i> Additional Orders: _____
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C	ANTIBIOTICS <input type="checkbox"/> No antibiotics. Use other measures to relieve symptoms. <input type="checkbox"/> Determine use or limitation of antibiotics when infection occurs. <input type="checkbox"/> Use antibiotics if life can be prolonged. Additional Orders: _____
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D	ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food by mouth if feasible. <input type="checkbox"/> No artificial nutrition by tube. <input type="checkbox"/> Defined trial period of artificial nutrition by tube. <input type="checkbox"/> Long-term artificial nutrition by tube. Additional Orders: _____
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REASON FOR ORDERS AND SIGNATURES	
E Discussed with: <input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Health Care Representative <input type="checkbox"/> Court-Appointed Guardian <input type="checkbox"/> Other: _____	My signature below indicates these orders are consistent with the person's preferences, if known. See medical record for further documentation.
Print Physician/NP/PA Name and Phone Number ()	Office Use Only
Physician/NP /PA Signature (mandatory) Date	

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
PA's Supervising Physician	Phone Number		

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/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 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. POLST is housed at Oregon Health & Science University's Center for Ethics in Health Care. Others seeking permission to use the copyrighted form may contact the Center for Ethics in Health Care. Research on the POLST program is available online at <www.polst.org> or by contacting the Task Force at <polst@ohsu.edu>.

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

APPENDIX B – POLST Paradigm Program Requirements (4/26/21012)

Program Requirements

The National Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Task Force (NPPTF) has developed this description of the four levels of a POLST Paradigm Program to further clarify requirements for a state or regional POLST Paradigm Program. The NPPTF believes this clarification is necessary because of the variation in proposals for programs and forms that the NPPTF has been receiving. The goal of this description is to make explicit the standards that are presently being met by endorsed POLST Paradigm programs. This description will continue to be refined based on input from all involved in the process of establishing or strengthening POLST Paradigm programs. The NPPTF strongly encourages POLST Paradigm Programs to develop on a statewide basis. It recognizes that barriers to statewide implementation may exist within individual states and will accept the application of a regional program within a state or within bordering states until the barriers to statewide implementation can be surmounted.

National POLST Paradigm Program Requirements

To be endorsed by the National POLST Paradigm Task Force, a POLST Paradigm program must meet specific requirements. The National POLST Paradigm Task Force has established these requirements based on research evidence with regard to use of the POLST Paradigm form and the experience of Task Force members in POLST Paradigm Program development.

Level 1: Developing POLST Paradigm Program Program Requirements for Developing Programs

1. Has a local or statewide coalition with defined membership, recognized leader(s) and is meeting on a regular basis.
2. Has or is developing a standardized form as described in Level 2.
3. Has reviewed existing state laws and regulations. Use of a POLST paradigm form is compatible with them or the coalition is working with the relevant regulatory bodies in the process of seeking changes in state law or regulation.
4. Has considered any local conflicts between current advance directive and surrogate decision maker statutes and POLST.
5. Has or is developing a plan to make the POLST Paradigm form portable across settings.
6. Has involved EMS, emergency departments, health care facilities and other stakeholders who will be using the form in patient care.
7. Has considered ways of establishing POLST Paradigm as a recognized standard of care and, if necessary, considered need for provider immunity for honoring a form.
8. Has reviewed the AARP Public Policy Institute report "Improving Advanced Illness Care: The Evolution of State POLST Programs."

Form Requirements for Developing Programs

1. Has reviewed and considered the Level 2 form requirements below as they develop their state form.

Level 2: Endorsed POLST Paradigm Program Program Requirements for Endorsed POLST Paradigm Programs*:

1. Has an effective statewide or regional coalition(s). If there are two or more regional coalitions within a state, they are working on a coordinated strategy towards statewide implementation.
2. Is identifying and building a research and quality assurance component.
3. Has identified champions who are active in the program implementation and education.
4. The POLST Paradigm Program is the preferred practice for the process of advance care planning and implementation across health care settings (e.g., emergency medical services, long-term care, hospital, and hospice) for persons with advanced illness and /or frailty whose clinicians would not be surprised if they died within the next year. The form is a set of current (in some states they may be accepted as standing) medical orders. The completion of a POLST Paradigm form should be based on the patient's goals for care to ensure that the patient receives the treatment he or she desires.
5. There is ongoing training of health care professionals across the continuum of care about the goals of the program, the creation and use of the form, and how to conduct a POLST conversation.
6. Mechanisms are in place to help assure that the orders are based on patient preferences. As allowed by statute and regulations, the National POLST Paradigm Task Force **strongly** recommends that all POLST Paradigm Programs require the signature of either the patient or the patient's legal representative (or witnessed verbal consent as allowed by and in accordance with state law) to make the form valid. The signature of the patient (or the patient's legal representative if the patient lacks decision-making capacity) provides evidence that patients or their legal representatives agree with the orders on the form. In this respect, the requirement that patients or their legal representatives review and sign the form provides a safeguard for patients that the orders on the form accurately convey their preferences. To increase

- accountability, it is especially important that programs being established without a governing state statute or regulation develop a process for POLST Paradigm form completion that documents, perhaps through a check box on the form, that review and approval of the form by the patient or the patient's legal agent has occurred.
7. Completion of the form and the decisions recorded on it should be voluntary and based on shared medical decision making.
 8. There is a plan for ongoing evaluation of the program and its implementation. It is key for each program to be able to receive feedback with regard to how it is functioning.
 9. There is an entity within the region or state that is willing to accept ownership for the program (e.g., hospital association, state dept of health, hospice and palliative care association, university-affiliated ethics center, etc) and has the resources to implement it.
 10. The program shows evidence of attention to the core elements of sustainability of state POLST Paradigm Programs.

Form Requirements for Endorsed Programs

1. The treatment being considered requires a medical order that needs signature by a health care professional.
2. The medical order is based on the patient's goals of care and a person's preferences for treatment (e.g. as expressed in an oral statement or written advance directive). The treatment is a "comfort measure"; or The order is an instruction regarding hospital transfer; or The medical order is a life-sustaining treatment that is being considered for use in a person with advanced progressive illness and/or frailty and has these characteristics: is frequently needed by health care professionals (e.g. EMS protocol, emergency department and ICU care, long term care or hospice); and/or is urgently needed by health care professionals (e.g. EMS protocol, emergency department and ICU care; long-term care or hospice); and/or requires an informed consent process that is complex (e.g. tube feeding treatment); and/or is not effectively specified as "Additional orders"
3. Within the written medical order sections, which are preferably all on the front of the form, there is an explicit statement that comfort measures are always provided and the patient may require transfer to another setting of care (e.g. "Transfer if comfort needs cannot be met in current location". In other words, the medical order sections of the form include language that affirms patients' rights to be transferred to receive comfort care and are free of language that might restrict or negate patients' access to comfort care. For example, forms shall not state in the comfort measures, "Do not transfer the patient" or "Avoid calling 911." The medical order set should also state that food and fluids are always to be administered by mouth if medically feasible (e.g. offer food by mouth if feasible).
4. In addition to orders with regard to CPR, the POLST Paradigm form must indicate the level of medical intervention for the patient (exact wording for each level may vary from state to state) comfort measures; limited additional interventions; or full interventions. The level of intervention shall contain a description of the services to be provided and the site in which they will be provided. For example, a comfort measures order may indicate that the patient is not to be transferred unless comfort needs cannot be met in the person's current setting. Treatments such as intubation and mechanical ventilation are to be included in the full interventions section. Patients who are already receiving long-term mechanical ventilation may indicate treatment limitations in the "Other Orders" space in the level of medical intervention section.
5. The form requires a valid clinician (Physician, Nurse Practitioner or Physician Assistant depending upon state laws and regulations about signers) signature and a date of signature. The medical orders shall be signed and dated and timed to clearly show the most current orders.
6. The form provides explicit direction about resuscitation (CPR) instructions or patient preferences if the patient is pulseless **and** apneic.
7. The form also includes directions about other types of intervention that the patient may or may not want. For example, decisions about transport, ICU care, artificial nutrition, etc. Space is provided for additional orders.
8. The form is uniquely identifiable and standardized within a state/region.
9. The form indicates with whom the orders were discussed or who provided informed consent.
10. The form indicates on the front page the name of the state or region.
11. The form may indicate that the program is an endorsed POLST Paradigm program.
12. Language in the forms should start with positive language. For example, the comfort measures description might read "Treat with dignity and respect. Keep clean, warm, and dry. Use medication by any route..." In the comfort measures section, the forms should avoid wording that starts with negative language and suggests that care and comfort of the patient are not paramount, "Do not intubate or transport..."
13. The NPPTF recommends that all medical orders be placed on the front page of the form.

