

**HIT Policy Committee  
Certification Adoption Workgroup  
Care Planning Hearing  
Transcript  
September 23, 2013**

**Attendance**

**Certification/Adoption Workgroup**

**The following members attended the meeting:**

- Larry Wolf
- John Deerr
- Joseph Heyman
- George Hripcsak
- Elizabeth Johnson
- Paul Tang
- Martin Rice

**The following members were absent:**

- Marc Probst
- Joan Ash
- Carl Dvorak
- Paul Egerman
- Stanley Huff
- Charles Kennedy
- Donald Rucker
- Latanya Sweeney
- Micky Tripathi

**Meaningful Use Workgroup**

**The following members attended the meeting:**

- Paul Tang
- George Hripcsak
- Christine Bechtel
- Arthur Davidson
- Leslie Kelly Hall
- Charlene Underwood
- Martin Rice

**The following members were absent:**

- David Bates
- Neil Calman
- Paul Egerman
- Marty Fattig
- David Lansky
- Deven McGraw
- J. Marc Overhage
- Latanya Sweeney
- Micahel Zaroukian
- Amy Zimmerman
- Tim Cromwell
- Joe Francis
- Greg Pace
- Robert Tagalicod

**Presentation**

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Good morning everyone. This is Michelle Consolazio with the Office of the National Coordinator. This is a meeting of the Certification/Adoption Workgroup. This is a hearing for Care Planning, a number of different workgroups though have been invited from across the FACAs. This is a public call and there will be time for public comment at the end of the call. As a reminder, please state your name before speaking as the meeting is being transcribed and recorded. I'll now take role for the Certification/Adoption Workgroup. Larry Wolf? I know Larry's here. Marc Probst? Carl Dvorak? Charles Kennedy? Donald Rucker? Liz Johnson?

**Elizabeth Johnson, MS, FHIMS, CPHIMS, RN-BC – Vice President, Applied Clinical Informatics – Tenet Healthcare Corporation**

Here.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

George Hripcsak?

**George Hripcsak, MD, MS, FACMI – Department of Biomedical Informatics – Columbia University**

Here.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Joan Ash? Joe Heyman?

**Joseph M. Heyman, MD – Whittier IPA**

Here.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Micky Tripathi? Paul Egerman? Paul Tang?

**Paul Tang, MD, MS – Vice President, Chief Innovation and Technology Officer – Palo Alto Medical Foundation**

Here.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

John Derr?

**John F. Derr, RPh – Health Information Technology Strategy Consultant – Golden Living, LLC**  
Here.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Stan Huff? Marty Rice?

**Martin Rice, MS, BSN – Deputy Director, Office of Health IT & Quality – Health Resources and Services Administration**

Here.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thanks Marty. So now I'll ask are there any Meaningful Use Workgroup members who have not already been called on the line.

**Christine Bechtel, MA – Vice President – National Partnership for Women & Families**

This is Christine Bechtel.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Leslie Kelly Hall.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

Charlene Underwood.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Sorry, could – I missed those two, could you restate?

**Ferdinando L. Mirarchi, DO – Medical Director – Emergency Department, UPMC Hamot**

Fred Mirarchi?

**Arthur Davidson, MD, MSPH – Director, Clinical Informatics – Denver Public Health**

Art Davidson.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Good morning Art. And are there any members from the Clinical Operations Workgroup on?

**Kim Nolen, PharmD – Medical Outcomes Specialist – Pfizer, Inc.**

Kim Nolen.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

And the Consumer Technology Workgroup? Is there anyone else on the line from a member of one of the FACA Workgroups that has not already been called for your workgroup?

**Mark Savage, JD – Director, Health Information & Technology Policy & Programs – National Partnership for Women & Families**

This is Mark Savage with Consumer Empowerment.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Okay, and are there any ONC staff members on the line?

**Michael Lipinski, JD – Policy Analyst – Office of the National Coordinator**

Mike Lipinski.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Okay. As a reminder, if you aren't speaking, if you could please mute your line. And I will now turn it over to Larry Wolf and Leslie Kelly Hall.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Did we lose Larry?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

I'm sorry?

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Did we lose Larry?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

We might have lost Larry, because he didn't announce himself during roll.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Okay, so I will – I'll start then and I just want to thank everyone for participating today. This is a subject that's been brought up many times during a variety of different workgroups, and it's going to be a quite broad perspective that we hear today. But I'd like to center that in really all about the patient and the patient wishes for care planning or end of life care or sustaining life care, patient wishes integrated in the care is very important. And I'll just tell one story, because it's quite recent.

My aunt, last week, was admitted into a hospital with advanced directives in place. She has Stage 4 metastasized cancer in her brain, her abdomen and her lung, not expected to live and her family was getting on airplanes to gather to be by her side. Her wishes included not dying in a hospital and having no further intervention. But when she presented to the hospital, her oncologist was on vacation and the information was not readily available so an order was placed to do a biopsy on a mass in her abdomen and although the family said there should be no interventions, they were assured that this was just a small and minor procedure. However, once my aunt was admitted, they found something; they removed it and actually removed a portion of her colon.

