# HIT Policy Committee Certification and Adoption Workgroup Care Planning Virtual Hearing September 23, 2013 Summary DRAFT

## KEY TOPICS

### Call to Order and Roll Call

Michelle Consolazio, ONC, opened the hearing with the Federal Advisory Committee (FACA) announcement. She referred to the opportunity for public comment and said that a transcript of the hearing will be posted on the ONC website. She reminded members and panelists to identify themselves for the transcript before speaking.

### Opening Remarks, Meeting Objectives and Expected Outcomes

Consumer Technology Workgroup Chairperson Leslie Kellie Hall talked about the importance of placing the patient front and center. Certification and Adoption Workgroup Co-chairpersons Marc Probst and Larry Wolf were not present to describe the objectives and expected outcomes.

### Presentation from Senator Mark R. Warner’s Office

Maureen Henry described the Care Planning Act of 2013 S. 1439 and a similar bill introduced in the House. Both bills have the objective that persons with serious illnesses receive the care aligned with their goals, values and preferences. The bills apply to Medicaid and Medicare services. Care planning is an interdisciplinary process, requiring multiple encounters to: explain the person’s illness; explore the individual’s goals of care; and evaluate the services available. This is a subjective process and documentation would rely on the provider’s judgment. She asked that members think about how Stage 3 can advance care planning. After presenting many details of the proposed legislation, she noted that it would prohibit HHS from imposing penalties when providers’ treatments are as directed by their patients. Both bills require that EMRs capture advance directives (AD) and other documents for care planning.

Wolf joined the meeting and emphasized his agreement with the goals described by Henry.

### Legal Perspective

**Charlie Sabatino, American Bar Association Commission on Law and Aging**, said that he had submitted his responses to the workgroup’s questions. Only about one third of adults have some type of directive, such as AD or advanced care plan (ACP). Prevalence increases with age; 51 percent of those over age 60 have a directive. He described several problems with the effectiveness of ADs. They are often too vague, not timely, or not placed in the record. Federal law does not required putting directives in the record. Another problem is that the designated proxy may not be well equipped to act on the patient’s directive. Because of the limitations of AD, the ACP has developed. He stated that everyone should have a care plan; the question is how to document it. Medical notes are important, such as Physician Orders for Life Sustaining Treatment (POLST) for advanced illnesses. These are portable orders across providers, settings, facilities, and levels of care. Everyone needs a care plan, but as illness advances, the plan becomes more important. Age is a poor proxy for determining the need for a plan.

The POLST works well as a document that follows the patient. Most states recognize ADs made in other states, but details may not be followed because interpretations differ. Clinicians do not report problems with the lack of recognition of ADs across states. Since ADs do not contain termination dates, they can become stale and lose relevancy. The quality of communication among clinician, patient, and the surrogate is the most important factor in directives.

#### Q&A

None

### Panel 1: State Perspective

Wolf emphasized the five-minute limit on presentations.

**Patricia Bomba, Excellus BlueCross BlueShield**, described the New York (NY) eMOLST, which is aligned with NQF preferred practices. It documents the designated agent (surrogate decision maker) in a Health Care Proxy for every patient in primary, acute and long-term, palliative, and hospice care, and the patient or surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change. It converts the patient treatment goals into medical orders and ensures that the information is transferable and applicable across care settings. The Medical Orders for Life-Sustaining Treatment (MOLST) is an endorsed POLST Paradigm Program that makes ADs and surrogacy designations available across care settings, through collaboration with the RHIO and eMOLST. eMOLST was adapted November 2003 from the Oregon POLST and combines DNR, DNI, and other orders. It incorporates NY state law and is consistent with PHL§2977(3). Its use will bring about a permanent change in EMS scope of practice. There is a secure web-based application that allows enrolled users to complete the eMOLST form and document the discussion in the correct MOLST Chart Documentation Form (CDF) and/or mandated OPWDD Checklist for Persons with Developmental Disabilities who lack capacity. The CDFs document goals for care, discussion, and ethical and legal requirements. Forms are created as pdf documents that can be printed for the patient and a paper-based medical record, are stored in an EMR via a link to eMOLST, and become part of the state eMOLST registry. There is continuous access to the registry database for emergencies. Time did not permit presentation of the 8-Step MOLST Protocol and the seven checklists, which are available in all settings.

