An Analysis of the New York State Medical Orders for Life Sustaining Treatment Initiative
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ABSTRACT
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New York State’s Medical Orders for Life Sustaining Treatment (MOLST) was created to ensure compassionate end-of-life (EOL) medical care for patients in New York State (NYS) who have become incapacitated and lack decision making capacity. The pioneers of NYS’ MOLST Initiative found that end-of-life needs were not being adequately carried out according to patient’s wishes under the then available practices. MOLST was created in order to replace or at least supplement advance directives (AD), health care proxies (HCP), and standalone do-not-resuscitate (DNR) orders. MOLST’s aim was to provide a more complete array of medical orders at end-of-life that could be carried out by Emergency Medical Services and in all healthcare facilities throughout the state. Similar to Oregon’s Physician Orders for Life Sustaining Treatment (POLST) Paradigm, MOLST was created by a coalition of diverse stakeholders to ensure community acceptance. Utilizing the methodologies and policy creation models advocated by Kingdon and Longest, I will analyze the creation of New York State’s MOLST Initiative and its current operational issues.

KEYWORDS
MOLST; POLST; Medical Orders for Life Sustaining Treatment; Physician Orders for Life Sustaining Treatment; Advance Directives; Health Care Proxies

1. INTRODUCTION
The need for compassionate and responsive end-of-life care has been identified in the United States ever since the recognition of patients’ rights and the need to respect individual self-determination and autonomy were heralded in Beauchamp and Childress’ Principles of Bioethics, originally published in the late 1970s.[34] Unfortunately, over 40 years later, there are still many parts of the U.S. and the world that have not yet adopted compassionate end-of-life care as exemplified in the POLST Paradigm. The goal of this paper is to highlight the need for a universal respect for end-of-life care through a POLST policy, as well as to detail the needed steps to create, implement, and modify such a policy, with a focus on the New York State’s MOLST policy.

The first state in the U.S. to create Physician Orders for Life Sustaining Treatment (POLST) was Oregon. It was established in the 1990s as a way to “honor the treatment goals of people with advanced progressive illness or frailty”.[1] According to OregonPOLST.org.

Oregon leaders in clinical ethics, emergency medical services and long-term care recognized that preferences for life-sustaining treatments of patients with advanced chronic progressive illness were frequently not found or not transferable and thus not honored. [2]

Oregon established a coalition to create a task force of ethicists, healthcare professionals, legal experts, social workers, religious leaders, and patient representatives to address the issue of unwanted end-of-life care. Like all coalitions, it was designed to ensure key stakeholder input into the decision-making process and eventual formulation of a policy. Their initial goal was to establish a clear difference between Advance Directives and their proposed POLST policy. Advance Directives give legal authority for a surrogate to make decisions on behalf of an incapacitated patient, while POLST are orders memorialized on a form (or electronically) by a healthcare provider
some states allow physicians and/or advance practice providers). POLST specifies various end-of-life treatment options, such as cardiopulmonary resuscitation, whether to be hospitalized, and what types of treatment would be acceptable if incapacitated. The next major focus was to address the regulatory and statutory barriers to implement POLST in all clinical and non-clinical settings across the state. After 4 years of development, evaluation, regulatory changes, statewide and healthcare worker education, and reevaluation, the Oregon POLST was made a law in 1995.[2] Over the next 2 decades, several other states joined Oregon in formulating policies to guide the end-of-life care and treatment of its residents by Emergency Medical Services (EMS) and medical providers.[1] As of 2017, there are 24 states with established (endorsed) POLST programs, and 22 states currently developing programs.[27]

2. Policy Models of Kingdon and Longest

Before an analysis of the NYS MOLST program, it is prudent to first describe the Kingdon and Longest models of policy creation.

Kingdon likens policy formulation to the confluence of a river, which is created by three separate tributaries, namely problems, policies (or possible solutions), and politics (or political circumstances). His model suggests that although the three streams may have originated independently of one another, they must combine in order for a policy to materialize. Undoubtedly each of the streams will have forces acting upon them individually which ultimately affects how they flow. However, it is the concerted efforts of advocates who ensure that the individual streams line up at the right time to combine and create policy. [26] See Figure 1.