Optional Elements for Endorsed Programs

The following issues may be handled by programs in different ways depending on state law and local preferences.

- Ideally, a legal surrogate should be able to make decisions about treatment choices and complete a POLST Paradigm form for a patient without decision-making capacity, but states have varying laws regarding surrogates and decision-making.
- Some states may recognize the form as the only out-of-hospital DNR form; in others there may be other means of DNR ID as well. Use of the form is always voluntary.
- The NPPTF recommends that states accept forms completed in other states (reciprocity).
- The National POLST Paradigm Task Force **strongly recommends** that all original, paper POLST Paradigm forms have a bright, easily seen uniform color but recognizes that FAXED, copies or electronic representations of the POLST Paradigm form on white paper are valid.

* **Note: Endorsed programs have a representative on the NPPTF Board.**

Level 3: Mature Endorsed Regional POLST Paradigm Program Program Requirements for Mature Regional Programs

1. The POLST Paradigm Program is the standard preferred practice for the process of advance care planning for persons of any age with advanced illness and/or frailty whose clinicians would not be surprised if they died in the next year and for older patients with strong, specific informed preferences with regard to treatment across health care settings (e.g., emergency medical services, long-term care, hospital, and hospice). The POLST Paradigm form is the standard of documentation for the POLST Paradigm Program.
2. The Program is established regionally and there is widespread POLST accessibility, use, and portability. The Program is able to provide the following evidence:
 - more than 50% of hospitals, nursing homes, and hospices use the program.
 - more than 75 percent of Emergency Medical Services (EMS) agencies have protocols that recognize and honor the POLST Paradigm form where there is regional implementation of the POLST Paradigm Program.
 - the program offers an education program with materials updated as needed and ongoing trainings, and health professional training includes the quality of the conversation.
 - there is an ongoing evaluation of the Program, and the program has developed quality measures and is measuring performance with both research and QA/QI components
3. Consideration has been given to methods to assure timely access to the form in a crisis such as a registry or centralized database system.
4. Reciprocity with out-of-state forms has been addressed.
5. Consideration of integration of the form into electronic health systems is being addressed.
6. Cross-cultural resources have been developed as appropriate, feasible and needed.
7. The Program is financially sustainable.

Optional Elements for Mature Regional Programs

1. Physicians and potentially nurse practitioners and physician assistants who work in practice settings such as hospitals, nursing homes, private offices, group practices or patient homes offer the POLST form to patients with serious or life-threatening illnesses.

Level 4 Mature Endorsed Statewide POLST Paradigm Program Program Requirements for Mature Statewide Programs

1. The POLST Paradigm Program is the standard preferred practice for the process of advance care planning for persons of any age with advanced illness and/or frailty whose clinicians would not be surprised if they died in the next year and for older patients with strong, specific informed preferences with regard to treatment across health care settings (e.g., emergency medical services, long-term care, hospital, and hospice) statewide. The POLST Paradigm form is the standard of documentation for the POLST Paradigm Program statewide.
2. The Program is established statewide and there is widespread POLST accessibility, use, and portability. The Program is able to provide the following evidence:
 - more than 50% of hospitals, nursing homes, and hospices use the program in all regions of the state
 - more than 75 percent of Emergency Medical Services (EMS) agencies have protocols that recognize and honor the POLST Paradigm form where there is statewide implementation of the POLST Paradigm Program in all regions of the state.
 - the program offers an educational program with materials updated as needed and ongoing trainings, and health professional training includes the quality of the conversation.
 - there is an ongoing evaluation of the program, and the program has developed quality measures and is measuring performance with both research and QA/QI components.
3. Consideration has been given to methods to assure timely access to the form in a crisis such as a registry or centralized database system.

4. Reciprocity with out-of-state forms has been addressed.
5. Consideration of integration of the form into electronic health systems is being addressed.
6. Cross-cultural resources have been developed as appropriate, feasible and needed.
7. The program is financially sustainable.

Optional Elements for Mature State Programs

1. State coalition leaders are encouraged to be available to mentor developing states.
2. Physicians and potentially nurse practitioners and physician assistants who work in practice settings such as hospitals, nursing homes, private offices, group practices or patient homes offer the POLST form to patients with serious or life-threatening illnesses.

Effective Date:

These requirements were adopted by the National POLST Paradigm Task Force on April 26, 2012 and continue to be revised based on requests of developing programs to provide greater direction and clarity with regard to requirements for an endorsed POLST Paradigm program. States previously endorsed are encouraged to work with their coalitions to meet the current endorsement requirements. Prior endorsements may be revoked if that state cannot show that it continues to meet at least Level 2 criteria.

APPENDIX C- COMMENTS BY RESPONDENTS ON OPEN-ENDED QUESTIONS

Question 14. For each unit of the facility, what are the criteria for offering a POLST form to a resident?

Three respondents answered this question. The question was skipped for the others based on prior answers. Check boxes were provided for frequently mentioned responses. Life limiting or terminal illness was mentioned twice. Would not be surprised if the resident was dead within one year was mentioned twice. Advanced frailty was mentioned twice. Other comments recorded appear below. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- Clinically compromised. They come with a living will. Not offered for short term rehabilitation residents if not clinically compromised.
- Cancer, multiple sclerosis, critically ill.
- Hospice. Looking for a living will. Patient specific, not unit specific. This is mostly short term rehabilitation and Alzheimer's unit.

Question 19. Which classifications of employees receive training on the POLST?

There were 19 responses to this question. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- In-service on policy with social workers and nurses but policy is different from actual implementation. Policy tells you who is responsible but not how to deal with what is on the form.
- Nobody trained.
- Social workers, nurse practitioners, and nursing staff.
- Social workers received training at (location redacted). Admissions coordinator received training at external source. No in-house.
- Nurses, social workers, activities, dieticians, everyone on the interdisciplinary team got thorough training. Other staff have overview via in-service.
- RNs, LPNs, social workers, and unit secretaries have training. Training available to all staff.
- Just social workers
- Everybody receives training on the POLST. Dining services, maintenance, everybody.
- Nursing, social workers, all doctors, medical records and admissions.
- Every employee gets trained.
- Social workers, nurses, and doctors.
- No training since policy came out. At some point, everyone in the facility is trained.
- Just social workers
- Social workers, nursing, and doctors.
- Admissions, social workers, and maybe RNs.
- No ongoing training. Handed down by word of mouth.
- Nursing, social services staff.
- Nursing and initially social workers too.
- Social services director. Unsure about nurses.