**Christie North, HealthInsights**, talked about the system in Utah. He emphasized that ADs are not sufficient. The proxy role can be confusing. It is difficult for families to complete the required documentation. A paper document can easily be lost or misplaced. In Utah, there is still no standard form. The AD is maintained by the patient. However, Utah is one of 15 states with an authorized POLST program. Considerable education is required; people still confuse it with cutting off care. Advocates in Utah are developing an electronic system similar to the one in NY described by Bomba. Time was called.

**Alvin Moss, West Virginia (WV) Health Information Network (HIN),** described the statewide system torespect patients’ wishes connected through WVHIN and the registry. The system includes EMS, every office and clinic, nursing home, hospital, inpatient hospice, assisted living facility, and personal care home. Potentially every apartment and private residence can be incorporated. Summaries of ADs and POLSTs are available online at any time through WVHIN. Patients’ wishes are respected across care settings. An annual mailing ensures accuracy of the registry. It is password-protected and HIPAA compliant. As of August 31, 2013, 20,559 forms had been received; most frequent (36 percent) were combined living wills and medical powers of attorney, followed by DNR cards (32 percent). ADs fail for many reasons. Most people do not complete them. They are often not readily available when needed. Even if completed, providers may not be aware of them. AD language is often too vague to be applicable to particular clinical circumstances. They are often invoked too late in the dying process. There is no system to ensure that patients’ wishes in ADs are discussed with families and providers in advance. At times ADs are overridden by providers and families. Moss described his research findings that POLSTs are more beneficial than ADs. The WV registry uses POLST to ensure consistency between patients’ wishes and the treatment received. He emphasized that implementation of an effective statewide system to respect patients’ wishes requires communication and coordination across health care settings and with the e-Directive Registry through WVHIN.

**Brian Yeaman, Oklahoma Health Information Exchange**, said that the durable power of attorney (POA) is a complex process that requires an attorney. The POA is frequently the agent that needs to deliver an AD at the time of need to the health care providers and too often the POA has not been assigned. According to him, a preferable option is to promote the appointment of a health care proxy. It is a free form off of the internet and requires only two witnesses and no notary. It allows the patient to be empowered and avoid the costs sometimes associated with creating the durable power of attorney. The health care proxy can be available in the short term. The meaningful use objective of whether or not an AD exists is not enough. The recognition of a health care proxy and her contact information is a key factor. Beyond that, an AD registry controlled by patients with an authentication layer to upload their health care proxy forms and their AD that could be shared with providers in a time of need would be a significant upgrade. Tying these into the HIE and EHR during the current state of health care technology still leaves too many gaps across providers in multiple states, within states, and even within some regions. In the near term he recommended a structured data field to capture proxy or MPOA in the C-CDA.

#### Q&A

The eMOLST eliminates incompatible medical orders. Appropriate signatures are required. As yet, there are no data on access. Staff is working to get forms into the system. EMS will be brought in later. In WV, access is voluntary. Ninety-nine percent of patients agree to have their forms submitted to the registry when it is explained to them. About 50 percent of WV residents say that they have ADs. About 50 providers are members of the information system. WV requires a patient signature on the POLST. In NY, forms are signed in the presence of two witnesses. Patients cannot sign the electronic forms so the two witnesses are used. Physicians are credentialed to have access to the system.

Paul Tang asked about a need for a national system and registry. Bomba replied that NY providers could not wait for a national system. State law mandates that a patient entering a nursing home be asked about resuscitation. There could be a national registry even though state requirements and processes differ. Moss said that national legislation to establish reciprocity across states would be helpful. Yeaman observed that although a national registry would be good, HIEs can serve a similar purpose. Getting the information is the first step. Sometimes proxies are confused with next of kin. If the patient can control access, national legislation may not be needed. Bomba pointed out the eMOLST is not a substitute for a proxy or MPOA.

Christine Bechtel inquired about creating capacity in EHRs to query to access ADs, ACPs, and POLST. Moss confirmed that it could be done in WV using the master patient registry.

Tang wondered about objections or push backs. Moss indicated that since participation in the registry is voluntary, there have been no objections in WV. Bomba responded that getting agreement on the ACP concept and POLST was important. Since nursing homes do not have EHRs, the existence of the registry is very important to them. Moss reported that to be declared a mature program, more than 50 percent of providers must participate. WV has experienced an increase in participation. In Utah, any push back is due to misunderstandings. There is high acceptance in nursing homes because they can document via the internet if they do not have EHRs. Emergency responders have access.