FIGURE 1. Kingdon’s Three Streams

Longest on the other hand, states that the policymaking process must go through some key stages: Policy formulation to implementation, which will then achieve the final policy goal. However, there is usually a need for policy modification, which feeds back on both the formulation and the implementation stages.[25] Longest model illustrates the circuitous nature of the steps to create policies, and the fact that the process may move in various directions, oftentimes non-sequentially as illustrated in Figure 2. It should be noted that Kingdon’s Three Streams model integrates perfectly into Longest’s Policy Formulation stage, and without such a confluence, a policy cannot be created.
3. MOLST Policy Formulation: Agenda Setting & Legislative Development

Similar to the creation of the Oregon POLST program, New York State realized it was not meeting the needs of its citizens in honoring their wishes for appropriate end-of-life care. Concerned citizens in New York State first identified a problem, namely a need for compassionate end-of-life care.[26] Several states across the USA were beginning to implement POLST programs, and members of a New York State coalition came together to address their own state’s needs. Similar to Oregon and other states’ POLST programs, a coalition of key stakeholders was created to address inappropriate and unwanted care associated with end-of-life. The New York coalition also felt that Advanced Directives were insufficient to ensure appropriate and compassionate end-of-life care.

Advanced Directives (AD) are comprised of documents such as living wills (LW) (a written statement detailing a person’s desires regarding their medical treatment in circumstances in which they are no longer able to express informed consent), power of attorney (POA) (the authority to act for another person in specified or all legal or financial matters), or a health care proxy (HCP) (a document that names someone you trust as your proxy, or agent, to express your wishes and make health care decisions if you are incapacitated).[30] There are several potential problems with each of these documents; a living will is only good if a patient had the foresight and detailed insight to specify what medical treatment they would (or not) want if they were incapacitated, and could provide that document to authorities legally able to honor those wishes (EMS in many jurisdictions cannot legally honor such documents); a power of attorney is dependent on a predetermined entity to make legally binding decisions on behalf of a now incapacitated patient, who may or may not have the a priori knowledge of the patient’s end-of-life treatment desires (in many states, including New York, this is still insufficient for EMS to honor in lieu of a signed DNR form); health care proxy similarly depends on a predetermined individual to make the right decisions on behalf of an incapacitated person, ensuring to respect the patient’s end-of-life wishes, which may sometimes conflict with the proxy’s wishes. Again, in New York State, “a living will or healthcare proxy are not valid in the prehospital setting”, and hence cannot be used to withdraw or withhold CPR by EMS.[32]

Several studies showed that Advanced Directives were being under-utilized and not deemed to be physician, patient and/or family friendly.[19] Advanced Directives often left more questions than provided answers for end-of-life decisions, and hence were not very “directive” to healthcare professionals who needed clear and concise orders at such critical times.
More than 15 years before the formulation of the MOLST policy, NYS had created a law allowing patients and their surrogates to make decisions regarding cardiopulmonary resuscitation (CPR). This was called a Do-Not-Resuscitate (DNR) order and was associated with a specific form or bracelet identifying patients that refused CPR.[15] In 1991, there was an additional modification to the law, which permitted the discontinuation or withholding of CPR in non-hospital settings, i.e. EMS and outpatient healthcare personnel could now honor a DNR form.[16] Unfortunately, DNR forms did not sufficiently address the totality of end-of-life care that patients and their advocates wanted. In addition to withholding or withdrawing CPR, patients wanted to express other treatment preferences, such as the use of antibiotics or tube feedings, as well as various procedures to be (or not) performed on them when they no longer had decision-making capacity.

Patricia A. Bomba, MD, Medical Director at Excellus BlueCross BlueShield had conducted several studies in Upstate New York to determine the local climate for end-of-life care and the use of Advanced Directives. In 2002, she conducted the “Employee Advance Care Directives Survey”, which concluded that,

Of the 2272 respondents, 77% or 1757 people reported knowing what an advance care directive is. When asked if they had ever appointed a health care proxy, only 30% (672 out of 2272) of the respondents reported that they had. Of the individuals who said that they knew what an advanced care directive is (77% or 1757 people), only 34% of those people have appointed a proxy. Conversely, 66% of people with knowledge have not appointed a health care proxy. Overall, 18% (412 out of 2272) of the total respondents said that they have completed a Living Will. Of the people who stated that they have knowledge of advance care directives, 20% have completed a living will, while 80% of people with knowledge have not yet completed one. Thirty-nine percent of the total respondents said that they would like to have more information regarding advance care directives.[3]

