

Patients Deserve a New York Statewide Registry for Health Care Proxies and eMolst

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Standard Medical Care vs. Advance Directives vs. Medical Orders

Standard medical care means a patient receives all necessary medical treatment, unless there is a medical order to withhold treatment. Advance directives, like the living will, document future care preference and are difficult to interpret in an emergency. For this reason, the Community-wide End-of-life/Palliative Care Initiative that began in Rochester in 2001 sought to find a better solution and two population health based advance care planning programs were created:

1. Community Conversations on Compassionate Care (CCCC) is an award-winning nationally recognized, evidence-based program developed to help individuals over 18 years of age complete health care proxies using storytelling and Five Easy Steps. The CCCC program is based on the behavioral readiness of individuals to take action and encourages regular discussion of what matters most to the individual over time.
2. Medical Orders for Life-Sustaining Treatment (MOLST) is a program for patients who are seriously ill or frail, for whom their physician would not be surprised if they died within the next year. MOLST is now a DOH medical order form approved for use in all settings. MOLST must be honored by EMS in the patient's home and anywhere in the community. MOLST is the only medical order form tested under legislative statute (2005-2008) in Monroe and Onondaga Counties. As a result, EMS can follow only both Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders on the MOLST form in the community.

The primary purpose of a health care proxy is to appoint an agent to make health care decisions in accordance with the patient's wishes and goals, if known and if not, in the patient's best interests. This law was enacted many years ago to comply with the Federal Patient Self-Determination Act and yet there are still many individuals who have never completed a proxy. If a patient does not have a health care proxy and does not have the ability to make medical decisions, a surrogate will be the decision maker, chosen

from a list under Family Health Care Decisions Act. This list may not reflect the best person to act on the patient's behalf.

MOLST is a set of medical orders signed by the physician or nurse practitioner (as of May 28, 2018) that defines life-sustaining treatment the patient wants to receive or avoid *now*. Living wills are difficult for physicians to interpret and operationalize as irreversible and potentially reversible conditions coexist. A MOLST done reflecting a patient's current health status, prognosis, goals for care and appropriate consent is more valuable to the physician making decisions than a living will done 20 years ago, especially when the same physician is not seeing the patient in every care setting.

As a physician who spent many years in private practice caring for frail elders, I recognize a real conversation requires time on the part of the physician and how invaluable it is for patients and families when a crisis occurred. That's why Excellus BlueCross BlueShield created the first time-based reimbursement model in the country in collaboration with community physicians that was linked to free training in 2008. Fortunately, Advance Care Planning CPT codes 99497 and 99498 (effective January 1, 2016) recognize time spent for these crucial conversations as a covered service that replaced our home grown model. Physicians should be able to take the time necessary to discuss options and ensure their patients understand the impact of their decisions through well-informed shared decision making.

Four different New York State Public Health Laws (NYSPHL) govern end-of-life decisions with or without the MOLST. A physician is accountable for the medical orders and appropriate documentation of the ethical-legal requirements. As of May 28, 2018, the authority will be extended to nurse practitioners, except for individuals with developmental disabilities who lack the ability to make medical decisions; for these individuals, Surrogate Court Proceedings Act (SCPA) §1750-b applies and only a physician can follow the special procedures and sign a MOLST form.

The MOLST form is being revised to comply with the nurse practitioner legislation. The revised MOLST form will include changes recommended by physicians and others to clarify language that is contributing to medical errors and will include MOLST Instructions. A robust review process was conducted statewide and feedback was sought from members of the MOLST Statewide Implementation Team, the EMS MOLST work group and key palliative care physicians who use MOLST or eMOLST extensively, including many from the Rochester community.

MOLST is not an Advance Directive. However, patients who are appropriate for MOLST should have an up-to-date health care proxy in case MOLST orders need to be revised after the patient loses capacity.

Access to Health Care Proxies and MOLST forms

As a caregiver for my mother who had a MOLST when she lived with us the last fifteen months of her life, I know how important access to health care proxies, MOLST and other clinical information is in an emergency. My mother had such an emergency when she traveled to Pennsylvania in 2007 and her MOLST was honored because it was available. I also know it takes time to educate families in order to ensure the patient or caregiver keeps the MOLST with them at all times whenever they leave home.

Unfortunately, health care proxy and MOLST forms are often unavailable when a patient who lacks decision-making capacity arrives at the emergency department. Too often, there is no health care agent or family member with the patient to help make crucial decisions. Therefore, hospital providers have no choice but to aggressively treat and if necessary, resuscitate the patient. This often results in unwanted end of life treatment including intubation. There have been instances where families or physicians make decisions which are in direct conflict to the patient's previously expressed wishes to withhold life-sustaining treatment documented on a MOLST.

eMOLST

New York's eMOLST system incorporates MOLST form completion and process documentation of a standardized communication process, including patient health status, prognosis, goals for care and the ethical-legal requirements and while also serving as the registry of MOLST forms for New York State. Access to eMOLST is free. The eMOLST system allows physicians and nurse practitioners (effective May 28, 2018) to thoroughly create a set of medical orders that defines life-sustaining treatment the patient wants to receive or avoid now that is 100% accurate and accessible. Other health care professionals can participate within scope of practice. eMOLST allows physicians to print forms to include with paper records. Physician practices and

health systems can also electronically integrate eMOLST with an EHR. The system allows physicians to sign MOLST orders electronically. The process-oriented nature of eMOLST ensures quality and patient safety and reduces patient harm to help achieve the triple aim. eMOLST provides 24/7 access to forms for any credentialed provider who wishes to access the system. eMOLST caters to physicians interested in improving clinical outcomes, legal outcomes and provider satisfaction, and meets the needs for a systems-based solution for health systems.