Wolf summarized. Panelists agree on the value of registries. There are good state examples. A national registry would be valuable. However, more information on the use of registries would be helpful. Information on what the various documents should include was provided. There was not much discussion of proxies and the need to track them. Bomba interjected that the NY system requires periodic reviews as well as review when the patient crosses settings or when decisions-makers change their minds.

Clem McDonald asked about the effect of registries on behavior. According to Moss, his research showed consistency between the expressed wishes and the treatment received in nursing homes in 94 percent of cases. Bomba talked again about the importance of education. Additionally, enhanced reimbursements for time used for eMOLST as well as readmission reduction incentives are important in acceptance. In WV, EMS personnel are taught to ask for a POLST before transmitting a patient to the ED.

Charlene Underwood referred to market forces: Are providers asking for this capability in EHRs and how does it work? Moss responded that although WV hospitals have different systems, all have been brought into the network. Bomba noted that it would be wonderful to have a platform across systems. To go beyond the link to information to integration has not been possible in NY due to lack of funds. She recommended that providers be given stage 3 credit for the function.

### Panel 2: Implementers – Hospitals and Providers

**Carol Wilson, Riverside Health System**, talked about the need to better understand the purpose of ADs, when they are to be followed, and when the living will portion is to be followed. Education of all actors is fundamental. Time for planning and the work processes that allow time for discussion are essential. Reliable communication across settings is facilitated by an AD and POLST Repository. She described her experience with compliance: ask for the AD at admission; conduct chart audits for deceased inpatients; and recognize that some staff “check the box” if they asked the question. She said that there was often no correlation of the care to the ADs in the record. Those persons assisting the patients are not always educated for the role. Patients must be informed of their health status and medical conditions. The care planning process should continue in long term care. She went on to list challenges of incorporating the capture of ADs in the workflow:

* Relying on patients and families to provide documents
* After hospital registration, managing paper is disruptive to workflow
* Limited availability of scanners
* Nursing homes do not typically send ADs to hospitals
* ADs may not be seen as relevant

Given these limitations, PO(L)ST promise a better system because the orders are in the EHR. They can be transcribed into in-house orders. They are much more likely to change than an AD. They accompany the patient. She agreed with the other presenters on the advantages of a registry.

**B. Lachlan Forrow, Beth Israel Deaconess Medical Center**, pointed out that regardless of political differences in political and religious views, everyone agrees that people should be taken care of in the way they prefer. Two fields should be required in the record in the case of serious illness: patient’s proxy and goals of care. The latter is much more complicated than DNR. The absence of this information for certain populations is malpractice. But there is not agreement on the definition of that population. Although Massachusetts has a law on informing patients about palliative care, regulations and funding have not been provided.

**Jeff Beane, Geriatrician**, observed that in managing transitions, the patient’s narrative often gets lost. The vision is for the ACP to be wired into the care process so that communication and documentation drive the care given by providers. The challenge is to keep the person at the center. Documentation should be searchable and retrievable. The providers can then identify those patients who have not indicated their preferences.

**Ferdinando L. Mirarchi, University of Pittsburgh Medical Center**, referred to several studies that indicate interpretation of DNR and POLST is a patient safety concern. Both over- and under-resuscitation are frequent. He said that 80 percent of living wills are misinterpreted in some way, which results in medical errors. Education in the clinical setting is required to reduce confusion. He talked about the need to pause prior to both writing and acting on orders. These pauses constitute safeguards. Accuracy and confirmation of identity is generally not checked at the point of input into a registry.

**Bernard Hammes, Respecting Choices and Humanities**, emphasized that documenting and communicating a patient’s preferences and goals regarding future medical care are essential functions of an EMR. Documenting and communicating a patient’s future treatment preferences and goals is as important as documenting and communicating the patient’s problem list, medication list, and the list of allergies. It becomes a medical error when clinicians fail to do the following:

* Ask patients, especially those who are at risk of major medical complications, to talk about their preferences and goals
* Document known preferences and goals
* Transmit or communicate preferences or goals to the next provider
* Incorporate these documented preferences and goals into critical medical decisions

A key element to ACP success is a well-designed, organized medical record that allows health professionals to document and communicate a patient’s care plan through time and across settings. He delineated essential ACP tasks of the EMR: easy navigation to ACP information available in all care settings; alerts to health professionals about the existence of any type of care plan, the need to review or update the plan, and information on loss of capacity and the need for a legally appointed surrogate to make decisions for the patient; and upload of ACP into any existing RHIO so that it is available to others when needed.