Question 20. Please describe the training that staff involved with completing the form for residents receive on filling out the form?

There were 17 responses to this question. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- In-service on policy for nurses and social workers.
- Social workers sat down with manual and had group training session. Nurse practitioners – social workers trained NPs. Nurses- social workers trained nurses. Chain has committee on this area.
- Admissions coordinator had external training at local hospital. Social work coordinator had training at the facilities.
- Interdisciplinary team had more than one hour training on policy and procedures so everyone understood their part. Others covered in in-service.
- Review of policy, DVD, and Q&A based on training.
- In-service.
- In-service on POLST for everyone.
- In-service.
- In-service as part of pre-work training.
- In-service when started using and one follow-up. Unsure if included in new employee training.
- In service when policy came out. Local POLST Task Force member did presentation.
- In-service from local POLST task force member.
- Someone came out 1 ½ years ago from local insurer. Brought up at in-service and doctor's meeting.
- Admissions – somebody came in and reviewed form. Social workers had training with ethics committee.
- Reviewed POLST policies. Someone from local hospital trained social work director. Social services director trained facility staff.
- Local insurer came out.
- In-service form local POLST task force member.

Question 27. Please describe the procedure the facility uses to make sure that POLST forms are regularly updated?

There were 15 responses to this question. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- As part of care conference. On return from hospital.
- Generally completed in first 48-hours. Social work contact within that time. Also reviewed at care conference within one week of admission. Every month social work department reviews POLST. Chart audit makes sure boxes completed and doctor's signature on it.
- If change in clinical status that may not be consistent with POLST.
- Care conference. If patient or family requests. Doctor points it out. Change in medical condition.
- We have audit every year. Presented to attending physician.
- If resident's condition changes only.
- Once a year, mail out to family.
- On admission from hospital and at quarterly care conference.
- Social worker does quarterly reviews. On admission and change in condition.
- At social worker assessment. Care conference meeting. Quarterly and annually. On return from hospital.
- If there is a change, they are updated.
- Any significant change in condition following a hospital stay.
- When patient comes back from hospital, social worker makes sure POLST is there. Don't know if doctor does it if change in condition. If social worker told drastic change, social worker will change POLST.
- When families or relatives attend care conferences, they are reviewed.
- Quarterly and care conference, return from hospital

Question 33. Under what circumstances does the facility allow a person designated by the resident to make treatment selections on the POLST, when the resident is physically and mentally able to make the decisions?

There were 17 responses to this question. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- When a resident indicates someone else should do it.
- Example, at care conference resident says, let my daughter do it. Person must be POA unless family member sitting there at the time.
- If resident is present with designee. If POA but resident is present.
- Patient directs other to sign form. Resident requests “talk to my daughter.”
- Patient gave permission to have someone else complete the form.
- At a family conference where resident is present.
- If resident requests that another person do it.
- If patient asks someone else then discussion and team meeting. Rare. At family meeting with present present.
- If resident says daughter makes decisions for me.
- Physician will often speak to family even if resident is capable.
- Whenever patient says so on a piece of paper.
- Resident says, “Let my daughter take care of it.”
- If they have POA to somebody. If person without POA, if they are designating that person to make decisions.
- If they tell us they want somebody else to do it.
- In conjunction with resident so resident is aware of decision.
- Resident and family member together make decision or POA.
- If resident requests that.

Question 38. What kind of medical determination does the facility require before a family member without a power of attorney can make selections on a POLST form to limit treatment?

There were 5 responses to this question. The question was skipped for the other respondents based upon prior answers. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- We work with psychiatry to determine inability to make decisions. Do require end-stage.
- Psychiatrist or doctor documents competency level.
- Why a resident cannot make own decision. No end stage certification.
- Statement of end-stage.
- End stage, terminal diagnosis, and patient is unable to make those decisions.

Question 46 When you explain Part A of the form to me, what will you tell me about cardiopulmonary resuscitation to help me decide whether to accept or limit the treatment for my mother?

There were 18 respondents who answered this question. Check boxes were provided for frequently mentioned responses. A low survival rate for CPR was mentioned 8 times. The risk of rib fracture was mentioned 16 times. The possibility of intubation was mentioned 14 times. Shocking of the heart was mentioned five times.

Other responses recorded by the interviewer appear below. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- CPR is only started under certain circumstances. Physically hard on a person. I would want to know what expectations you have if CPR is administered.
- I let the charge nurse explain. Nurse explains low survival.
- If we initiate CPR, staff will begin chest compressions.
- If I walk into your mother's room, she has stopped, what do you want me to do? Describe CPR – on the floor, chest compressions. Once we start we can't stop. You are going to have to be the one to say stop.
- If demented, talk about specifics what would happen. How we would use defibrillation. What happens in the room. If not demented, talk about what they know about CPR. Easier discussion.
- We have to call 911. Paramedics administer treatments. Transportation to hospital.
- Nursing starting compressions. Call 911.
- If patient found not breathing and without pulse would they want staff to attempt CRP. Explained, if they ask, what it is.
- Nurse will do mouth to mouth till 911 gets here if elected. Crash cart. Do everything possible to keep patient alive.
- Everything would be done if CPR selected. If no CPR, letting nature take its course. Take into account patient's condition, diagnosis, and prognosis. Outcome is not always real good.
- Explain is doctor's orders for treatment based on current condition. Code status is only thing that needs to be filled out. Doctor explains details.
- Explain what CPR is.
- Call ambulance, transfer to hospital.
- We need to know if something happens to mom, should we start resuscitation. Explain what CPR is. Call 911, patient will go to hospital. Discussion of quality of life after resuscitation.
- CPR not created for older persons with multiple disorders. Created for people who are younger who had an accident. Talk about complications.

- If staff found patient unresponsive, would you want CPR?
- Effort will be continued, 911 called, patient will be hospitalized. Once we start CPR, it is out of our hands.
- We do everything to sustain life.

Question 47. When you explain Part B of the form to me, what you will tell me about the medical interventions to help me decide whether my mother will receive comfort measures only, limited additional interventions, or full treatment?

There were 18 respondents who answered this question. Check boxes were provided for frequently mentioned responses. For comfort care, 15 respondents mentioned that there will be no pain or suffering and 10 respondents mentioned that the resident may be transferred to the hospital for comfort. On limited interventions, 7 respondents mentioned that there will be no invasive testing and 11 respondents mentioned there will be no intubation. For full treatment, 14 respondents mentioned that intubation will be used if needed and 13 mentioned that mechanical ventilation will be used if needed.