As the family arrived, she tried to remove all of her placements of lines in order to leave, she wanted to leave the hospital so badly and die at home. Unfortunately on Thursday my aunt passed away without her family coming. So this is something that's dear to all of us, I know there are stories that each of us has to say. But I think the importance is that all of us have the most at stake when we are a patient, and our – are the stakeholders that should be the best represented. So I thank you all for your commitment and your participation in the meeting today and for letting me tell my story. And I'll turn it over to Larry if he's joined. All right Michelle, with that, I think when Larry joins us, he'll be happy to provide comments. I know he's also quite committed to coordinating care along the continuum, has spent the last few years working on, and demonstrating the importance in long-term post-acute care and the coordination of care throughout the environment, so I'll have him make comments when he comes. And with that, I'm very honored to invite Maureen Henry to speak, who represents Senator Warner's office, who together with other Senators has presented to – legislation forward for discussion on end of life. And so Maureen, I'm going to turn it over to you and invite you to tell the group what you have to say. Thank you.

**Maureen Henry, JD – Health and Aging Policy Fellow – Office of Senator Mark Warner**

Thank you. I'm Maureen Henry; I'm a Health and Aging Policy Fellow, serving in Senator Mark Warner's office this year as part of his healthcare team. Thank you to the Certification/Adoption Workgroup, to Michelle and especially to Leslie for involving us in this briefing. I'm here to talk about the Care Planning Act of 2013. This is a bipartisan bill that was introduced in the Senate by Senator Warner and Senator Johnny Isakson of Georgia. It's also important to acknowledge Congressman Earl Blumenauer's Personalize Your Care Act of 2013, which was introduced in the House this session of Congress, with Congressman Phil Roe, a physician from Tennessee and a Republican, as an original co-sponsor. At last count, I believe there are five Republicans in addition to the 13 or so Democrats co-sponsoring Congressman Blumenauer's Bill.

The two bills represent somewhat different attempts to achieve the same objective. The objective is to assure that people with serious illness receive the care that's aligned with their goals, values and preferences. I'm very saddened by Leslie's story, but I think it offers an example of where the – where her family member did not receive care that was aligned with her goals, values and preferences. The Care Planning Act has three primary elements, the benefit, system change and education. So let's start by talking about Planning Services.

The first element is a Medicare and Medicaid Benefit that we call Planning Services. We sometimes call this informed consent on steroids. Eligibility for the benefit is based on the presence of dementia at any stage, locally advanced or metastatic cancers, late stage organ failure or neurodegenerative disease or frailty. And we've defined frailty as a need for assistance in two or more activities of daily living. Planning Services is a goal-spaced, interdisciplinary team process and I want to emphasize that word process. The objective here is not to have a single brief encounter, but rather probably a multi-encounter process. It has four parts, explanation, exploration, evaluation and documentation.

One part is the explanation of the person's illness with an emphasis on the typical trajectory of the disease and how the illness is likely to affect the person's life. As many of you would know, often times people do not get that kind of information with – once their struck with serious illness. The second part is an exploration of the person's goals of care, how does he want to live his life given the realities of serious illness? Are there things she wants to achieve? How can providers measure treatment success? The third part is an evaluation of available treatments. The provider, the person and caregivers will evaluate burdens and benefits of a relevant range of treatments. The evaluation process must be based on the person's goals, values and preferences because there is no objective measurement of clinical outcomes at this stage in the disease process.

And I think that's a particularly important point in addressing the HIT side of the question, because I think too often we're quick to say, okay, well we'll find proxy measures that will substitute as an objective measure. But I think it's important to continually emphasize that this is inherently subjective and as we measure it and as we record it, that we need to accommodate the subjectivity. The last part of Planning Services is documentation. The Care Planning Act does not dictate the type of documentation, but instead it relies on judgment of providers to use systems that are effective in the locality where the plan will be implemented. We encourage this committee to seriously consider how meaningful use standards could support the care planning process, whether for a woman preparing to have a baby or for an elderly man facing serious illness. Ideally the system will be more than an electronic filing cabinet. The ideal system will have functionality that actively supports the care planning process.

We also encourage the committee to consider how meaningful use standards can be sufficiently flexible to allow providers to capture the range of documentation options that are available across the country. As we drafted the Care Planning Act, we were very cognizant of the risks of documentation. This Bill avoids the suggestion that the mere presence of an advanced directive can be viewed as a proxy measure for care planning quality. Instead, when we drafted the bill, our focus was on the presence of a goals-driven, achievable plan of care. To support this approach, the health records must have the capacity to capture goals, different treatment options can be measured against. Plans should be accessible by members of the care team, including the patient and authorized caregivers.