#### Q&A

McDonald wondered why, in view of the 80 percent inconsistencies in preferences and care received, the process has not been simplified. Mirarchi referred to a long-time confusion about acting on DNRs. He repeated his recommendation on safeguards—pauses, explaining that a checklist is used to standardize the pause process when an order is completed and when it is retrieved. Hammes disagreed with Mirarchi about the frequency of errors in following patients’ preferences. He reported that in his organization, in 96 percent of deaths accompanied by an ACP, the orders were followed correctly. Another panelist said that if they were not correctly followed, there would be evidence in law suits, complaints, and state examiners’ reports. Mirarchi disagreed, saying that many inconsistencies never come to light. Another panelist said that the greatest problem is the lack, not the quality, of information. Someone observed that end of life preferences should not be held to higher standards than other aspects of medical practice. Literature was cited.

Liz Johnson talked about the storage of data. Systems vary in their capacity. Working with vendors to capture information is a necessity. Mirarchi repeated his position that check lists are necessary.

Underwood referred to consumable data: What about goals and preferences in free text or codes? Wilson said that he had attempted to document patients’ daily goals. He learned that the patient’s goals are often very different from the clinician’s goals for the patient. Someone talked about a dashboard and a lack of consensus among workers, saying that rather than waiting for agreement on standards, goals can be captured in narrative notes. Beane said that POLST is a binary document and easily standardized. Standardizing the process would be helpful. Another panelist agreed, saying that in his organization standardizing the process came first. Having ongoing clinician’s notes helps ED staff to assess and communicate with patient and proxy.

### Panel 3: Implementers

**Paul Malley, Aging with Dignity**, described the Five Wishes, which is written in everyday language, intended to promote peace of mind, helps avoid guessing and guilt, and is a discussion tool for family and physician. It includes designation of health care agent and preferences regarding life sustaining treatment, comfort, dignity, relationships, and spirituality. The national version was introduced in 1998 and it meets the legal requirements in 42 states. To date, 20 million copies have been distributed in 27 languages. Five Wishes is now available on-line. Users can answer questions on-screen and print their completed copy, ready for signature, or they can print a Five Wishes PDF in any of the 27 available languages and complete the document by hand. Video tutorials are provided in each section. However, the document is not easily transferred to an EHR because state statutes require signature of the principal and two witnesses and/or notary. But its existence can be documented in EHRs. He noted the lack of consistency in EHR methods of AD documentation. According to Malley, the best practice is to document whether the patient has an AD and to include a copy of the full directive in the record (scanned image of a completed Five Wishes). He went on to talk about the challenges of ACP. Unlike other data stored in EHRs, advance care planning is not binary and easily defined by a check mark or data point. He emphasized that documentation of ACP in EHRs cannot be used to relieve clinicians of their responsibility to involve patients and caregivers in end-of-life decisions. He recommended that given the confusion between ADs and POLST, two distinct tracks for meaningful use measures should be considered.

**Jeff Zucker, MyDirectives**, said that the technology exists for patients to make their wishes known and for providers to access them at any time and place. He made several recommendations pertaining to meaningful use: change the template for the longitudinal record; tighten conformance in the C-CDA documents; make AD a core objective; adjust the age constraint downward; and confirm a minimum vocabulary for AD. He emphasized that the technology is available to support much more than the low bar currently set by meaningful use requirements. MyDirectives® was certified as a 2012 compliant EHR module and is used in 40 states and many countries.

**Doug Winesett, Epic**, described his employer’s product. The AD is created on paper and a staff member scans the paper into the electronic record. It is stored at the patient level and noted in the header so that it can be clicked to view. CareEverywhere can be used to indicate that the AD is available from any setting. Regarding POLST, he said that some providers collect the data as discrete elements within the EHRs. Then a legal document can be generated for the patient to sign and/or it can be transmitted to the Oregon state registry.

#### Q&A

Wolf asked how these efforts relate to state registries. Malley talked about positioning advocacy to support local and regional efforts. The delivery model should be as good as possible. The POLST can link the patient’s wishes with their care. But providers can use the orders inappropriately. Providers must involve patients and their agents in the final process of decision making. Winesett reported that in his experience 20 percent of forms completed on paper had some type of error, such as missing or incorrect information. By incorporating the documents into EHRs, they could be completed and corrected for submission to a registry.

