LeadingAge New York

November 16, 2018

Mark Kissinger
Special Advisor to the Commissioner of Health
New York State Department of Health
Office of Primary Care and Health Systems Management
Empire State Plaza, Corning Tower, 14th Floor
Albany, NY 12237

Re: Advance Care Planning Request for Information

Dear Mr. Kissinger:

Thank you for the opportunity to submit comments in response to the Department's Advance Care Planning RFI. Our responses are attached for your review. Please don't hesitate to contact us if you would like any additional feedback.

Sincerely yours,

Karen Lipson
Executive Vice President for Innovation Strategies



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# Advance Care Planning RFI

1) Please provide your contact information, including the name of your organization (if applicable), name of contact person, title, phone number, and e-mail address.

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**Questions for Healthcare Providers Only**

2) Do you assist individuals in filling out a Health Care Proxy, Nonhospital DNR, and/or MOLST? a. If yes, who do you typically assist in filling out forms? For example, are the majority that fill them out over 65, over 85, female, male, recently diagnosed with an illness, etc.?
b. If yes, which form do you use most often?

- LeadingAge New York represents approximately 400 non-profit providers of long-term/post-acute care and senior services and managed long term care plans. Among our members are providers that assist individuals in completing Health Care Proxy forms, that employ clinicians who complete MOLST and DNR forms, that implement the decisions and orders reflected in those forms, and that provide care management to individuals and families who may need to engage in advance care planning.

- We have surveyed our members on the issues raised by the Department's RFI. We received 22 responses – 15 from nursing homes, 4 from assisted living facilities, 1 from a LHCSA, 1 from a CHHA, and 1 from a care management provider. The following comments consolidate and paraphrase key points raised in response to our survey and include recommendations developed by LeadingAge New York based on policy analysis and other member input.

- 91 percent of respondents indicated that they assist residents or clients in completing health care proxy forms; 73% assist residents with the MOLST form; 14% use eMOLST; 59% use Non-Hospital DNRs; and 36% use Hospital DNRs.

3) Do you regularly have advance care planning conversations with patients?
a. If so, how often do you initiate advance care planning conversations?
b. If so, who do you typically have the conversation with? For example, are the majority that you have the conversation with over 65, over 85, female, male, do caregivers bring it up first, recently diagnosed with an illness, etc.?

- Typically, all residents, patients, and clients are offered assistance with some form of advance care planning, whether it is simply appointing a health care agent using a Health Care Proxy form or, if appropriate, considering life-sustaining treatment orders, such as MOLST or DNR. A

conversation about advance directives is often initiated at admission. Any advance care planning documents and life-sustaining treatment orders are gathered and incorporated into the medical record. More detailed, clinical conversations are conducted as needed, as the resident's/patient's treatment or condition progresses, and when there are changes in condition.

4) Explain the barriers to regularly discussing advance care planning with your patients.

- The most significant barrier to advance care planning is the readiness of the resident/patient and, where applicable, his/her family to engage in a conversation about the end of life. When a resident/patient is first admitted to a facility or service, he/she may need time to adjust to new circumstances and a new prognosis before he/she is ready to have a discussion about appointing a health care agent or making decisions about life-sustaining treatment. Even after the transition is made, a conversation about treatment options may be too overwhelming. Family dynamics and disagreement over goals for care present additional challenges. This can lead to delays in decision-making until a health care crisis forces the issue.

- A second barrier is the availability of medical professionals in continuing care settings to engage in advance care planning conversations and sign life-sustaining treatment orders. MOLST forms and DNR orders must be signed by physicians or nurse practitioners. Since many nursing homes rely on community physicians and/or the residents' personal physicians, who are not present in the facility on a daily basis, it is often difficult to engage physicians in these conversations. The enactment of Chapter 430 of 2017, authorizing nurse practitioners to sign MOLST and DNR orders, was a significant step toward reducing this barrier. However, the DOH MOLST and DNR forms have not yet been revised to reflect this change in the law. The absence of explicit authorization on the forms for NP signatures has caused confusion and impeded the effectiveness of the change in law.

- Other barriers to advance care planning conversations include cognitive impairment on the part of residents/patients and the lack of any family or friend who can serve as a decision-maker.

- Once the advance care planning conversation takes place and documents are signed, providers may face challenges in implementing those decisions. For example:
    - Sometimes health care agents are ill-prepared to make decisions on behalf of patients who lack capacity.
    - Family members may try to change decisions previously made by the patient, even in the absence of a change in condition that would justify a new decision.
    - When a patient retains capacity to make decisions, family members may not understand that a patient with capacity has the right to make decisions. They may try to substitute their judgment for the patient's.
    - Occasionally, there appear to be inconsistencies in patient's wishes. For example, the patient's MOLST may indicate that he wants full treatment, but he is unwilling to seek medical attention. This suggests that additional conversations between the patient and his/her health care practitioner are needed.
    - Sometimes, EMS workers do not acknowledge the nonhospital DNR forms.
    - The Adult Care Facility (ACF)/Assisted Living (AL) provider is unable to honor MOLST orders, which causes confusion and conflict for the resident. For example, if the MOLST form indicates that the resident does not wish to be hospitalized, the facility must still

access emergency services or send the resident to the emergency room when there is an event, because the staff in the ACF/AL setting are typically not permitted to assess the resident. With the exception of the enhanced assisted living residence (EALR), these facilities—even if they have a nurse on staff---are not permitted to conduct those assessments.