I'm going to move on now from the benefit design to system changes. The Care Planning Act modifies the Patient Self-Determination Act in a number of ways. We have very specific objectives in these changes. We want to re-focus the inquiry away from technical legal quandaries to two specific questions, what do we know about this person's goals, values and care preferences? And secondly, how do we deliver care that honors this person's goals, values and care preferences. In some cases the answer's going to be straightforward, in other cases it could be quite difficult. The changes to the Patient Self-Determination Act in our Bill require providers to consider the stated preferences of patients with decisional capacity. The Care Planning Act requires that for people who lack capacity, the provider should reconcile conflicts that are not otherwise reconciled under state law, by delivering care that's consistent with the person's goals, values and preferences, to the extent that they are known. To that end, the Bill prohibits HHS from seeking penalties against providers who make reasonable attempts to deliver care that's consistent with the patient's goals, values and preferences.

The Care Planning Act also requires that providers ask if individuals have current advanced directives or portable treatment orders and when they do; it would require them to ask for a copy and to put the copy in the medical record. If enacted into law, these provisions would have very direct impact on information technology requirements. The Care Planning Act also requires that health records must capture the content of care plans, advanced directives and transferable medical orders. In a similar vein, Congress in Blumenauer's Personalize Your Care Act requires the HHS Secretary to establish standards that allow the contents of advanced directives and portable treatment orders to be included in the EHR.

In a separate but related section of the Bill addressing conditions of participation, the Care Planning Act requires providers to document plans made during a facility stay in a manner that allows orders to be followed after transfer to the community or to another facility. This too will place demands on EHRs and other HIT systems. Both the Care Planning Act and the Personalize Your Care Act provide grounds to develop infrastructure to support care planning. The Care Planning Act would fund grants to organizations and localities to develop resources to support care planning, in addition to separate grants to develop a platform for resource dissemination. A third category of grants would fund the National Education Campaign about the resources.

In conclusion, the Care Planning Act and the Personalize Your Care Act represent serious bipartisan efforts to address the planning needs of Americans. The recommendations that come out of this committee in the final Stage 3 meaningful use regulations will have a direct impact on the kind of care delivered to people facing serious illness, whether or not one or both of these Bills are passed into law. I'm happy to discuss the Bill further on a one-on-one basis. We trust that your – will help to promote our central objective, assuring that the care people received is aligned with their goals, values and preferences. So thank you very much for inviting us to participate.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Thank you very much Maureen for that great overview and encouraging remarks and inviting of participation is really very much appreciated. Has Larry joined us?

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

Yes, I'm back on.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Oh great. So we passed over your opening comments Larry, would you like to add them?

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

Well I sort of jumped in the middle of this first presentation so I'll just quickly say that I'm really glad we were able to get this hearing together. As you can tell, it's both a timely and meaningful topic, both personally to a lot of individuals and I think also to really the intention of HITECH and meaningful use to really move us into an age where the technology supports better care and better care definitely includes the patient values and choices. Without that, we really don't have the full context of the care we're delivering, we're sort of in a – world and we really want to be in a person-centered world. So, I'm glad to have addressed my technical issues, hopefully they won't recur and looking forward to the hearing moving forward.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Great. Michelle, I think we have our first – well, Charlie – not a –

**Charlie Sabatino, JD – Director – American Bar Association Commission on Law and Aging**

Yes, can you hear me?

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Yes we can.

**Charlie Sabatino, JD – Director – American Bar Association Commission on Law and Aging**

Oh good. Okay. Well thank you for holding this hearing today. I'm Charlie Sabatino, I'm Director of the American Bar Associations Commission on Law and Aging, which is a research, education and advocacy program within the American Bar Association, and healthcare decision making is one area that we have a tract law and legislation for a couple of decades. So, I'm really pleased to be here. And we have also been very attuned to the development of the meaningful use standards and hopefully can assist in making them exactly that, more meaningful.

I submitted a statement in the format of answering a number of questions that were raised, and it's somewhat lengthy so I'm not going to be able to recap it all. So I'm going to jump around a bit to try to touch upon certain highlights and then if there are questions later, we can go into other aspects of it. But starting with advanced care planning as a concept that is key here, the most visible thing that people think of when they think of this whole issue are advanced directives, which has now been around under state law since the mid-1970s. And they are simply legally recognized documents that either appoint a healthcare agent or proxy or that provide instructions or guidance about medical decision-making, nominally related to life support and palliative care.

We know that only about a third of all adults have some form of advanced directive, either the healthcare power of attorney, which is the proxy directive or the living will, which is the instructional type of directive. But we also know that the percentage of people with advanced directives does increase with age. A study done not too long ago by AARP found that of people 60 and older, 51 percent had some form of advanced directive, but they – we don't really know the details of those advanced directives. There has been a long history of problems with advanced directive's effectiveness for a number of reasons. Very often they're – most often they are written in canned language which provides guidance that is often too vague to apply.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Sorry. If you aren't speaking if you could please mute your line.

**Charlie Sabatino, JD – Director – American Bar Association Commission on Law and Aging**

So the research tells us that they're often too vague to apply to specific decisions that often occur some years after the time the directive was made. Providers have been documented to often misperceive what an advanced directive implies without even reading the advanced directive. Too often advanced directives aren't in the record. It's really the individual's obligation to provide them to their medical providers and get them in the record. There really is no – even though there is an obligation under the federal law for providers of facilities to ask if you have an advanced directive and document whether you have one, there's nothing in current law at the federal level that requires you to actually put a copy of it in the record.

