30 September 2013

Ms. Michelle L. Consolazio
Mr. Michael Lipinski
HIT Policy Committee's Certification and Adoption Workgroup
Office of the National Coordinator
Patriots Plaza III
355 E Street, SW
Washington, DC 20201

RE: Advance Directive Virtual Hearing, Panel 1: Legal Perspective Testimony

Dear Ms. Consolazio and Mr. Lipinski,

This written testimony is submitted in conjunction with the Virtual Advance Directive Hearing, Panel 1: Legal Perspective scheduled for September 23, 2013 in which I was unable to participate due to a client emergency. The following responses are based on my experience in serving as Corporate Counsel for MaineHealth, the largest integrated delivery system north of Boston, MA as well as participation in various state and national workgroups relating to advance directives including the development of end-of-life planning resources for healthcare consumers and the broader healthcare community as part of the American Health Lawyers Association's Public Interest mission.

The following are my responses to the questions that you posed:

1. What has been the experience thus far with the implementation of advance directives?

The State of Maine became active in implementing advance directives in the early 1990's and enacted the Uniform Health-Care Decisions Act.[1] The experience overall has been very positive to date. Maine's statewide consensus advance directive form (see attached) continues to be widely supported and utilized by healthcare providers and patients. Going forward, it would be useful for both healthcare providers and patients if advance directives were accessible through either the statewide health information exchange ("HIE") or a national registry. Additionally, advance directives should be integrated with the increasingly popular, but often misunderstood, Physician's Orders for Life Sustaining Treatment ("POLST") form. A POLST form is a set of medical orders based on a patient's preferences for care (*e.g.*, cardiopulmonary resuscitation; level of medical intervention including hospitalization, antibiotic therapy, and artificial hydration and nutrition) and is signed by the patient's healthcare provider; these orders follow a patient across care transitions and are applicable in all care settings. By integration, I mean the resolution of any conflicts between an advance directive and POLST form to ensure that the

[1] *See* 18-A Me. Rev. Stat. Ann. §5-801 *et. seq*.

values and care preferences expressed by the patient on both documents are consistent. Combining an advance directive with a POLST form into a single document would facilitate consistency with a patient's expressed wishes and simplify the updating process to ensure that a patient's stated preferences are current. If a patient declines to complete a POLST form with a physician, then this fact should be noted on the advance directive. Completing a POLST form without an advance directive should be discouraged.

The Maine Hospice Council has provided leadership for the coalition working to advance Maine's POLST initiative since adoption of a standardized state form in April 2009. Partnering with MaineHealth and the Maine Health Care Association, the Maine Hospice Council has supported training of "conversationalists" skilled in facilitating discussions of goals of care and determining preferences for treatment options. The Maine POLST Coalition is supporting development of policies and procedures for healthcare facilities, a patient/family brochure and an online educational curriculum for Maine's EMS providers that will complement extensive ongoing efforts to train physicians, nurses, social workers and chaplains throughout the State in the POLST model.

Maine also has a statute authorizing an advance directive for mental health treatment which allows a patient to make his choices known regarding mental health treatment in the event that the individual develops a mental illness which makes him unable to make decisions.[2] Even if an advance directive for mental health treatment is appropriate for a particular patient, many patients opt not to execute one due to a perceived stigma associated with psychiatric diagnoses. Additionally, mental health information is subject to heightened levels of statutory protection which makes the sharing of a mental health directive among healthcare providers more challenging.

2. As part of advance care planning, what information should be included in or with a patient's advance directive? A POLST/POST/MOSLT form, care planning notes, other?

From a hospital's or healthcare facility's perspective, it is desirable to include the following advance care planning information in a patient's medical record: (i) advance care medical notes by the physician that reflect a discussion with the patient regarding goals of care and treatment preferences including related discussions about quality of life; (ii) a copy of the patient's advance directive; (iii) a copy of a POLST form; and (iv) identification of the patient's legally authorized surrogate(s) to make health decisions and contact information for such surrogate(s).

3. In consideration of the previous question, how could the meaningful use measure for advance directives be improved (*Record whether a patient 65 years old or older has an advance directive*)? Additionally, do any legal implications arise from removing or changing the age threshold?

The Committee may wish to consider changing the age threshold of the meaningful use measure from 65 years old or older to all adults aged 18 and older. Anyone may face a sudden and unexpected acute illness or injury with the risk of becoming incapacitated and unable to make

[2] *See* 34-B Me. Rev. Stat. Ann. §11001.

medical decisions or be diagnosed with an advanced and eventually fatal illness such as cancer. According to the Centers for Disease Control and Prevention, most deaths today occur after a period of chronic, progressive illness.[3] By specifying age 65, the meaningful use measure arguably discourages healthcare providers from discussing advance directives with younger patients. Moreover, the age 65 threshold is contrary to the Medicare CoP: "§482.13(b)(3) which states, "The patient has the right to formulate advance directives and to have hospital staff and practitioners who provide care in the hospital comply with these directives…" Consequently, all adults age 18 and older should be encouraged to: (i) engage in advance care planning discussions with family, loved ones and his primary care physician; (ii) identify a healthcare surrogate(s); and (iii) complete an advanced directive.