Other responses recorded by the interviewer appear below. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- Full – all out everything done, sent to the hospital and ICU. Limited – transferring to hospital but ICU not encouraged. Use IV fluids. No advanced airway. Chances of survival limited. Comfort – use medications, oxygen. Also told about hospice. Very limited active treatment.
- Family always asks about hospital. Facility always contacts family regardless of what is on the form for hospitalization.
- Full treatment – self explanatory, invasive testing, everything done.
- Everybody gets comfort measures only. If no CPR, then limited is middle of the road. No mechanical ventilation. No heroic measures. Transfer to hospital but no ICU. Full is everything to save mom.
- Limited – read off the form. Comfort care – talk about hospice care. Talk about measures to keep them comfortable. Doctor comes along to meeting.
- If you don't elect CPR here, we can still do some interventions in the hospital. DNR and full treatment conflict. Comfort measures will be done here. DNR and limited or comfort do not conflict.
- Look at quality of life today. Comfort measures are for hospice and end-stage. Limited – routine medical treatment. Patient avoids ventilation. Full treatment – everything possible including ventilation, intubation.
- Read the form explanations. Emphasize transfer to hospital provision. Answer questions about intubation and procedure if asked.
- Basically read off form.
- Comfort measures – still use oxygen and suction, no CPR or intubation. No transfer for diagnosis or testing. Limited – some IV fluids and cardiac monitoring. No intubation/ventilation. Transfer if needed for stabilization but no ICU. Full – everything possible – CPR, intubation, all kinds of tests.

- Make sure selections make sense. No full treatment and DNR. Review what is written on the form.
- Full treatment and no CPR don't go together. Comfort measures – no extra measures but keep her comfortable and help her pass. Limited intervention – antibiotics and IV will be given if needed. Can be changed at any time.
- Need to determine goals for treatment. Some types of care not provided by the nursing facility.
- Do you want us to send her to the hospital or just keep her comfortable? If we send her to the hospital, do you want her to be on a breathing machine or have any other heroic measures?
- Ask them if they want parent sent to hospital if unable to take care of pain. If they prefer no transfer, talk about comfort. If they prefer hospital, talk about additional levels.
- Tube feeds – would you want IV fluids?
- Not many people who are comfort measures and not hospice. Talk about all scenarios.
- Comfort care – we're not going to treat them. Full treatment – do everything possible.

Question 48. When you explain Part C of the form to me, what will you tell me about antibiotics to help me decide whether to accept or limit that treatment for my mother?

There were 18 respondents who answered this question. There were no check boxes for frequent answers. Responses recorded by the interviewer appear below. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- Expand on what's on the form. We can use antibiotics to extend life. A lot is related to previous choices. If questions, can talk to a nurse or doctor.
- Always we can do IV fluid antibiotics and make person comfortable.
- Discuss UTI. Want to be comfortable. Most people say determine use when infection occurs.
- Do you have any objection to receiving antibiotics if necessary? Do you want us to ask you first? Do you have a religious preference?
- Give example of UTI. Nobody really asks questions.
- Most people pick determine when infection occurs. Few people check no antibiotics. Antibiotics can be a comfort measure.
- Pretty self explanatory. Usually choose determine as needed.
- Read form to patient or family. Self explanatory. Expand on second – determine when need occurs.
- People rarely put no antibiotics. Seldom have to explain.
- No antibiotics – don't treat infection. Determine use – may be determined if needed to treat for comfort, e.g. UTI. Long term – want to be sure to make person survive longer.
- Most people determine use when infection occurs.
- Something we can go step by step, situation by situation.
- Basically what is on form. Unless comfort care, not relevant at this point.
- I don't need to elaborate on that. If something happens do you want it or not. Discussion of quality of life if clinically appropriate.
- Ask if want antibiotics to prolong life. Antibiotics can be used as comfort measure. Guide to determine use or use antibiotics generally. Not very pressuring.
- Usually make point of saying not make loved one better. Steer towards determine as need arises.
- Most families want to use antibiotics. Nobody has ever declined them. People want to look at it when need arises. Case by case situation.
- Either you don't want except to relieve pain. How far do you want us to go?

49. When you explain Part D of the form to me, what will you tell me about artificially administered nutrition to help me decide whether to accept or limit that treatment for my mother?

There were 18 respondents who answered this question. Check boxes were provided for frequently mentioned responses. Twelve respondents mentioned that food by mouth will always be given. Seven respondents mentioned that when people stop eating, it often means they are dying.

Other responses recorded by the interviewer appear below. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- Can choose not to do tube feeding. No pain involved. Can try tube feeding for a while and then stop. Probably distinguish between food and water. Have to respect if patient doesn't want it. Discuss how long patient can live without food or water. Booklet- Hard Choices for Loving People.
- Trying to stop the natural process of death may be harmful. Not eating is not painful.
- Do you want a tube down your throat? Describe procedure. Not starving, normal body function to shut down.
- Use a stroke scenario that does not affect the mind but can't eat, do you want a feeding tube? Tell them it can be removed after trial. Don't distinguish between food and water.
- Don't fill out "D" unless there is an issue or living will is clear. No distinction between food and water.
- When you are unable to eat, artificial nutrition is necessary. Artificial nutrition cannot be provided for a long time with an IV. Most people not on tube feeding choose no tube – this is an observation not told to patients. If they are on tube, check #2 or #3.
- Always a delicate subject. Explain trial period, what that means, rehab may be able to get back to eating.
- Talk about feeding tubes. Asked to define trial period often. Most patients don't want it at all.
- We stress patient wishes if incapacitated. What is purpose of tube feeding?
- First choice – no feeding by tube. Second, there has been a condition, not clear if part of dying process, perhaps patient will revive and have better quality of life. Long term – continue if prolonging life.
- Do you have strong wishes about tube feeding? Don't have to fill out boxes if not sure. Encourage doctor discussion.
- Pull in dietician or nurse if questions. People always ask questions. We talk about the dying process.
- Comfort means not doing this. This is talking about long term feeding tube not short term.

- If something happens and doctors want a tube, would you want that? If unsure, did patient ever talk about that? There are several choices including middle ground.
- First, ask about patient preferences. It depends upon where the person is at. If end stage, then talk about pros and cons of artificial nutrition and guilt feelings associated with rejection. If not yet end-stage, emphasize more the trial period. Tubes can always be removed if not helpful. Talk about natural shut down process and lots of reasons to stop eating.
- If unable to eat, do you want a surgical procedure for tube feeding? May prolong life. Not a comfort measure.
- Living will often says no feeding tube.
- Either you don't want it at all, we can do it for a trial period, or we can do it forever. You can always change your mind.

50. There are many ways of doing end of life planning with a nursing home resident. The POLST form can be used to plan for end of life care in different ways. For example, you can first have a discussion of resident values and treatment goals and then introduce the POLST at the end of these discussions to record the decisions that were made. Another way of using the form is to introduce the POLST form at the beginning of the end of life conversation, and then use the form to structure the conversation by going through the various treatment options. There may be other ways of using the form too. Can you describe how your facility typically uses the POLST in end of life planning?

There were 19 respondents who answered this question. There were no check boxes for frequent answers. Responses recorded by the interviewer appear below. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- Varies by unit. Six units, own nursing supervisors. All dynamics are different
- At care conferences, if it hasn't been filled out we use it to structure EOL conversation. Usually people know what they want.
- Use at end of conversation depending upon conversation. Code status discussed earlier in different format.
- Use form to structure conversation.
- On admission, used with resident or within 48-hours. Go through POLST. Use POLST to structure conversation.
- Not used as EOL planning tool. We want guidance for here and now issue. It helps resident and family think about EOL if they haven't.
- Immediately upon admission. POLST used as a device to structure conversation.
- Use form to structure conversation.
- For new admissions, as a tool to structure conversation because it's a requirement on admission. On reassessments at end of conversation about current orders and how things stand.
- Initial conversation between doctor and patient. Up to each doctor to decide how to present the form.
- Typically introduced on admission to resident or family by social worker. Introduced before care planning. Gaining a bigger role in care planning. Seeing more doctors participate.
- POLST is done at time of admission. 70% come here for rehabilitation and have a POLST. Not looked at as an end of life tool. Sense in selecting DNR age is a factor in rehabilitation. Our DNR rate is not 90%. 70% in a generic unit – facility as a whole. Rehabilitation or long term, if elderly then same DNR rate.