If it is in the record, we also know that it often isn't consulted, because they can be buried in the record, and those directives that appoint a healthcare proxy, which is a vitally important task to accomplish with advanced directives, often don't function as well because the proxy was not well-equipped with enough discussion with the individual making the directive to really know what they would have wanted anyway. And even if they do, they find dealing with the healthcare system to be a daunting undertaking. So there are a lot of problems with advanced directives and over the last couple of decades, I think that is one of the reasons that the concept of advanced care planning has come to, I think, fruition because it recognizes that advanced directives are only one tool for developing an individual's care plan.

Everybody should have a care plan, whether you're going in for minor knee surgery or whether you're being treated for advanced cancer. The question is how is that care plan best documented. Of course if the individual has a directive that provides guidance, provides certainly the appointment of a proxy that really does need to be documented. But if that's all we're documenting, then that is going to be insufficient because, as I said, advanced directives don't really amount to a care plan, they amount to some evidence of what the individual would like. The care plan can be not only the advanced directive, it can be medical notes – in the medical record, and those are probably the most timely and occur in real time. Whether you have an advanced directive or not, there's still going to need to be those conversations, ideally, like Maureen Henry explained, explaining the illness, exploring goals, evaluating options and then documenting it. So, medical notes are important.

And then thirdly, a tool that has developed more recently, called physician's orders for life sustaining treatment or POLST, an extremely useful document for those who face advanced illness. And because you have some terrific experts who are going to talk about that later on, I'm not going to spend a lot of time explaining what POLST is, except to say they're essentially portable medical orders, most relevant to making sure there is a plan in the face of critical care decisions that may need to be made for somebody who's at advanced stage of illness. Now – so that's a little bit about what makes up advanced care planning.

Let's talk about what documentation is most important are any and all of those three. There may be all three in the form of an advanced directive, medical notes that flesh out what's going to happen right now and for patients with advanced care, physician's orders for life-sustaining treatment. For the healthy 40-year-old going in for knee surgery you wouldn't expect there to be a POLST form, that wouldn't be appropriate for them, but for the 75-year-old with serious and multiple chronic conditions, you would expect that. So for whom is documentation most important? Just to reiterate, everybody needs a care plan, so there should be some documentation of it from the minor health interventions to the major. But, it is most important, as one gets in an advanced stage of illness, because that's when the big crises can happen on a moment's notice and without a care plan, bad things happen to people that they didn't want to happen.

So, in terms of documentation, it can be useful to think about, okay, how do we capture those people who are at a more advanced stage of care to look at how health information technology could better have recorded the care plan for those individuals. The use of age, particularly 60 or 65, is a very poor proxy for capturing this group. Certainly you can argue that over age – most people who are – who die in a given year in this country are over age 65, but there's some 30 percent who are not. There are plenty of 65 year olds who are perfectly healthy; there are a good number of 50 year olds who have very advanced stages of various kinds of conditions. So that is a poor proxy. We had suggested in comments we provided earlier, that the most accurate way to identify those people with advanced stages of illnesses is to look retrospectively at the population of people who died within the past year. And then looking to see what kind of documentation – whether there was documentation in the record of a care plan, which could be indicated by the existence of the advanced directive, medical notes specifically laying out a care plan or POLST orders.

Okay, so let me jump to another issue that was raised and that is the issue of portability and also staleness of documents. Advanced directives have actually had very little problem with portability across state lines. The bigger problem with portability is really going – the portability from one provider to another, from one venue of care, hospital to nursing home to home, making sure the advanced direct – and the care plan, whether it be in any of the three forms I suggested, actually follows the patient. The POLST orders were specifically created to be that tool that works across care settings and has been shown to work very well in doing that, making sure that documentation actually follows the patient.

Across state lines, most states actually have portability provisions, which recognize an out of state directive as valid, if it was valid in the state where executed. That provides at least a modicum of security because it – while the directive may be valid, it may not be interpreted the same way across state lines because of different state rules regarding what language you must have to have in your directive if you want certain things to happen. I always use the example of Illinois. If I said that my agent has the authority to make all healthcare decisions, that would indeed, include all healthcare decisions, including those of life-support. If I took that over the line into Wisconsin, well it would not be interpreted that way unless I specifically spelled out in the document, for example, nutrition and hydration, that my agent would not have the authority to withhold nutrition and hydration, unless that were expressly spelled out in Wisconsin. So, the document sure, valid in both states, but not interpreted the same way.

Having said that though, we hear as a practical matter from practitioners, very few problems about portability across state lines, they do come up, but it has not been a major issue. It is a major issue in the perception of the public, because they want the security of knowing their directive is good nationally. There is no real national advanced directive that can be used anywhere. I think you'll hear later on about Five Wishes, which I think comes the closest, but it is because the law is so balkanized in its formalities across state lines, particularly in required language that one must have, that makes it impossible to do a reasonable advanced directive nationally. So portability issues will remain for the foreseeable future.