The survey illustrated a seeming disconnect between awareness of and actually completing an Advance Directive. After this initial study and over the next two years, she conducted workshops on End-of-life/Compassionate Care, and conducted a before and after survey on workshop attendees’ responses. In 2004, she found that before the workshop, 52% of attendees did not have Advanced Directives, and after the workshop that number decreased to 45% (conversely, 48% had advanced directives before, which increased to 55% after the workshop).[4] She used the data from these studies to show the need for a MOLST program in New York State, thereby setting an agenda for the creation of a MOLST policy.

Dr. Bomba’s coalition took advantage of a “Window of Opportunity”, as described by Longest (See Figure 2), in order to establish the MOLST policy agenda.[25] A review of the economic health of NYS during this time, lends another postulated window of opportunity, i.e. New York State’s need to save costs1; several think tank groups had recently released reports decrying the exorbitant amount of healthcare dollars devoted to end-of-life care.[5,6]; New York needed to save money from its high healthcare spending and expansion in the years post the 9/11 attacks[9]; New York’s healthcare spending was almost 50% of its state budget, much higher than most other states in the U.S.[28,33].

Bomba would be described by Kingdon as a policy entrepreneur, which is defined as,

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1 According to the Finance writer Andrew DePietro, “The 9/11 attacks disrupted taxes, including an incredible $3.5 billion decline in the state of New York in the first 18 months after the event, according to a 2002 report prepared by DRI WEFA for the New York State Senate Finance Committee”. [8] Several studies conducted on Medicare end-of-life expenditures have shown the disproportionate costs associated with end-of-life care. An article by Hoover et al in 2002 found that from “1992 to 1996, mean annual medical expenditures (1996 dollars) for persons aged 65 and older were $37,581 during the last year of life versus $7,365 for nonterminal years.” They further discovered that “Last-year-of-life expenses constituted 22 percent of all medical, 26 percent of Medicare, 18 percent of all non-Medicare expenditures, and 25 percent of Medicaid expenditures.”[5] This and several other studies at the time, including the Dartmouth Atlas of Health Care study showed that despite there being no significant benefit in health outcomes in terminal patients, and >80% of terminal patients expressing the desire to avoid hospitalizations, care was still being rendered, and at a great cost.[6]
individuals in the policy process who advocate for a specific policy proposal, build coalitions or secure political action and are willing to invest their own resources as well as their social and political capital in hopes of a future payoff. Policy entrepreneurs are individuals who attempt to influence the policy process and its outcomes through their opportunistic or incremental actions. Their success in the policy-making process has been associated with the convergence of four factors: behavioral traits; institutional factors; network position and political capital.[26,29]

The New York State MOLST program grew out of a regional collaborative initiative in the Rochester area with the mission to develop a set of broad end-of-life/palliative care goals. Kingdon’s Problem, Proposal and Politics streams require key players in the agenda setting and development of legislative proposals.

Dr. Bomba developed a coalition of stakeholders similar to other state POLST programs, which consisted of healthcare workers, ethicists, legal experts, clergy, patient representatives and social workers.[13] This coalition was called the Community-Wide End of Life/Palliative Care Initiative and was based in Rochester, NY, home to the region’s largest health insurer, Excellus BlueCross BlueShield.[14]

Like most successful Policy Entrepreneurs, Dr. Bomba was very politically connected. She was based in the Rochester area, which was a key political constituency for then Governor Pataki, not to mention her role as the Medical Director for the region’s largest employer.[12] Utilizing the 3rd branch in Kingdon’s policy streams (politics), the key players involved in the formulation stage of MOLST legislation were local and state governmental officials, the Governor, and the MOLST coalition. With this last stream secured, Dr. Bomba was able to combine the streams; the identified problem with end-of-life care, a MOLST proposal to fix the problem, and the political backing to create the legislation.