4. What concerns, if any, does an electronic environment (use of EHRs and HIE) introduce for advance directives (*e.g.*, a transition of care)?

In certain EHR environments, it is not possible to program the format of a POLST Form into the EHR. Although a POLST Form can be scanned into an EHR, a scanned document would not necessarily translate into identical physician orders.

It would be helpful to have a specific tab in the EHR that contains a patient's advance directive, POLST/MOLST document and any other documents relating to the development and goals of the patient's advance care plan including documentation of any relevant conversations with healthcare providers. Such information should be easily accessible and not buried in what may be a voluminous medical record, particularly if the patient has one or more chronic health conditions.

HIE provides an opportunity for all healthcare providers to have access to a patient's most recent health information including an advance directive. Healthcare providers, however, need to be certain that the HIE has a reliable process in place to ensure that only the most recent advance directive is available and that patients can be correctly identified. The inability to access a patient's most current advance directive could lead to unintended consequences. Multiple advance directives and/or POLST forms increases the risk of outdated advance planning information being carried forward across transitions of care.

Several states including Virginia, Idaho, Montana and West Virginia have created online advance directive registries with the intent of connecting them to statewide HIEs. Other states are partnering with organizations such as the U.S. Living Will Registry[4] to file and store advance directives. One advantage of connecting such an advance directive registry with a statewide HIE is that healthcare providers would be able to view advance directives without having to contact a relative or surrogate which would be beneficial when a patient is incapacitated and relatives or a surrogate are unavailable or unknown. While it is crucial for family members to understand the content of an advance directive if available, such individuals may not have the patient's

[3] Centers for Disease Control and Prevention, "Chronic Diseases are the Leading Causes of Death and Disability in the U.S" *available online* at http://www.cdc.gov/chronicdisease/overview/index.htm.

[4] *See* U.S. Living Will Registry *available online at* www.uslivingwillregistry.com.

password to a national registry. In such an instance, healthcare providers being able to access advance directive through an HIE could be very helpful. Healthcare providers would find it particularly useful to know whether or not a patient has an advance directive and POLST form and that such documents were available in a single defined location, such location being specified within the EHR.

- **What type of privacy and security issues exist for advance directives?**

  Advance directives have the same privacy and security issues as with any PHI in the HIE. Additionally, a patient should have access to a portal to be able to view/edit/file his advance directive in the HIE or online advance directive registry. Finally, there will need to be appropriate processes in place to ensure that any updates to an advance directive were executed by the patient who had the decision-making capacity to amend an advance directive and that any such amendment was made of his own free will and not influenced by a spouse or other relative(s) who had ulterior motives.

- **Are there any requirements for the length of time an advance directive must be maintained in the information system?**

  Under Maine law, advance directives do not have an expiration date. Accordingly, an advance directive should remain in a healthcare provider's clinical information system as long as the rest of the patient's PHI. As noted above, it is important to ensure that a healthcare provider has the patient's most current advance directive.

5. **What legal implications arise with a transition of care (e.g., the use of an advance directive or POLST by another provider, across state lines, etc.)?**

   Transition of care is problematic with respect to the POLST form. Although a POLST form is characterized as a physician order, only physicians credentialed and privileged by a particular hospital can write orders for a patient admitted to that facility or treated in the facility's emergency department. Long term care facilities typically do not have such limitations which is the reason that a POLST form is so valuable in that setting. This issue is one of the reasons that I believe an advance directive and POLST form should be one integrated document. Additionally, transitions of care across state lines raise the issue of variable state requirements with respect to the execution of such documents (*e.g.*, whether one or two witnesses are required; whether a notary is required).

6. **Is there an approach that would allow a single advance directive to meet all medical needs similar to how a single will functions?**

   Wills are drafted to be implemented after an individual's death. In contrast, an advance directive is implemented during an individual's lifetime and the content may change over time depending upon a patient's evolving medical condition. As such, an advance directive and POLST form should be the subject of periodic discussions with the patient and his surrogate(s) to ensure that there is no misunderstanding as to the patient's wishes that could result in undesired care or premature death. For example, an elderly individual with a

DNR/no life support advance directive may present to a hospital for minor surgery or an acute minor issue that could be quickly resolved in the emergency department. If a provider blindly followed the advance directive without talking to the elderly patient first, then such patient could die during that hospital visit contrary to his own true wishes. This example illustrates that there can be variability in the interpretation of advance care planning documents which could lead to outcomes that the patient did not anticipate. Gundersen Health System's *Respecting Choices*, an internationally recognized, evidence-based advance care planning program, notes that "[o]ne of the greatest misconceptions about advance care planning is that it is a static process — a one-time event. Attempting to plan for all possibilities in a single document or at a single point in time is both impossible and unnecessary."[5]

7. Are there legal concerns regarding when the advance directive was executed and last updated?

Since Maine and many other jurisdictions do not place an expiration date on advance directives, it is recommended that physicians periodically engage in advance care planning discussions on an annual basis during wellness visits or when there is a significant change in the patient's condition. Since a POLST form provides a set of medical orders addressing the current status of patients with advanced care, such orders should be initiated and reviewed as a patient's condition changes closer to the time of death.