Finally the issue of staleness or do advanced directives have a termination data. They don't in any state law, you could put a termination date in your advanced directive, but an advanced directive that you did 20 years ago is still going to be legally valid. Will it be useful, probably not in the eyes of the providers or even perhaps the family members, for guidance that was given such a long time ago? The obligation of surrogate decision makers under an advanced directive, or even without an advanced directive –

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Charlie, this is Michelle, your time is just about up.

**Charlie Sabatino, JD – Director – American Bar Association Commission on Law and Aging**

Okay. Staleness is an issue because the obligation of your decision makers is to make decisions as you would have made them if you could speak for yourself, we call it substituted judgment, or in your best interest. Obviously the longer time that your guidance was given, from the time it was given to the time the decision needs to be made, becomes an issue. And that really points to the fact that this is all essentially a process of communication.

I'll end with a point that I frequently try to make and that is simply that for advanced directives and for POLST, even for medical notes, the beating heart as well as the Achilles' heel of this process is the quality of the conversation between the healthcare providers and the patients and their surrogates. And that's something that goes beyond the documentation that you're dealing with, but there are a lot of good people trying to do good work on that. Thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

So this is Michelle. I'm just going to remind workgroup members if you'd like to ask a question, if you could use the raise the hand feature to get yourself in the queue. I don't see anyone as of yet, so Larry and Leslie, I'm not sure if you have any questions to get us started.

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

So, I guess I'd like to second the thanks to Charlie for his presentation. He's had a lot of issues that we're going to be hearing more about during the day and I guess I'll remind us as we head into Panel 1, that we're asking each presenter to stay within their five minute presentation time, because there will then be discussion afterwards. So if there aren't any specific questions for Charlie, maybe we can get started on Panel 1.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thanks Larry. And this is Michelle. I'd just like to reiterate, so each panelist only has five minutes and just to warn you in advance that when the five minutes is up, I will cut you off and we will move on to the next panelist. So, apologies in advance, but we just need to keep to the time schedule. Because there are a number of participants and we want to make sure that we are able to get to everyone, so thank you.

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

So, I guess I'll remind folks that this is maybe a good instance of less is more, so if there are a couple of things that you want to make sure that we really hear, focus on those very few things rather than trying to be exhaustive. Feel free to reference any written materials you've supplied us, or to send us something after the hearing if you feel that there's something that you wanted to cover but you didn't get a chance to present. So with that, why don't we get started with Panel 1. So is Patricia ready?

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

This is she. I was waiting for the slides to come up, but I will get started. I'm Pat Bomba, I Chair the New York State MOLST Statewide Implementation Team and I serve as the eMOLST program director. Thank you for the opportunity to highlight the work. We're talking about advanced care planning as a process, but I will focus, given the time constraint, on my five minutes on eMOLST, which is the electronic version of the medical orders for life-sustaining treatment and the New York State eMOLST Registry.

eMOLST is a statewide, multitenant web application that can provide an eMOLST form and documentation of the goals for care and the discussion and the process to any provider, at any time, across New York state instantly. And our development aligns with the Triple Aim of improving the patient experience of care, the health of those populations and reducing per capita cost of healthcare by reducing unwanted hospitalizations at end of life, based on the decisions made by the seriously ill person through a standardized, shared decision making process that is well informed, based on an ethical framework and New York state public health law, for making decisions to withhold or withdraw life sustaining treatment with or without a MOLST. Next slide.

Our work aligns with the National Quality Forum's preferred practices for advanced care planning and we view advanced care planning as a wellness initiative, as anyone can face sudden and unexpected acute illness or injury with the potential risk of the loss of the ability to make decisions. And in particular in our state, we didn't have surrogacy laws until June 1, 2010 and choosing the right agent, not just any agent and having ongoing discussions at the kitchen table has been something that we have been promoting as we move forward with the process. Next slide.

As both Maureen and Charlie have pointed out, advanced care planning is a process. There are two different types of documents that you'll see in the next slide. Advanced directives have been discussed by both the previous speakers, Maureen referred to, in the legislation, to portable medical orders, in this slide you see actionable. It means they're medical orders signed by, in our state the physician that can be followed at all care settings. Charlie mentioned the term POLST, POLST stands for Physician Orders for Life-Sustaining Treatment, it is the national name for the model. In our state it's MOLST, in other states it's named other names. The difference for these documents is that advanced directives is for everyone 18 and older, seriously ill patients who should consider it are people who want to receive or avoid specific life-sustaining treatments, reside in a long-term care facility or might die in the next year. The New York State eMOLST Registry instantly provides a person's current eMOLST form to any authorized system or health professional across the state. Next slide.

As we've talked about so far in the hearing, the medical ordered program, MOLST in our state, POLST nationally is an end-of-life care transition program. Accessibility to the forms, which is the end product of a process, needs to be available in all care settings. EMS cannot follow advanced directives; they can follow medical orders. eMOLST ensures the patient preferences for care and treatment can be honored at any time and across all settings and followed as medical orders by all healthcare professionals. Next slide.