- Depends on the situation on how we present it. Typical person, we ask if you know your end of life wishes. We have a form that can help. If they don't know what they can do we show them the form. If they have an advance directive/living will they don't need a POLST but we will offer it.
- Start with form to structure conversation.
- POLST is used to guide conversation.
- Normally done at admission. Done with doctor at hospital if they go to hospital or if change in condition. May role is when somebody is hospice appropriate. Guide conversation. Helpful for patient to be looking at end. Allows to start a conversation about EOL regardless of condition.
- Initial assessment with each patient as to need. Family member approaches us as to need. POLST used to structure conversation.
- Use POLST when admitted. Look at if full code or not. Use it most to ensure that code status is documented. Structure conversation.
- Depends on who is doing it. Nurses go through options, nitty gritty of form. Social worker sits down and elicits values first.

51. Tell me how you think the POLST has changed the way your facility approaches end of life issues with residents

There were 19 respondents who answered this question. There were no check boxes for frequent answers. Responses recorded by the interviewer appear below. The interviewer recorded only the gist of what was said, and this was read back to the respondent for confirmation.

- Encourages more dialog because we do it on everybody. More discussion and awareness by staff. May have increased comfort level with staff. Insures EOL issues are discussed with residents. Make doctors more aware.
- Don't know
- It hasn't. Always had EOL conversation prior to using form.
- More discussion with residents and family. Prior to POLST, would just ask DNR or not until something came up.
- Not sure it has helped. Not sure it has changed much.
- We have more confidence in decision the family makes. If there is a change in condition, first question staff asks is what does the POLST say? Staff has more confidence in decisions. Change in condition triggers reviewing POLST.
- Does very well. Improves communication. Better than a living will. Big impact on nursing communication. Nurses know what to do.
- Fits in well with hospice services. Consistent with work we do and how we do it with view of aging process without being intrusive. We can be respectful of wishes. Not changed things a whole lot but it fits in well.
- More discussion of EOL issues. More options. More structure. Follows patient through process. More people now have EOL instructions. Staff has more guidance in planning.
- Resident rights issue. Don't know how it was done in the past.
- Greater doctor participation in care process
- POLST is another mechanism for protecting peoples' wishes. Helpful to codify current wishes.
- Not at all.
- I don't know that it has right now. We've always had CPR statement in the chart. If POLST is done correctly, it will expand on that. If doctors do it correctly, it will be an improvement. Helpful for doctors to initiate a conversation. Can't leave UPMC facilities without a POLST.
- Prompted people to talk about EOL issues. Opened door to hospice and comfort care.
- Makes EOL an ongoing conversation. Don't know if it has really changed the conversation that much.
- Not changed a whole lot. We don't use it as much as we should.

- Gives facility a chance to have people think about EOL before the need arises.
- It takes indecision out of medical staff's mind. Don't always have to err on the side of life. Good tool. Gives chance for family to think about future.

APPENDIX D – FREQUENCY COUNT OF MULTIPLE CHOICE RESPONSES

1. This question asked for documents and was not tabulated.

2. Is the facility part of a chain? A chain is defined as having two or more homes under single ownership or operation.

Yes	17
No	2
Uncertain	0

3. Which of these categories best describes the ownership of the facility?

For profit	7
Private Non-profit	8
Government owned	4
Department of Veteran Affairs	0
Uncertain	0

4. Is the facility religiously affiliated?

Yes	14
No	5
Uncertain	0

5. How many beds does the facility have?

3-49	0
50-99	4
100-199	10
200+	5
Uncertain	0

6. Are you knowledgeable about the policies and procedures that apply to use of the POLST form in your facility?

Yes	19
No	0

7. I would like you to estimate how long the facility has been regularly using the POLST form for its residents? Which of the following choices most accurately describes how long the facility has been regularly using the POLST?

Less than six months	2
Six month to one year	3
More than one year	14
Uncertain	0

8. Does your facility have any written policies or procedures relative to the POLST?

Yes	16
No	3
Uncertain	0

9. Different versions of the POLST form exist. May I see the form that is used in your facility so I can record which version you are using?

Oregon form	19
Non-Oregon form	0

10. Does the facility have any residents requiring the following types of care?

Alzheimer's and related dementias	19
AIDS/HIV	3
Behavior Unit (non-Alzheimer's)	3
Disease Specific (e.g. Dialysis, Brain injury)	13
Children with disabilities	0
Hospice	19
Short term rehabilitation	19
Respite Care	15
Ventilator/Pulmonary	1
Other	6

11. Does the facility offer the POLST to **all** residents in **all** units of the nursing facility? In other words, is it offered to everybody in the facility?

Yes	16
No	3
Uncertain	0

12. We would like to know about the criteria your facility uses for selecting patients to be offered the POLST. Does your facility have written criteria for selecting residents to be offered the POLST?

Yes	1
No	3
Uncertain	0
Skipped question	15

13. In which units is the POLST form used?

This question was skipped for 16 respondents based on prior answers. Of the three who answered, one respondent said all units used the form. The other two respondents answered outside of the multiple choice format. One respondent said the POLST was offered to critically ill residents regardless of unit. One respondent said the POLST was offered on a case by case basis, but usually not for short term rehabilitation residents.

15. Does your facility have nurse practitioners practicing in your facility?

Yes	17
No	2
Uncertain	0

16. Does your facility have physician assistants practicing in your facility?

Yes	5
No	13
Uncertain	1

17. We would like to know which members of the facility staff are involved in helping residents or their representatives make the selections on the POLST form. Please indicate if any of the following staff are **sometimes** involved helping residents or their representative make selections on the POLST form?

	Yes	No	Uncertain
Admission staff	3	16	0
Social work staff	18	1	0
Nurses	15	4	0
Nurse Practitioners	11	8	0
Physician Assistants	2	14	3
Doctors	16	3	0

18. Of the types of facility staff people who you indicated are involved in helping patients or their representatives make the selections on the POLST form, which facility staff person is **most likely** to be the one helping a resident or their representative make selections on the POLST form?

Member of the admission staff	2
A social worker	8
A nurse	4
A nurse practitioner	0
A doctor	4
More than one usually involved	1
Other	0

21. Which of the following types of non-physician health care professionals practicing in your facility can sign box E of the POLST form in your facility?

Nurse Practitioner	10
Physician Assistant	1
Neither. Only a physician can sign	9
Other:	0

22. We would like you to characterize how the facility presents the POLST form to the resident. You could characterize the way the facility presents the POLST form to residents as being required, recommended, optional, or you could use another description? How would you describe it?

Required	11
Recommended	6
Optional with resident	2
Other	0
Uncertain	0

23. We would like you to estimate the completion rate among all residents offered the form in the facility. Would you estimate that completion rate to be:

Less than 50%	3
50% to 80%	2
More than 80%	7
Other	7
Uncertain	0

24. Does the facility regularly screen POLST forms for errors, like multiple boxes checked in the same section?

Yes	15
No	4
Uncertain	0

25. Is the POLST form typically reviewed as part of the resident's comprehensive care planning conference?

Yes	13
No	4
Uncertain	2

26. Does the facility make sure POLST forms are updated on a regular basis?

Yes	13
No	4
Other	0
Uncertain	2

28. Does the facility make sure that the POLST form is updated whenever there is a significant change in the resident's medical condition?