Wolf observed that there is value in the online, structured document: Are we at a tipping point? Zucker observed that patients do not like paper forms. His company designed a system to allow updating and changes at any time. It can be used as an open ended document. The user can upload video messages. He advocated moving to a digital format. Winesett reported that most organizations are not capturing the documents as structured data. Some elements cannot be captured digitally at this time. But having immediate, easy access to changes is very important. He agreed that incorporating these documents into the EHR and putting a notice in the header was important, and is possible with the current state of technology. Malley said that the process cannot be completely digitalized at this time. The patient can be allowed to make the document in a choice of platforms. Then it must be available and accessible in the EHR.

In response to a question from McDonald, Malley explained the distinction between ADs and POLSTs. The latter are absolute and definitive with no trigger decision. ADs are if-then documents. POLSTs are for end-of-life care, when the patient knows the diagnosis and the patient and clinician have had a discussion. A clinician cannot do a POLST without a basis for the order. At the end of life, many of the variables are known. But exactly how they will play out is not known. Many people do not understand the distinction between ADs and POLSTs. This committee can help to educate the public, according to Malley. POLST is preferred by clinicians as it is consistent with the medical model. Zucker agreed, saying that there is no substitute for ACP, which can set the stage for POLST. He opined that everyone should have an emergency ACD.

### Panel 4: Patient Perspective

**Amy Berman, The John A. Hartford Foundation**, disclosed that she is terminally ill. She emphasized that anyone can and should have a health care proxy. Goals and preferences change over time. At the end of their lives, 75 percent of persons are not able to make decisions. POLST is designed for planning around known specifics. Most people will live with multiple conditions and will not know when the end of life is near. ACPs are recommended. HIT can support access to information, making it possible to move from a reactive to an active stance. Preferences can be embedded so as to be fundamental to decisions. Consumer facing portals are needed so that a patient can share her information with proxies. A consistent national approach is needed. A central repository accessible by emergency responders could be organized similar to poison control centers. Time was called.

**Mark Savage, National Partnership for Women and Families**, said that ADs are a critical and well-accepted way for people to identify the care they do and do not want when certain conditions or illnesses occur. Providers must have patients’ preferences in order to act according to their patients’ choices. They are essential for patient- and family-centered care. Care plans are a critical way that people can identify their goals and preferences across a range of life situations. The care planning process can identify and communicate goals, values, and preferences for all care, including ADs. ACPs help to shift from episode or illness-based planning to all-encompassing health and wellness planning. ACPs must incorporate cultural and linguistic preferences, and literacy of diverse patient populations and caregiver communities. He referred to his organization’s health and care planning principles draft 2.0. His organization has submitted specific recommendations on ADs and care plans for Stage 3. He emphasized that the current draft proposals are not sufficient.

**Karen Wyatt, Physician, Author**, related her experience with her terminally ill mother, who used the hard copy Five Wishes. But more important than the form itself, which her physician and hospital had, was having the conversation with her adult children and making them aware of her wishes. The form was sufficiently simple that the mother could fill it out and be assertive with her doctor. Subsequently, she revised her will. According to Wyatt, having a document in her mother’s hand writing has been helpful with the grief process. Both a digital and hand-written document should be required. Wyatt went on to say that having this documentation had helped with sibling conflict.

#### Q&A

Kelly Hall said that patient preferences are important in all aspects of care. Technology now makes it possible to document and share these preferences.

Hammes reported that at his institution a patient can select among methods, including writing her own entries on an AD form. He believes that the patient has a constitutional right to have her preferences respected even if that right is not strictly stated in accordance with legal requirements.

A panelist inquired about the next steps of the workgroup. Consolazio replied that the workgroup is scheduled to meet September 27 and will use the testimonies to draft a recommendation on ACP in Stage 3 to present to the HITPC. Pending action by the HITPC, the recommendation will be assigned to the Meaningful Use Workgroup for incorporation in its recommendations. Wolf added that the workgroup will report on a summary of the testimonies in order to educate the HITPC members. A panelist declared that it is unacceptable for a patient to have prepared and presented an AD that is not accessible in the electronic record.

Kelly Hall encouraged the panelists to listen to the workgroup meetings and to give public comment.

Wolf referred to the documentation of allergies and documentation of patient preferences analogy, saying that more than technology is required.

Bomba requested contact information on the panelists. Another panelist agreed. The meeting of the Certification and Adoption Workgroup will be open to the public, as are all FACA meetings.

### Public Comment

None

## SUMMARY OF ACTION ITEMS

None

## Meeting Materials

* Agenda
* Submitted written testimonies
* Questions
* Presentation slides
* Bios
* Letter from members of U.S. Congress