You'll see in New York we have spent a lot of time on developing MOLST and it's only been in recent years that we've worked on eMOLST. The work has gone slow because we've had major changes in our public health law, but in terms of that, we've been able to also use the platform that we've developed to be able to incorporate those changes. There is a difference, as demonstrated in the next slide, between eMOLST and the eMOLST Registry. eMOLST is a secure web-based application. It allows the users to complete the eMOLST form, document the discussion in the proper chart documentation form and a specific checklist that the Office for Persons with Developmental Disabilities created for those individuals who lack capacity. The forms are created and they become stored in the Registry. The Registry, on the other hand, is an instant access to the person's current eMOLST form, and that is provided to any authorized system or healthcare professional across the state.

If we can advance beyond the next slide, I would like to be able to show the pathways for using eMOLST, if Michelle is able to show it. eMOLST is able and – yes. eMOLST basically, the application creates, digitally stores and provides access to MOLST forms. Anywhere there's access to the Internet, one can use the eMOLST application. It's developed, not only about the form, but it's about the process. Each organization uses the same eMOLST Registry, it's centrally hosted, is a singular statewide, multi-tenant system. There's a system and infrastructure that supports it and will support everyone in the state who needs to use it. The next slide.

You'll see in the next slide there's a process. I'm not going to read it, it just shows that there is a process. It's the process that Maureen was describing, that's integrated into eMOLST. The next slide demonstrates the complexity of the ethical framework for the persons who are making these decisions. There are seven checklists or clinical pathways that are codified into New York State Public Health Law. Next slide shows that both of these are in eMOLST and at the end of that process, it creates both the form as well as a copy of the documentation. That is available in all care settings, moving from hospital to nursing home to home, etcetera.

Next slide shows some screen shots from eMOLST that I'll show you quickly. This is the access to eMOLST, it gives you a little glimpse of it. An enrolled user has a clear user name and password. There are clinical and administrative roles assigned, access to the level of what the clinical end-user needs, whether it's the person having the discussion, the physician who's having the discussion and signing, the nurse or the EMS who just needs to have a read-only form.

The next slide shows you the first, screen that –

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

I'm sorry Patricia, your time is up.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

Okay, thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. If we could move on to Christie North. Christie, are you ready?

**Christie North, MBA, FACHE – Vice President, Utah Programs – HealthInsight**

I am here and I am ready. Thank you very much, it's a pleasure to be with you and I really appreciate the fact that this hearing is taking place. As has been noted by all of the previous speakers, this is a really important issue that we need to understand completely and that we need to be aware of what's going on in other areas, but we really need, as most people have said, healthcare is very local. So national perspectives are interesting and helpful and Utah has been watching very closely what's been going on in New York. I would gladly give some of my time back to Pat so she can finish. That was very, very interesting.

Utah has been fortunate to have key stakeholders for a very long time who are concerned about assuring, as Maureen said, that people have the care planning and the care that aligns with their goals, values and preferences. We have had advanced directives made available for many, many years. The unfortunate thing about advanced directives as everyone has pointed out, is that they may not go far enough in describing the actual wants and needs of any given patient at any given time. They do give attempts of direction and, if nothing else, can assign a proxy, which is a very important role; important but confusing. I think one of the challenges that we have with the current documentation is its cumbersome and it's very difficult for families to a) have the conversation, but b) complete the documentation in a meaningful way. Then again, the advanced directive belongs to the patient. In Utah, there is no standard form. The forms can be adapted in any way, completed in any order or not completed, some of them; any way that the patient is comfortable. They're then legalized, so to speak, by having them co-signed by a non-care provider, and then they're kept by the patient. So they may or may not ever emerge in the healthcare setting. Asking the patient if they have an advanced directive is a very good start, producing them and making them part of the medical record would be invaluable to actually making sure that the – continues, once the patient needs care.

As Pat pointed out, the POLST paradigm has been around the United States since the early 1990's and Utah was a bit of a latecomer, but still there are only about 15 states who actually even have an authorized POLST Program. And by authorized, I just mean endorsed by the National POLST Organization. In Utah we have a POLST, physician orders for life-sustaining treatment and have had since the mid-2000. We struggle because there's a lot of misunderstanding. There are still some who say you just want to cut off care if you're asking people to complete a POLST form. In fact, it just assures that patients are able to say what they prefer and it being a legal document, people are much more likely to actually get the care they say they want.

The challenge with the POLST form is, in fact, that if it's paper, it is easily misplaced, it's lost, there's version control, there's staleness, there are any number of issues. Utah has been working side-by-side, although we were hoping New York would be ahead of us and get something published so we could learn from them. But we've been developing an electronic POLST that has the same attributes that Pat described in New York, secure online completion by providers that follows on a series of conversations between patients and family, patients and providers, providers and family and patient, and document those values and preferences around end-of-life care.