5) How easy is it to learn if a patient has a Health Care Proxy, DNR, or MOLST?

- One respondent indicated that it experiences some difficulty obtaining documents from physicians and attorneys.
- Several respondents noted that too often patients/residents admitted from hospitals arrive without advance care planning documents. If new MOLST or non-hospital DNR orders are executed in the hospital, it can be challenging to obtain them from hospitals after a hospital admission or ER visit.
- Widespread use of eMOLST would alleviate difficulties in identifying the existence of a MOLST form and retrieving the most recent version of the form.

6) How easy is it to access advance care planning documents during a health emergency?

- In nursing facilities and assisted living residences, MOLST, DNR and health care proxy forms are typically maintained in the resident's medical record. In private homes, patients typically post their MOLST forms or non-hospital DNR orders on the refrigerator or next to their bed. It is not difficult to access these forms in an emergency.
- One respondent indicated that it experiences some difficulty obtaining documents from physicians and attorneys.
- Several respondents noted that too often patients/residents admitted from hospitals arrive without advance care planning documents. If new MOLST or non-hospital DNR orders are executed in the hospital, it can be challenging for nursing homes, assisted living facilities, and home care agencies to obtain them from hospitals after an admission or ER visit.
- When eMOLST forms are completed, it is easy to access the form and to be fairly certain that it is up-to-date. eMOLST makes care transitions easier.

8) What are the most common errors made in completion of the Health Care Proxy, MOLST, and nonhospital DNR?

- Documents created prior to admission to the nursing home often contain errors that call into question their validity. One respondent indicated that this has occurred on multiple occasions with patients/residents with dementia who lack the capacity to create a new directive. Some examples of errors cited by respondents are:

    - Lack of witnesses to the health care proxy or using the agent as a witness.
    - Appointment of an agent on the health care proxy using a name other than the agent's legal name.
    - A health care proxy form signed by someone who lacked capacity to appoint a health care agent at the time the document was signed.

- Inconsistent MOLST orders, e.g., ordering full CPR on the first page, while limiting intubation on the second page.
- Absence of requisite signatures on the MOLST form.

9) Do you or your organization offer advance care planning education for patients, public, and/or health care providers? If so, would you be interested in having a contact for you or your organization listed on a NYS Department of Health Advance Care Planning website?

- Some respondents offer advance care planning education for patients and families through family support groups and palliative care teams. Several would be interested in having their trainings listed on DOH advance care planning website. Most respondents offer training to staff. Most would be interested in additional training for staff and consumers.

**What changes should be made in the forms?**

LeadingAge New York recommends that the MOLST form be updated to reflect the change in the law that permits nurse practitioners to sign MOLST orders. In addition, clinicians associated with the statewide MOLST implementation team have suggested updates to the clinical elements of the form. Specifically, the intubation instructions should be clarified to permit a trial of BIPAP or CPAP, and provide an option to select, a "do not intubate" order if the trial fails. The Do Not Hospitalize order should be clarified to alleviate concerns that it is ambiguous or implies that a patient can never be hospitalized, even when necessary to alleviate discomfort or to comply with the palliative care plan.

One respondent suggested that the health care proxy form include a space to indicate that the patient declines to donate his/her organs.

Another respondent noted that the forms can be confusing to the general public. and that incorporating some definitions or glossary of terms might help.

**Are there any other actions that the State should take to promote advance care planning?**

LeadingAge New York recommends that the State provide financial support for expanding the use of eMOLST in order to facilitate proper completion of MOLST forms and efficient and effective use of the forms once completed. We also recommend that the Department establish an advance care planning policy team that meets regularly, and updates and disseminates information to the public, and responds to questions from consumers and providers. Finally, although not directly related to advance care planning, we join our members in asking the State to allow providers to honor resident preferences at the end of life by expanding access to hospice in assisted living facilities.

Nearly all respondents indicated that greater public awareness and education of providers, including physicians, is critical to promoting effective advance care planning that supports consumer preferences.

Many respondents expressed frustration at the lack of engagement of some physicians and mid-levels in conversations about prognosis, goals for care, and advance care planning. Some suggested that these conversations should be a billable service to encourage medical professionals to take the time to conduct them. However, at least under Medicare Part B, these conversations are reimbursable. In

January 2016, the Center for Medicare Services (CMS) approved two new CPT codes 99497 and 99498 to allow physicians and “other qualified health care professionals,” to be reimbursed for having an advance care planning conversation with their Medicare patients. The responses to our survey suggest that professionals may be unaware of the approval of the advance care planning CPT codes. In addition, we do not know whether the Medicaid physician fee schedule likewise provides for a special rate for physicians and mid-levels when they engage in advance care planning conversations. If it does not, an adjustment to the fee schedule to incentivize these conversations with Medicaid beneficiaries may be helpful.