Yes	17
No	0
Uncertain	2

29. Does the facility regularly screen POLST forms to make sure they are signed by the appropriate health professional in box E before they are put into the chart?

Yes	13
No	6
Other	0
Uncertain	0

30. Does the facility require that the resident or a representative sign the back of the form?

Yes	9
No	6
Other	3
Uncertain	1

The three “other” responses were recommended or encouraged. These were classified as “no” in table 4.

31. Now I want to talk about the situation where someone other than a resident makes the treatment selections for the POLST. Are there circumstances when the facility allows an individual other than the resident to make the treatment selections for the POLST?

Yes	19
No	0
Uncertain	0

32. Sometimes a resident is mentally capable of making treatment decisions, but prefers that somebody else make them. Does the facility allow a person designated by the resident to make treatment decisions on the POLST, when the resident is physically and mentally **able** to make the decisions?

Yes	16
No	3
Uncertain	0

34. In the next few questions, I am going to refer to a health care power of attorney. A health care power of attorney is a written legal document signed and dated by the resident and witnessed by two individuals that authorizes one or more designated individuals to make health care decisions for the resident. Do you understand what I am referring to when I use the term health care power of attorney?

Yes	19
No	0
Uncertain	0

35. If a resident cannot speak for himself or herself, and a family member or other representative has a health care power of attorney, does the facility allow the representative to make selections on the POLST to limit certain kinds of medical care?

Yes	19
No	0
Uncertain	0

36. If a resident cannot speak for himself or herself, and a family member or other representative does not have a health care power of attorney, does the facility allow the representative to make selections on the POLST that limit certain kinds of medical care?

Yes	18
No	1
Uncertain	0

37. In these same circumstances – resident cannot speak for himself and family member without a written health care power of attorney -- does the facility require a certification of the patient’s medical condition by the resident’s doctor before the family member or other representative can make selections to limit treatment on the POLST form?

Yes	4
No	13
Uncertain	0
Other	1

(The “other” response indicated an end stage certification was recommended. This was classified as “no” in table 9)

39. Do you personally assist residents and their representatives with making selections on the POLST form?

Yes	19
No	0

40. In your experience, is the POLST typically completed in one session or multiple sessions?

One session	14
Multiple sessions	5
Uncertain	0

41. When a resident is personally involved with completing the POLST form with facility staff, are family members typically present to help the resident?

Yes	5
No	6
Other	2
Uncertain	6

42. I am now going to ask you a few questions about residents who do or do not have a living will. You probably know what a living will is, but I am going to define it just to be sure we are both referring to the same thing. When I use the term living will in this survey, I am referring to a legal document that provides instructions on specific medical treatments the resident wants or does not want. Living wills are sometimes also called instruction directives. Do you know what a living will is?

Yes	19
No	0

43. Which of the following choices most accurately describes how much total time it typically takes to fill out a POLST form for a resident who has already completed a living will?

Less than 10 minutes	10
10 – 20 minutes	5
20 minutes to one hour	3
Many hours	0
Uncertain	1

44. Now for a resident who does **not** have a living will, which of the following choices most accurately describes how much total time it typically takes to fill out a POLST form for the resident.

Less than 10 minutes	4
10 – 20 minutes	5
20 minutes to one hour	7
Many hours	1
Uncertain	2

45. Do you feel you have sufficient training to explain to residents and family members the medical terms on the POLST including intubation, advanced airway interventions, mechanical ventilation, and cardioversion?

Yes	17
No	2
Uncertain	0

APPENDIX E – SURVEY INSTRUMENT

POLST FACILITY QUESTIONNAIRE

Survey Number: _____ Interviewer: Manne
Interviewee Role _____ Degree (i.e. MSW, MD) _____
Tenure with Facility _____ Date of Interview: _____

Instructions for the Interviewer

Instructions relating to individual questions are printed within the question in italics and should not be read to the respondent. Do not read the section headings to the respondent. Additional comments by the respondent clarifying answers to questions should be inserted in the blank space next to the answers.

Read the introductory script now.

Introductory Script

Thank you for agreeing to participate in this survey of how the POLST form is used in Allegheny County nursing facilities. The POLST is a new end of life advance planning device that is rapidly gaining acceptance throughout the United States. The POLST is intended to enable residents to control the provision of life-sustaining medical treatment when they become unable to make decisions.

This survey is being conducted as part of my doctoral dissertation research project at the University of Pittsburgh. This research is intended to fill gaps in the published literature regarding the POLST. I will survey as many facilities in Allegheny County that use the POLST as possible. Once the surveys are completed, I will write a dissertation paper that will be published on the Internet and possibly published in a scientific journal.

This face to face survey should take around 20 minutes to complete. I will ask you questions and record your answers. I will write down your title and professional degree, but I am not recording your name or the name of your facility on the survey instrument. In that way, your survey responses will be kept confidential. Participation in this survey is voluntary. There are no foreseeable risks to you or the facility, nor any direct benefit. Participants will not be compensated. Participation in the survey is completely voluntary. My name is Jason Manne and my telephone number is 412 951-5718.

If you don't understand any question, or think the question is ambiguous, you should ask me for clarification. If I have given you multiple choice answers, and if you don't think any of the choices fit the question, feel free to provide a different answer and I will write it down. Additionally, if you want to elaborate on any answer, you should feel free to do so. I will add what you say to your answer.

1. Before we begin the formal interview, I asked you to bring some documents with you to the interview when we scheduled this meeting. These documents were a copy of the POLST form used in your facility and any facility policies, procedures, training materials for employees, or educational materials for residents. May I have whatever you brought with you for me now?

- a. Yes
- b. No

Interviewer should check off the types of materials that were provided and retain with the survey form.

POLST form

Facility policies

Training materials

Educational materials for residents

Other

Facility Background Information

2. Is the facility part of a chain? A **chain** is defined as having two or more homes under a single ownership or operation.
 - a. Yes
 - b. No
 - c. Uncertain

3. Which of these categories best describes the ownership of the facility?
 - a. For profit
 - b. Private Non-profit
 - c. Government owned
 - d. Department of Veterans Affairs
 - e. Uncertain

4. Is the facility religiously affiliated?
 - a. Yes (*prompt for denomination*) _____
 - b. No
 - c. Uncertain

5. How many beds does the facility have?
 - a. 3 – 49
 - b. 50 – 99
 - c. 100 – 199
 - d. 200+
 - e. Uncertain

POLST Background Questions

6. Are you knowledgeable about the policies and procedures that apply to use of the POLST form in your facility?
- Yes
 - No. (*If “no” end survey and find another respondent*)
7. I would like you to estimate how long the facility has been regularly using the POLST form for its residents? Which of the following choices most accurately describes how long the facility has been regularly using the POLST? (*Read choices (a) – (c). If respondent is uncertain then circle (d).*)
- Less than six months.
 - Six month to one year
 - More than one year
 - Uncertain
8. (*If facility’s POLST policies were provided in document review, skip to next question*)
- Does your facility have any written policies or procedures relative to the POLST?
- Yes (*ask for copies and retain with survey*)
 - No
 - Uncertain
9. *If POLST form was provided in document review, skip to next question*
- Different versions of the POLST form exist. May I see the form that is used in your facility so I can record which version you are using?