I'm very sorry to hear Leslie's aunt's story. Unfortunately, it's too common. Everyone I talk to has an end-of-life story, unfortunately, most are unhappy stories where our health system has failed in meeting the needs of patients. To that end, our electronic POLST forms are stored in a database that is accessible only to care providers. And I believe Pat described it as instantaneously. It is instant and it is connected through the Vital Records in the state database so that version control can be handled so that the EMS systems can get to it as needed, en route to 911 calls or when a patient is brought to an emergency department.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

I'm sorry Christie, your time is up.

**Christie North, MBA, FACHE – Vice President, Utah Programs – HealthInsight**

Okay. Thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. Is Alvin Moss free?

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

Can you hear me?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

We can hear you.

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

Okay. All right, well if I can have my first slide. Let me just say that I'm from the West Virginia Center for End-of-Life Care, and the West Virginia Center for End-of-Life Care oversees an e-Directive Registry which is a node on the West Virginia Health Information Network. And I'm grateful to Kathy Moore, the Chief Information Officer for the West Virginia Health Information Network to allow me to speak for the Network to this Committee. If I could have the next slide please.

I think all of the speakers have been talking about what we envision as high quality, individualized, patient-centered medical care. We have a conversation, as Charlie alluded to, that informs and identifies a patient's wishes as part of advanced care planning and advanced directive and as appropriate, a POLST form is completed. It would be submitted in West Virginia to our e-Directive Registry, in an emergency that advanced directive or that POLST form could be accessed online. And thereby, we could respect patient's wishes across healthcare settings and provide for smooth transitions of care. If I can have the next slide please.

So what – really this addresses really the time to abandon the silo mentality in healthcare. I think this speaks to where we hope we can be with Meaningful Use Part 3 and all the following healthcare settings can be part of a statewide system, which it is in West Virginia, to respect patient's wishes, connected through the West Virginia Health Information Network, through the West Virginia e-Directive Registry. So emergency medical services, every office and clinic, every nursing home, hospital, inpatient hospice, assisted living facility, personal care home, potentially every home, apartment or private residence can be part of our statewide system to respect patient's wishes. Next slide please.

And this is just what our system in West Virginia can provide basically accurate, relevant information and available in a crisis, about a patient's wishes. A care summary if you will of the patient's advanced directives and medical orders would be available online 24 hours a day, 7 days a week. We also make sure that we respect patient's wishes by doing an annual mailing to ensure the accuracy of the wishes that we have in the Registry. We archive patient's who've died and the whole thing is password protected and HIPAA compliant. Next slide please.

So this shows you that we've received over 20,000 forms in our registry. The most common form is a combined living will and medical power of attorney form, do not resuscitate cards are second and POST forms, which are a variant of the POLST form, are third. Next slide. We have, on our most recent survey of over 1,000 West Virginians randomly sampled, 50 percent of West Virginians now have a living will, a medical power of attorney or both. Next slide. And what I want to show you is, one of the questions for this panel was about advanced directives and how useful can they be. And you'll see from this slide that 60 percent of people do not have special directives or limitations written on their advanced directive, 38 percent do. If I can have the next slide please.

And I'm not going to go into this, I think several speakers have already alluded to it, but there are multiple reasons why advanced directives fail, and that's the reason why we need a portable medical order system to compliment advanced directives. Next slide. This is research on which I was fortunate to be a co-author, and I know that Bud Hammes will be speaking later during the day, but what our study showed, and this was conducted in nursing homes in Oregon, Wisconsin and West Virginia, is that the POLST program offers significant advantages over traditional methods to communicate preferences about life-sustaining treatment, so there were advantages over advanced directives and do not resuscitate orders. If I could have the next slide please.

This is what a POST form Physician Orders for Scope of Treatment form looks like in West Virginia. It's very similar to Pat's MOLST form or to the POLST form that's in Wisconsin and Oregon and this form is part of our registry, so that it would be available, so the patient's wishes could be respected. If I can have the next slide. This speaks to this idea of meaningful use extending beyond hospitals. You'll notice this is a slide that shows where does the Registry receive its forms from, a third roughly from hospitals, a fifth from hospices. If there's not a face sheet, we don't know where they're coming from, that's the 19 percent. Then we have non-healthcare settings, because a lot of our public employees submit forms from the schools where they work or their places of occupation. Notice nursing homes are about a tenth of the forms that we receive. Clinics, private practices, private individuals, home health, so that basically – electronic health record, meaningful use can allow patient's wishes to be submitted from multiple healthcare settings.

And if I can have my final slide please. West Virginia has a system to ensure that patient's wishes are respected across transitions of care. And its advanced care planning with forms sent to the Registry with 24/7 online access to the Registry by treating physicians. Use of the POST form allows consistency between the patient's wishes and the treatment received. I would recommend, of course, that advanced directives and POST forms be part of the care summary that would be available online to sort of compliment what might be available in paper form, and that it is possible to implement an effective statewide system to respect patient's wishes. And this statewide system requires communication and coordination across healthcare settings and with the e-Directive Registry through our West Virginia Health Information Network, and let me conclude at this point. Thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you Alvin. Brian Yeaman, are you ready?