8. What legal initiatives have been implemented at the state level?

- **Can you provide insight into the status of advance directives/POLST/POST/MOST at the state level (*i.e.*, any legal or legislative requirements)?**

  The State of Maine has a statute which imposes certain obligations on healthcare providers with respect to advance health-care directives.[6]

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[5] *See* Gundersen Health System Respecting Choices: Advance Care Planning *available online at* http://www.gundersenhealth.org/respecting-choices.

[6] 18-A Me. Rev. Stat. Ann. §5-807 provides in pertinent part:

(a). Before implementing a health-care decision made for a patient, a supervising health-care provider, if possible, shall promptly communicate to the patient the decision made and the identity of the person making the decision.

(b). A supervising health-care provider who knows of the existence of an advance health-care directive, a revocation of an advance health-care directive or a designation or disqualification of a surrogate shall promptly record its existence in the patient's health-care record and, if it is in writing, shall request a copy and if one is furnished shall arrange for its maintenance in the health-care record.

(c). A primary physician who makes or is informed of a determination that a patient lacks or has recovered capacity or that another condition exists that affects an individual instruction or the authority of an agent, guardian, or surrogate or the validity of an advance health-care directive shall promptly record the determination in the patient's health-care record and communicate the determination to the patient, if possible, and to any person then authorized to make health-care decisions for the patient.

(d). Except as provided in subsections (e) and (f), a health-care provider or institution providing care to a patient shall:

Additionally, there is a coalition of stakeholders interested in adding a POLST requirement to the existing advance health-care directive statute, but have yet to introduce a bill.

- **Do you have any concerns or opinion about these initiatives?**

  As noted in my response to Question #1 above, an advance directive and POLST form should be integrated in order to resolve any conflicts between the two documents to ensure that the values and care preferences expressed by the patient are consistent.

- **Is there a "floor" for compliance, and have there been sufficient analyses to demonstrate where states currently do not meet or currently exceed the "floor" established?**

  Given the Medicare CoP: "§482.13(b)(3) relating to advance directives, it is difficult to imagine any state in which hospitals do not use, encourage or assist with advance directives. The use of advance directives obviates the need for a patient's next of kin, spouse or other responsible party to obtain a guardianship or court order for treatment in the absence of a patient demonstrating appropriate decision-making capacity.

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(1). Comply with an individual instruction of the patient and with a reasonable interpretation of that instruction made by a person then authorized to make health-care decisions for the patient; and
(2). Comply with a health-care decision for the patient made by a person then authorized to make health-care decisions for the patient to the same extent as if the decision had been made by the patient while having capacity.

(e). A health-care provider may decline to comply with an individual instruction or health-care decision if the instruction or decision appears not to be in compliance with this Act or for reasons of conscience. A health-care institution may decline to comply with an individual instruction or health-care decision if the instruction or decision appears not to be in compliance with this Act or if the instruction or decision is contrary to a policy of the institution that is expressly based on reasons of conscience and if the policy was timely communicated to the patient or to a person then authorized to make health-care decisions for the patient.

(f). A health-care provider or institution may decline to comply with an individual instruction or health-care decision that requires medically ineffective health care or health care contrary to generally accepted health-care standards applicable to the health-care provider or institution.

(g). A health-care provider or institution that declines to comply with an individual instruction or health-care decision shall:
(1). Promptly so inform the patient, if possible, and any person then authorized to make health-care decisions for the patient;
(2). Provide continuing care to the patient until a transfer can be effected or a court of competent jurisdiction issues a final order regarding the decision; and
(3). Unless the patient or person then authorized to make health-care decisions for the patient refuses assistance, immediately make all reasonable efforts to assist in the transfer of the patient to another health-care provider or institution that is willing to comply with the instruction or decision.

(h). A health-care provider or institution may not require or prohibit the execution or revocation of an advance health-care directive as a condition for providing health care.

Finally, MaineHealth's patient population includes a significant number of patients from other cultures and translating the concepts of advance directives and POLST forms into other languages poses a number of challenges.

Thank you for allowing me to share Maine's experience with advance care planning with the HIT Policy Committee's Certification and Adoption Workgroup.

Sincerely,

Elisabeth Belmont
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Enclosures