However, in order to formally develop the legislation for MOLST, Dr. Bomba presented the MOLST Initiative to the the New York State Department of Health, which promulgates regulations and legislates health law.[17] According to the site for the MOLST program (CompassionandSupport.org)-

“Discussions with the New York State Department of Health (NYSDOH) were initiated in March 2004 regarding the MOLST form and program. Collaborative review of the form with NYSDOH resulted in the first revision of the MOLST form in October 2005”.[18]

Furthermore,

Governor Pataki signed the MOLST bill (A.8892, S.5785) establishing a pilot of the MOLST program in Monroe and Onondaga Counties on October 11, 2005. This bill allows the use of the MOLST form in lieu of the New York State Nonhospital Do Not Resuscitate (DNR) form.[18]
FIGURE 2. Policymaking process.

Source: Longest, Health policymaking in the United States (2014)

4. MOLST Policy Implementation and Modification of Existing Laws

In its initial period, the use of MOLST outside of institutions was not possible due to barriers in the state’s DNR law, a problem also found in Oregon’s POLST implementation, and seen in several other states’ POLST Paradigm. Hickman et al found that the most common barriers to implementation of the POLST Paradigm as follows:

*The most potentially problematic barriers are detailed statutory specifications for out-of-hospital DNR (do not resuscitate) protocols (n = 9 states). Other potential barriers include limitations on the authority to consent to forgo life-sustaining treatments (n = 23 states), medical preconditions (n = 15), and witnessing requirements (n = 12) for out-of-hospital DNR protocols. [19]*

New York State had the distinction of falling subject to all of the above-mentioned legal barriers in its implementation, and as result, needed to make changes to the DNR laws in order to operationalize MOLST.

By enacting the MOLST Initiative into New York State Public Health law, the New York State Department of Health (NYSDOH) was authorized to provide alternative forms to issue orders for DNR in Monroe and Onondaga counties. New York State authorized a MOLST Community Pilot program for individuals in these counties to use a completed MOLST form for Emergency Medical Services (EMS) to follow DNR orders. MOLST forms were later approved by the legislature and Governor for use in hospitals, nursing homes, and other in-patient facilities, as the legal equivalent of traditional in-patient DNR forms, throughout NYS. Finally, the capstone on MOLST legislation occurred in July 2006, when Governor Pataki signed a bill that allowed MOLST forms to also be used by EMS as Do Not Intubate (DNI) orders for residents of Monroe and Onondaga counties.²

In order to make the law operational it needed to be implemented, which established new key actors in this stage, namely, state and local government officials, the Governor, public and specific interests groups, and now the

² Prior to this, EMS was still obligated to intubate a cardiopulmonary arrest victim despite having a DNR order, which was interpreted legally to only mean “no chest compressions”. This changed the scope of practice of EMS personnel for the first time since the inception and regulation of the EMS system by the state.[18] This should be an important point of consideration for readers in heavily regulated areas, such as New York.
NYSDOH, which served as the bureaucratic machine that provided guidance and specificity to the law vis a vis rules and regulations.

Collaboration with groups across the state expanded, as did engagement with the Department of Health. Dr. Bomba’s coalition followed the Oregon POLST Paradigm’s model of slow implementation with pilot programs in local areas to test out the MOLST program.[20] This allowed for better analyses and corrections before a statewide implementation occurred. The evidence-based success of the pilot helped bring about legislation in 2008 to make MOLST permanent and statewide as of July 8, 2008.

FIGURE 2. Policymaking process.

Source: Longest, Health policymaking in the United States (2014)

5. MOLST Policy Modifications

As describe by Longest and detailed in Figure 2, the policy modification stage is as a result of feedback from stakeholders of the MOLST Initiative who have experienced the effects of the policy, as well as assessed its performance and impact “by those who formulate and implement them” which in turn will further influence “future policy formulation and implementation”. In summary:

1. **2005 Legislation Added Persons with Developmental Disabilities (DD) to the Health Care Decisions Act (Surrogate’s Court Procedure Act § 1750-a)**
   - Patient with DD with capacity can complete MOLST form
   - Physician should consult legal counsel for DD patients without capacity.

