

Advance Care Planning RFI: Common Themes and Recommendations

The New York State Department of Health (Department) initiated a comprehensive review through a Request for Information (RFI) of the advance care planning process. The purpose of this RFI was to gather input on necessary changes to ensure the Medical Orders for Life Sustaining Treatment (MOLST), Nonhospital Order Not to Resuscitate (DNR), and Health Care Proxy forms are used appropriately and are understandable to the general public. The Department was also interested in learning how it could support advance care planning conversations. The RFI sought recommendations for language changes, educational materials, information on barriers to having a conversation about advance care planning, and any data organizations may be collecting on this process.

The RFI recommendations are for informational purposes and should not be interpreted as obligations on the part of the Department to implement.

Background on the Advance Care Planning (ACP) RFI

The RFI was available for two months, generating 44 responses from individuals, including providers, caregivers, service agencies, and advocacy organizations. Of the responses received, 23 were from individuals and 21 were on the behalf of an agency, organization, or association. Individual respondents included:

- 12 Physicians
- 4 Social Workers
- 3 Registered Nurses
- 2 Attorneys
- 1 Certified Family Nurse Practitioner
- 1 Unidentified

Agencies, organizations, or associations that responded included:

- 1st Choice Home Care Services
- ADVault
- Cobble Hill Health Center
- ElderONE
- Empire BlueCross BlueShield HealthPlus
- End of Life Choices NY
- Greater New York Hospital Association (GNYHA)
- Help for Healing
- Hospital and Palliative Care Association of New York State
- Icahn School of Medicine at Mount Sinai
- LeadingAgeNY
- Mount Sinai Palliative Care Department
- Not Dead Yet
- Nurse Practitioner Association
- NY Civil Liberties Union
- NY eHealth Collaborative
- NYS Association of Health Care Providers
- NYS Health Facilities Association

- Office for People with Developmental Disabilities (OPWDD)
- Optum
- Representation of Palliative Care Providers

The RFI included a series of 17 questions, asking respondents that directly assist with advance care planning to provide input on the following:

- holding an advance care planning discussion;
- filling out the State's advance care planning documents;
- locating the documents;
- common errors in completing these documents;
- whether the documents are easy to understand;
- language change recommendations; and
- common barriers to advance care planning.

Recommendations

Below are the recommendations based on the responses received from the RFI. Broken down into three categories, they are:

- General Recommendations
- Recommendations for MOLST
- Recommendations for the Health Care Proxy

General Recommendations on ACP in New York State

- Address the lack of awareness among the general population on ACP, including the benefits and the types of forms available.
- Establish a statewide registry for ACP forms that is accessible through the SHIN-NY/RHIOs; or establish alternatives to increase interoperability and facilitate the sharing of these documents across all settings.
 - Increase the ability to complete and share forms electronically among providers, facilities, and patient/agents.
- Clarify an individual's right to designate multiple proxies/agents in case of unavailability.
- Consider the addition of a glossary of common terms to the MOLST and Health Care Proxy to better inform individuals and their caregivers.
- Consider providing and/or mandating workforce training on how to conduct ACP discussions with residents and their caregivers, as well as provide instructions on how to properly fill out the form(s); require refresher training bi-annually.
 - Scripted materials to standardize discussion could be beneficial.
 - E-learning series or webinar on forms and initiating discussion tailored to providers and caregivers would be useful.

- Provide clear education on treatment options that are setting specific; i.e., may only be available in a hospital.
- Consider the addition of a dementia specific section on the Health Care Proxy Form or providing for whether preferences may change based on whether a person develops dementia.
- Provide more comprehensive education on when it may be appropriate to recommend/provide patients and caregivers with information on Hospice/Palliative Care.
- Consider requiring facilities to update advance directives at least annually and following a transfer or change in condition.
- Due to limited provider time, increase general awareness of billing codes for ACP discussions; consider including ACP conversations as a personal care/care coordination activity to facilitate billing for these conversations within Adult Care Facilities.
- Establish penalties for when an advance care planning document is deliberately ignored; require Adult Care Facilities to track and at least annually update forms for all residents – in cases where resident refuses, require that these facilities routinely ask/redirect resident on filling out the forms.

Recommendations Regarding the MOLST Form and Process

- Make form and required supplemental materials easily accessible on the DOH website.
- Provide clear instructions on the supplemental materials needed and better instruction on who may be considered a concurring provider.
- Consider providing information and education on the issue of when a person does not have someone to appoint as an agent/proxy.
 - Specifically, awareness and education on the provisions of PHL 2994-g – Health Care Decisions for Adult patients without surrogates.
- Consider whether to mandate filling out a MOLST as part of Skilled Nursing Facility (SNF) admission process.
- Consider requiring the completion of a MOLST as part of the discharge or transfer to hospice to help facilitate hospice care planning prior to admission to hospice.
- Clarify discrepancies between information on DOH websites and information contained in links from the DOH webpage to MOLST.org.
- Ensure confidentiality and security of personal health information (PHI) for eMOLST.
- Consider adding a section for the naming of a proxy on the MOLST.
- In the case of preferences surrounding intubation, address a person's options for a trial of Bilevel Positive Airway Pressure (BIPAP) or Continuous Positive Airway Pressure (CPAP)

and provide an option to select a “do not intubate” order if the trial fails.

- Locate section on intubation on or near the same page as the Full Code/DNR section – since they are commonly linked and frequently checked.
- Consider addition of a checkmark for situations when the decision to withhold life sustaining treatments in question was made by an attending physician in accordance with the Family Health Care Decisions Act (FHCDA) for those without a surrogate and lacking decisional capacity.
- Consider providing instruction and education on situations that may arise when a patient or resident has a Non-Hospital DNR and a MOLST, especially if there is a discrepancy.

Recommendations Regarding the Healthcare Proxy Form and Process

- Determine whether existing laws and regulations conform to the requirements of the FHCDA.
- Establish the ability to name a proxy on a driver’s license, similar to organ donation.
- Consider the removal of language on the form indicating “from what you have said and what you have written” in regard to guiding an agent’s decision regarding nutrition and hydration in form instructions as this is not in the enacting legislation.
- Consider changing language to address importance of passage of time in assessing potential for recovery when considering treatment options, especially for “permanent coma.”
 - Consider substituting: “Whether you would want life support initiated, continued, or removed, if you are determined to be unresponsive and unlikely to regain consciousness after an appropriate length of time.”
- Enact a regulation that provides that all prior enacted proxies are considered null and void upon the completion of a new form; i.e., the most recently enacted proxy controls.
- Provide clear instructions regarding who cannot be a witness (i.e., the agent or alternative).

Actions Already Taken

In addition to the above recommendations, the Department received comments through the RFI on issues for which there were already State actions underway. The following are comments received that the State has already addressed.

- Modifying the MOLST to include Nurse Practitioners as a signee.