Record:

- Oregon form
- Non-Oregon form

Criteria for Using the POLST

10. Does the facility have any residents requiring the following types of care?
(Read list below and circle all that apply, fill in other for ones not listed)
- a. Alzheimer's and related dementias.
 - b. AIDS/HIV
 - c. Behavior Unit (non-Alzheimer's)
 - d. Disease Specific (e.g. Dialysis, Brain injury)
 - e. Children with disabilities
 - f. Hospice
 - g. Short term rehabilitation
 - h. Respite Care
 - i. Ventilator/Pulmonary
 - j. Other _____

11. Does the facility offer the POLST to **all** residents in **all** units of the nursing facility? In other words, is it offered to everybody in the facility?

- a. Yes (*Skip to 15*)
- b. No
- c. Uncertain

12. We would like to know about the criteria your facility uses for selecting patients to be offered the POLST. Does your facility have written criteria for selecting residents to be offered the POLST?

- a. Yes (*Ask the respondent if the criteria are in the documents that were provided in the document review and if they are not, then ask if they can be obtained and provided*).
- b. No
- c. Uncertain

13. In which units is the POLST form used?

a. All units

b. Specific ones (*record list of units*): _____

c. Uncertain (*Skip to 15*)

14. For **each unit** of the facility, what are the criteria for offering a POLST form to a resident? (*Use additional pages if more than 3 units*)

Unit _____ (*Indicate "all" if the respondent says the criteria is the same for all units*)

This is an open-ended question with probable responses based on the POLST paradigm. Circle all that are mentioned and add any additional criteria provided by the respondent. Prompt "anything else" as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the "Confirmed by Read Back" blank.

a. *Life-limiting or terminal illness.*

b. *Not be surprised if dead within one year.*

c. *Advanced frailty.*

d. *Other* _____

CONFIRMED BY READ BACK: _____

Unit _____

This is an open-ended question with probable responses based on the POLST paradigm. Circle all that are mentioned and add any additional criteria provided by the respondent. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank.

- a. *Life-limiting or terminal illness.*
 - b. *Not be surprised if dead within one year.*
 - c. *Advanced frailty.*
 - d. *Other* _____
- _____
- _____

CONFIRMED BY READ BACK: _____

Unit _____
:

This is an open-ended question with probable responses based on the POLST paradigm. Circle all that are mentioned and add any additional criteria provided by the respondent. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” box.

- a. *Life-limiting or terminal illness.*
 - b. *Not be surprised if dead within one year.*
 - c. *Advanced frailty.*
 - d. *Other* _____
- _____
- _____

CONFIRMED BY READ BACK: _____

Completing the POLST Form - General

15. Does your facility have nurse practitioners practicing in your facility?

- a. Yes
- b. No
- c. Uncertain

16. Does your facility have physician assistants practicing in your facility?

- a. Yes
- b. No
- c. Uncertain

17. We would like to know which members of the facility staff are involved in helping residents or their representatives make the selections on the POLST form. Please indicate if any of the following staff are **sometimes** involved helping residents or their representative make selections on the POLST form?

Read the list below and record response:

a. Admission staff	YES	NO	UNCERTAIN
b. Social work staff	YES	NO	UNCERTAIN
c. Nurses	YES	NO	UNCERTAIN
d. Nurse Practitioners	YES	NO	UNCERTAIN
e. Physician Assistants	YES	NO	UNCERTAIN
f. Doctors	YES	NO	UNCERTAIN

Prompt for any others and record response:

18. Of the types of facility staff people who you indicated are involved in helping patients or their representatives make the selections on the POLST form, which facility staff person is **most likely** to be the one helping a resident or their representative make selections on the POLST form?

Circle the category that is mentioned or if not listed, record in "other"

- a. Member of the admission staff
- b. A social worker
- c. A nurse
- d. A nurse Practitioner
- e. A doctor
- f. More than one usually involved
- g. Other: _____

19. Which classifications of employees receive training on the POLST?

This is an open-ended question, record response and read back. Prompt "anything else" as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the "Confirmed by Read Back" blank.

CONFIRMED BY READ BACK: _____

20. Please describe the training that staff involved with completing the POLST form for residents receive on filling out the form?

This is an open-ended question, record response and read back. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank.

CONFIRMED BY READ BACK: _____

21. Which of the following types of non-physician health care professionals practicing in your facility can sign box E of the POLST form in your facility?

Show the Oregon POLST form to the respondent and point out box E. If someone other than a NP or PA is mentioned, record under “other”.

- a. Nurse Practitioner
- b. Physician Assistant
- c. Neither. Only a physician can sign
- d. Other: _____

22. We would like you to characterize how the facility presents the POLST form to the resident. You could characterize the way the facility presents the POLST form to residents as being required, recommended, optional, or you could use another description? How would you describe it?

Circle response below. If the respondent mentions something other than the three choices provided in the question, indicate what the respondent said under "other". If respondent is uncertain, circle (e)

- a. Required
- b. Recommended
- c. Optional with resident
- d. Other: _____
- e. Uncertain

23. We would like you to estimate the completion rate among all residents offered the form in the facility. Would you estimate that completion rate to be:

Read choices (a) through (c) below and circle the response. If respondent provides an answer other than (a) –(c), circle (d) and fill in the response. If the respondent is uncertain, circle (e).

- a. Less than 50%
- b. 50% to 80%
- c. More than 80%
- d. Other: _____
- e. Uncertain

24. Does the facility regularly screen POLST forms for errors, like multiple boxes checked in the same section?

- a. Yes
- b. No.
- c. Uncertain

25. Is the POLST form typically reviewed as part of the resident's comprehensive care planning conference?

- a. Yes
- b. No.
- c. Uncertain

26. Does the facility make sure POLST forms are updated on a regular basis?

- a. Yes
- b. No (*skip to 28*)
- c. Other: _____
- d. Uncertain

27. Please describe the procedure the facility uses to make sure that POLST forms are regularly updated.

This is an open-ended question, record response and read back. Prompt "anything else" as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the "Confirmed by Read Back" blank.

CONFIRMED BY READ BACK: _____

28. Does the facility make sure that the POLST form is updated whenever there is a significant change in the resident's medical condition?

- a. Yes
- b. No
- c. Uncertain

29. Does the facility regularly screen POLST forms to make sure they are signed by the appropriate health professional in box E before they are put into the chart?

Show the Oregon POLST form to the respondent and point out box E. Circle the response if yes or no. If the respondent's response is equivocal, for example by saying that the forms are supposed to be signed but nobody checks, record the response in (c). If respondent is uncertain, circle (d).

- a. Yes
- b. No.
- c. Other: _____
- d. Uncertain

30. Does the facility require that the resident or a representative sign the back of the form?

Show the back of Oregon POLST form to the respondent and point out where there is a place for the resident or surrogate signature. Circle the response if yes or no. If the respondent's response is equivocal then record the response in (c). If respondent is uncertain, circle (d).

- a. Yes
- b. No
- c. Other _____
- d. Uncertain

Questions about Who Makes Selections on the POLST

31. Now I want to talk about the situation where someone other than a resident makes the treatment selections for the POLST. Are there circumstances when the facility allows an individual other than the resident to make the treatment selections for the POLST?