   - Permits NYS Department of Health to authorize MOLST form in lieu of Nonhospital DNR in Monroe and Onondaga Counties
   - Carve-out: OMH and OMRDD (Office of Mental Health and Office of Mental Retardation and Developmentally Disabilities)
3. **MOLST Pilot Project Chapter Amendment (Amended PHL § 2977(13) (L. 2005, Ch.734; L. 2006, Ch. 325))**

- Authorization for EMS to honor Do Not Intubate (DNI) instructions prior to full cardiopulmonary arrest in Monroe and Onondaga Counties during MOLST pilot
- Carve-out: OMH and OMRDD

4. **Health Care Decisions Act for Persons with Mental Retardation (MR) (Surrogate’s Court Procedure Act § 1750-b)**

- Patient with MR with capacity can complete MOLST form
- Allows a guardian (Surrogate’s Court Procedure Act § 1750-b) of a mentally retarded person to make end-of-life health care decisions
- Physician should consult legal counsel for MR patients without capacity.

5. **Family Health Care Decisions Act (FHCDA)**

- Family Health Care Decisions Act effective June 1, 2010
- Applies in hospitals and nursing homes
- Allows surrogates to make medical decisions

6. **Medical Orders for Life-Sustaining Treatment (MOLST)**

- **Family Health Care Decisions Act**
- MOLST is integrated into FHCDA
- The New York State Department of Health revised the MOLST form (DOH-5003) in June 2010 to make it more user-friendly and to align the form with, and to support implementation of, the Family Health Care Decisions Act.
- Surrogates can make decisions to withhold and/or withdraw life-sustaining treatment using surrogate standards, clinical standards and special requirements set by FHCDA.[21]

These policy modifications led to legislative changes in the MOLST policy that were consistent with changes in New York State’s public health law codes. There were legislative inclusions and modifications of the rights of various stakeholders not previously included, as well as the inclusion of surrogates in the decision-making process for end-of-life care for their loved ones. Key points to consider in these policy modifications are the provisions created in New York State public health law to protect the rights of those with developmental delays or mental retardation. As a vulnerable group, NYS made sure to prevent the indiscriminate and unethical termination of healthcare access in such individuals.

6. **MOLST Policy Monitoring and Evaluation**

According to the American Association of Retired Persons (AARP), most states in the U.S. with POLST lack formal monitoring or evaluation processes.[1] The most common approach in states with more extensive experience in using POLST is the use of an expert working group or committee to periodically solicit and review feedback from stakeholders and recommend changes to the form or procedures as needed. A commonly identified challenge was the limited focus that the state department of health, or other agency with approval authority over POLST, gave to monitoring the proper use of POLST. [1] Research as shown that most MOLST forms are used for just its DNR/DNI sections, and less often to stipulate other end-of-life treatment wishes.[31] This may be due to the fact that the MOLST form was initially marketed and legislatively created as an alternative to the DNR form, as alluded to previously in Policy Implementation.

Additionally, the lack of an Electronic Health Record (EHR) version of MOLST (eMOLST) makes tracking, monitoring and evaluating the program difficult. Nonetheless, New York could rely on data compiled from individual healthcare institutions, which would be better able to track the use of POLST forms amongst their
patients. Since by law, all hospitals receiving CMS funding must have an EHR, data could be compiled from both recently deceased as well as patients with conditions meeting criteria for EOL care (advanced cancers, multi-organ failure, etc).

In 2016, Clemency et al studied the use of MOLST forms in Emergency Departments in NYS for completeness, and found that of the 100 forms studied, 69% had at least one section left blank, and “Inconsistencies were found in patient wishes among a subset (14%) of patients, wherein their desire for “comfort measures only” seemed contradicted by a desire to be sent to the hospital, receive IV fluids, and/or receive antibiotics.” [22] He concluded that although patients and their loved ones may believe they can choose and forego some treatments, the manner in which many do so may lead to undesirable outcomes.

Dr. Bomba wrote a response to Clemency by stating,

> in publishing this article, the authors unfortunately have (1) explained incompatible orders in ways that are not medically accurate and made errors in the standards for reading and following MOLST orders; (2) created misunderstandings about the MOLST process; and (3) failed to recognize potential solutions to the problems they describe, including New York's eMOLST.[23]

She stressed the need to create an eMOLST in NYS arguing that it would eliminate most of the problems raised by Clemency. Bomba did agree with many of the errors cited by Clemency, such as patients checking Do Not Intubate, yet also wanting CPR performed, but explained it was due to patients not fully understanding what CPR was and its poor survival rates.