Registry Legislation

Recently, New York State Assemblyman Morelle introduced legislation to remedy many of these problems by creating a statewide registry for both MOLST and health care proxy documents. The bill defines MOLST and confirms that MOLST also acts as a non-hospital Do Not Resuscitate (DNR) order. When a MOLST is completed and signed, the provider would have 14 days to submit it to eMOLST, the electronic registry.

This bill also establishes a registry for health care proxy documents as well as living wills, and judicial orders appointing a guardian to make health care decisions for the patient. The New York State Department of Health will be responsible to operate the registry and there will be no cost for submission of the documents or to search the registries. When either the MOLST or proxy is revoked or modified, the person who originally submitted the document must notify the registry of such changes.

Having a registry for both advance directives and medical orders which encompasses the entire state not only would solve the concerns noted above but would hopefully increase the use of eMOLST, the electronic version of MOLST. The benefit to patients as well as the medical profession is to enable the retrieval of these documents in a timely manner, and ensure that the patient's goals and preferences for treatment will be met at the end of life.

This legislation is critical to the continued success of the MOLST Program and needs your help to succeed. I ask that you urge your local Senators and Assembly members to support this legislation as soon as possible. A draft letter of support has been crafted and is available on the Proposed Legislation page on MOLST.org. I encourage you to add your personal experience and the value of eMOLST in improving quality & patient safety, ensuring accessibility in an emergency and achieving the quadruple aim. Thank you in advance for your support of this legislation and the MOLST Program!

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Response to Concerns Expressed by MSSNY

MSSNY has long been a supporter of the MOLST program. However, MSSNY is opposed to mandates. In his May 11, 2018 Physicians Message, Dr. Thomas Madejski shared his thoughts about potential problems but he is open to better understanding the value of eMOLST.

Before addressing the concerns, I want to clarify a misconception regarding the MOLST Registry legislation that was included in the Message ("If passed, physicians who use the MOLST form will then be required to report patient related information from the MOLST form to the registry within 14 days.") Rather, the correct statement is "If passed, the legislation requires physicians who use the MOLST form to submit a copy of the completed and signed MOLST to the registry."

Doctors fear OPMC problems if they do not comply with the law.

Do you have evidence of OPMC problems with failure to follow Family Health Care Decisions Act (FHCDA) or the Palliative Care Information Act (PCIA)? Similarly, are their concerns with OPMC enforcement issues related to physicians reporting immunizations to the New York State Immunization Information System (NYSIIS)? The reporting requirement contained in this legislation was modeled on the 2008 requirement that all practitioners enter immunizations administered to children into the NYSIIS within 14 days of administration of the immunization. To date, we are unaware of any enforcement by OPMC related to reporting to this registry.

This provision is also designed to encourage the use of eMOLST, rather than the paper version, which would eliminate any concerns related to reporting within 14 days as completion on eMOLST would automatically be submitted to the Registry, requiring no additional action by the physician.

Doctors are concerned that the data may not be housed at NYS DOH.

Concern about data not being housed by NYS DOH: Under the structure of the legislation, it is envisioned that the Department of Health would contract with an entity, presumably the MOLST Program, to operate the Registry. While not "housed" at the NYSDOH, the Registry operator would be under contract with the DOH for the operation of the Registry and would be subject to significant oversight by DOH. In addition, the current eMOLST system operated by the MOLST Program is not housed by the NYS DOH, but is housed in a separate secure server, electronically storing all MOLST forms completed through

the eMOLST system. The data is encrypted and separate from the application. The Registry would be operated in the same manner as the current eMOLST application. Importantly, this means that access and information transmitted through the application complies with HIPAA, Department of Health privacy rules and New York State Public Health Law. In keeping with New York State's vision for open-system solutions, the eMOLST application was developed following open architectural principles for the benefit of the community and other Regional Health Information Organizations (RHIOs) across the state, as well as serving as a data source for the Statewide Health Information Network for New York (SHIN-NY).

Lastly, the information contained on the MOLST is not intended to remain with the DOH; rather, it is meant to be accessed by all health care providers.

Doctors are concerned about multiple different documents which may have conflicting data

This legislation would assist in eliminating this concern by creating 2 Registries – an advance directive registry and MOLST Registry. The advance directive registry would assist in ensuring accurate documents, such as health care proxies. Patients who are appropriate for MOLST should have an up-to-date health care proxy in case MOLST orders need to be revised after the patient loses capacity. Similarly, the MOLST registry would only allow for the most recent valid MOLST to be accessible to health care providers, eliminating the concern that the form may be out of date or had been revoked.

Learn More

CompassionAndSupport.org, a community-wide end-of-life/palliative care website, has been redesigned recently thanks to support from Excellus BlueCross BlueShield. Additionally, a sister website, MOLST.org has been created.

The websites, which are complementary, focus on a population health approach. Together, CompassionAndSupport.org and MOLST.org aim to engage, educate and empower patients, families, health care and other professionals about the key pillars of palliative care. CompassionAndSupport.org focuses on advance care planning and advance directives for the general population, along with palliative care and hospice, pain and symptom management, and death and dying. MOLST.org focuses on advance care planning and medical orders for seriously ill people supported by a person-centered, family-oriented, 24/7 responsive palliative care plan.

Your comments and suggestions about MOLST, eMOLST, legislation and the websites are welcome. Please email me at Patricia.Bomba@ExcellusBCBS.com.