- a. Yes
- b. No (*Skip to 39*)
- c. Uncertain

32. Sometimes a resident is mentally capable of making treatment decisions, but prefers that somebody else make them. Does the facility allow a person designated by the resident to make treatment decisions on the POLST, when the resident is physically and mentally **able** to make the decisions?

- a. Yes
- b. No (*Skip to 34*)
- c. Uncertain (*Skip to 34*)

33. Under what circumstances does the facility allow a person designated by the resident to make treatment selections on the POLST, when the resident is physically and mentally **able** to make the decisions?

This is an open-ended question, record response and read back. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank.

CONFIRMED BY READ BACK: _____

34. In the next few questions, I am going to refer to a health care power of attorney. A health care power of attorney is a written legal document signed and dated by the resident and witnessed by two individuals that authorizes one or more designated individuals to make health care decisions for the resident. Do you understand what I am referring to when I use the term health care power of attorney?

- a. Yes
- b. No (*skip to 39*)
- c. Uncertain (*skip to 39*)

35. If a resident cannot speak for himself or herself, and a family member or other representative has a health care power of attorney, does the facility allow the representative to make selections on the POLST to limit certain kinds of medical care?

- a. Yes
- b. No
- c. Uncertain

36. If a resident cannot speak for himself or herself, and a family member or other representative does not have a health care power of attorney, does the facility allow the representative to make selections on the POLST that limit certain kinds of medical care?

- a. Yes
- b. No (*Skip to 39*)
- c. Uncertain

37. In these same circumstances – resident cannot speak for himself and family member without a written health care power of attorney -- does the facility require a certification

of the patient's medical condition by the resident's doctor before the family member or other representative can make selections to limit treatment on the POLST form?

- a. Yes
- b. No
- c. Uncertain.
- d. Other: _____

38. (Skip if answer to preceding question was "no" or "uncertain") What kind of medical determination does the facility require before a family member without a power of attorney can make selections on a POLST form to limit treatment?

This is an open-ended question, record response and read back. Prompt "anything else" as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the "Confirmed by Read Back" blank. Probable answers are listed below and check the blank next to the answer if mentioned.

- ___ *incompetent*
- ___ *end stage*
- ___ *permanently unconscious*

CONFIRMED BY READ BACK: _____

Completing the POLST Form – Personal Experience

39. Do you personally assist residents and their representatives with making selections on the POLST form?

- a. Yes
- b. No (*Skip to 50 if answer is no*)

40. In your experience, is the POLST typically completed in one session or multiple sessions? (*If respondent is uncertain, circle (c)*)

- a. One session
- b. Multiple sessions
- c. Uncertain

41. When a resident is personally involved with completing the POLST form with facility staff, are family members typically present to help the resident?

- a. Yes
- b. No.
- c. Other _____
- d. Uncertain

42. I am now going to ask you a few questions about residents who do or do not have a living will. You probably know what a living will is, but I am going to define it just to be sure we are both referring to the same thing. When I use the term living will in this survey, I am referring to a legal document that provides instructions on specific medical treatments the resident wants or does not want. Living wills are sometimes also called instruction directives. Do you know what a living will is?

- a. Yes
- b. No (*Skip to 45*)

43. Which of the following choices most accurately describes how much total time it typically takes to fill out a POLST form for a resident who has already completed a living will? (*Read choices (a) – (d) and circle the response. Circle (e) if respondent is uncertain*).

- a. Less than 10 minutes
- b. 10 – 20 minutes
- c. 20 minutes to one hour
- d. Many hours
- e. Uncertain

44. Now for a resident who does **not** have a living will, which of the following choices most accurately describes how much total time it typically takes to fill out a POLST form for the resident. (*Read choices (a) – (d) and circle the response. Circle (e) if respondent is uncertain*).

- a. Less than 10 minutes
- b. 10 – 20 minutes
- c. 20 minutes to one hour
- d. Many hours
- e. Uncertain

45. Do you feel you have sufficient training to explain to residents and family members the medical terms on the POLST including intubation, advanced airway interventions, mechanical ventilation, and cardioversion?

- a. Yes
- b. No
- c. Uncertain

Explanation of POLST Form - Open-ended Questions

Now I am going to take you through the POLST form and ask you what information you provide to residents and their representatives when you help them fill it out. In answering this question, I want you to pretend that I am the son of an 85 year old resident who has suffered a stroke and is unable to communicate. I have her health care power of attorney and I am going to make the selections on the POLST form for my mother. As you talk, I am going to summarize what you are saying, and then when you have finished your answer, I am going to read you back what I wrote down to see if I have correctly.

46. When you explain Part A of the form to me, what will you tell me about cardiopulmonary resuscitation to help me decide whether to accept or limit that treatment for my mother?

This is an open-ended question. Listen to the respondent and write down the main points of the response. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank. Some common responses are listed below and the blank next to each should be checked if mentioned.

Interviewer: Check if any following are mentioned:

____ *Low survival rate*

____ *Risk of rib fracture*

____ *Possibility of intubation afterwards*

____ *Shocking of heart*

CONFIRMED BY READ BACK? _____

47. When you explain Part B of the form to me, what will you tell me about the medical interventions to help me decide whether my mother will receive comfort measures only, limited additional interventions, or full treatment?

This is an open-ended question. Listen to the respondent and write down the main points of the response. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank. Some common responses are listed below and the blank next to each should be checked if mentioned.

Interviewer: Check if any following are mentioned:

Comfort care:

___ *There will be no pain or suffering*

___ *May be transferred to hospital for comfort*

Limited treatment:

___ *No invasive testing*

___ *No intubation*

Full treatment:

___ *Intubation used if needed.*

___ *Mechanical ventilator used if needed*

CONFIRMED BY READ BACK? _____

48. When you explain Part C of the form to me, what will you tell me about antibiotics to help me decide whether to accept or limit that treatment for my mother.

This is an open-ended question. Listen to the respondent and write down the main points of the response. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank.

CONFIRMED BY READ BACK? _____

49. When you explain Part D of the form to me, what will you tell me about artificially administered nutrition to help me decide whether to accept or limit that treatment for my mother.

This is an open-ended question. Listen to the respondent and write down the main points of the response. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank. Some common responses are listed below and the blank next to each should be checked if mentioned.

Interviewer : Check if any of the following are mentioned:

___ *Food by mouth will always be given*

___ *When people stop eating, it often means they are dying*

CONFIRMED BY READ BACK? _____

Embedding in Comprehensive EOL Program

50. There are many ways of doing end of life planning with a nursing home resident. The POLST form can be used to plan for end of life care in different ways. For example, you can first have a discussion of resident values and treatment goals and then introduce the POLST at the end of these discussions to record the decisions that were made. Another way of using the form is to introduce the POLST form at the beginning of the end of life conversation, and then use the form to structure the conversation by going through the various treatment options. There may be other ways of using the form too. Can you describe how your facility typically uses the POLST in end of life planning?

This is an open-ended question. Listen to the respondent and write down the main points of the response. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank.

CONFIRMED BY READ BACK: _____

51. Tell me how you think the POLST has changed the way your facility approaches end of life issues with residents:

This is an open-ended question. Listen to the respondent and write down the main points of the response. Prompt “anything else” as often as necessary to obtain a complete response. Then read back the response and when the respondent confirms the accuracy, check the “Confirmed by Read Back” blank.

CONFIRMED BY READ BACK: _____

ADDITIONAL SPACE FOR ANSWERS:

Conclude the survey and thank the respondent for participating in the survey.

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