Dr. Bomba has continued to study MOLST after its implementation. In a study by MOLST and the National POLST Paradigm conducted in 2010 to determine the effectiveness of their respective programs;

> The study found that patients with POLST forms saying they wished to receive care primarily focused on relieving their pain and suffering were 59 percent less likely to receive unwanted treatments such as hospitalization than those who had had only a DNR order. At the same time, the study showed that patients with POLST forms requesting fewer medical interventions continue to receive pain management; when compared to other patients, they were found to receive identical levels of treatment for pain and other symptoms. [24]

This suggests that POLST forms prevent many patients from unwanted end-of-life treatments, yet ensures their suffering and pain are adequately addressed. However, it also reveals a large (>40%) failure rate by clinicians to comply fully with all patients’ written orders. It is important to recall the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) project, where it was found that despite clearly expressed end-of-life directives by patients, physicians largely ignored them and were largely resistant to accommodating these requests or even talking about them.[7, 35] Clinicians are often the rate limiting step to the success of any POLST program, and unfortunately have been reluctant to embrace any form of end-of-life planning as was found in SUPPORT. Additionally the AARP states, “Training and Education for physicians posed the greatest implementation challenge” for the POLST Paradigm’s implementation.[1]

As a follow-up study in 2016, Bomba released a report stating that the reasons there were failures in following MOLST orders were as follows,

- Clinicians, patients, families are unaware of their obligations to follow MOLST and implications of failure to follow MOLST
- Advance care planning is not recognized as a dynamic process, including MOLST
- Emphasis should be on communication
- Forms are the end of the process
- Attention is given to the discussion, but ADs or MOLST are not completed or done incorrectly (incompatible orders)
- Avoiding early discussions or focusing on interventions, rather that personal values, beliefs and goals for
In order to overcome these failures, she recommends,

- **Strengthen clinician training**
- **Encourage public education and engagement in advance care planning**
- **Expand use of eMOLST.**[31]

### 7. SUMMARY AND CONCLUSION

The creation of MOLST in New York State, demonstrates the necessary steps to successfully create a policy as shown by both Longest and Kingdon. By bringing together the 3 streams of **problems, policies** (or possible solutions), and **politics** (or political circumstances) one can formulate policy. Once policy is formulated, it is then implemented to create policy goals. As input from key stakeholders is obtained, policy modification can occur feeding back into implementation of a new and improved policy. Another key factor in the successful creation of a policy is identifying and ensuring that Policy Entrepreneurs leverage their political and social contacts to establish and set policy proposal agendas. Policy success is typically achieved with appropriate timing of the agenda setting and policy formulation to take advantage of a “Window of Opportunity”, such as political, financial, or healthcare issues affecting the public. It is crucial to incorporate the right blend of stakeholders when adopting policies to ensure they represent all voices that may be affected by the policy. It is also important to identify the key actors (players) at each step of the policymaking process in order to ensure successful policy creation.

Despite two decades since adoption, NYS’s MOLST Initiative is woefully underutilized across healthcare institutions and amongst eligible individuals.[31] Physicians and other health care providers are still reluctant to encourage, educate, or implement EOL decisions expressed by patients as ev
denced in the SUPPORT trial.[7,35] NYS’ MOLST form has just become available in an electric version (eMOLST), which will allow better implementation, transferability, and monitoring. Further studies will need to be conducted to ensure widespread adoptability and use.

Healthcare providers and the public at large, need to be educated on the proven benefits of a MOLST form documenting the multitude of treatment options in the event of a loss in decision making capacity. Multiple follow-up studies have shown that an improvement has been made in end-of-life care after the implementation of the MOLST Initiative when compared to Advance Directives. Currently, the medical community is empowering more than the traditional primary care provider to increase the expanse of providers able to help patients with their EOL needs. Even in the ED, which is known for its limited time, information, and devoid of long-term relationships, multiple studies and initiatives are being undertaken to show the benefit of engaging in EOL discussions.[36, 37] It is hopeful that with a renewed public outreach the NYS’ MOLST Initiative may become as successful as the Oregon POLST Paradigm. If all members of society are to be respected especially at their most vulnerable, incapacitated stage (EOL), then all members of the medical community (and not just the local Department of Health) need to take ownership in ensuring the adoption, use, and monitoring of POLST forms.
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