**Brian Yeaman, MD – Chief Medical Informatics Officer – Norman Regional Health System, Norman, Oklahoma**

Yes, I'm ready. This is Brian Yeaman. I'm a family physician in Norman, Oklahoma and I have with me today Annette Prince, she is an attorney and the previous Assistant Attorney General in the State of Oklahoma. And we prepared our list of questions and then after this call I will come back with a PowerPoint of some of the directives that we've put into place here in Oklahoma. I think one of the things that I really want to highlight, because of course we completely agree with everyone that has spoken on the call previously that we have to find a way to enable the portability of these advanced directives and enable the portability of information such as who is the proxy or power of attorney.

And I think one of the things that we really want to highlight from Oklahoma is that our state, much like the rest of the country, has a certain amount of political and religious and financial constraints that create an issue with creating some of these registries. And unless we have one that works across the country, we do have issues, of course, when they begin to try to cross state lines. And many of these patients near the end-of-life frequently do that when they go to live with a loved one in another country who's going to be their primary care provider. One of the things I think I would highlight is that just in terms of today what could be done with meaningful use, even in a phase 3 effort, we believe is, if there's a structured data field that states whether there's an existence of an advanced directive or not, that would be very helpful.

But, we like the health proxy model here in Oklahoma. The way that that works for us is a much easier thing for the patient and their loved ones to execute rather than the power of attorney. And we believe that if the health proxy or power of attorney information is also captured in a structured – and shared in a CCD as a requirement for meaningful use. That at least we can tackle some of the low hanging fruit in terms of being able to contact that – the appropriate individual at the point when this information should be needed. So that, of course would just be the lowest hanging fruit on the tree, but we believe that that would actually accomplish quite a bit in terms of honoring patient's wishes. We have advanced a POLST form in the state of Oklahoma, we've done that through the University of Oklahoma and we approved a Registry to be created within the state for those forms, but currently we've not been granted any funding in order to make sure that that can happen.

What we have done, I am the principle investigator on an ONC long-term care Challenge Grant and one of the things that we're currently building and constructing, and I'll share this in our PowerPoint. The route that we decided to take was, and I like to call it Blue Button on steroids, where essentially attached to the patient's personal health record would be a registry in the background where they, or their proxy, can access that system. And then access that registry, which is completely owned, managed, controlled by the patient and then they can release those forms or pull them down at the appropriate time, when necessary, for a provider or potentially push that message via a secure channel in the background to a provider in a health information exchange. And I think that it's very clean, it's very lightweight.

There's a mechanism of manual intervention still, of course, by the patient and the proxy, but it does help us overcome some of the political, financial and legal challenges that we know currently exist in that structure. And one of our main points of course being that we want to make sure that the document hasn't become stale or that you have the most recent version. And in the state of Oklahoma, of course the patient, and I think everywhere, can change their determination on their end-of-life care verbally at any point in time. But when they're unable to do that, we want to make sure that we have the most recent copy of that to ensure the patient gets what they want, and also to protect the provider. So, in conclusion, I think that we see some potential with some low hanging fruit with meaningful use in phase 3, of just passing some key structured data. Continue to push towards that finish line of state registry or national registry for POLST and advanced directives and I think that certainly we're looking at ways to empower the patient through the personal health record and Blue Button type functionality, to take that next step in portability. Annette, do you have anything to add? Okay, I think we're good. That's it from Oklahoma.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you Brian. That was perfect timing. So as a reminder to you, the workgroup members on the line, if you have a question, please use the raise hand feature and I see that Wes Rishel has a question. Go ahead Wes.

**Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated**

Thank you. My questions are primarily going to be directed at Pat Bomba and Alvin Moss, based on the experience they've described in New York and West Virginia. The general question is, what measures do you have of percentage use, both in putting records in and in actually accessing the records? And for Alvin, I caught two numbers and I wasn't quite sure of how they related to each other, one was 20,000 registrations and the other was 50 percent entry into the thing, so perhaps they just came by so fast I couldn't relate them. And then finally, I notice particularly in West Virginia a wide variety of sources, what processes are used to assure that these POST documents are not being created without the proper authorization of the patient?

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

Michelle, who would you like to go first?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Maybe we can start with Pat.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

Sure, that's fine. There are a lot of questions that you've asked in between there. I would start with sort of the last issue in question, in terms of ensuring that they're done completely. I didn't get to show the screen shots, but essentially, with the application that we've developed, there's only one way to do the process, it's a standardized process, with the right medical decision maker, the person with capacity, the healthcare agent who's identified if the person has one and they lack capacity, alignment with surrogate, etcetera. The other value of the online eMOLST system is that it eliminates any potential for incompatible medical orders, which can occur in the paper world and I'll give you an example.

A person, if the discussion is not done correctly, and there's not shared decision making and discussion of benefits and burdens, one might say, I do want to be resuscitated, but I want comfort care measures, no going to the hospital, no ventilators, no feeding tubes, no IV fluids. That's not a promise we can make and so the system doesn't allow that, so it's not only ensuring that the right process is used, the right decision maker is documented, proper consent with two witnesses, but also ensuring that the orders are done correctly. As well as there's appropriate signatures, everything in place for EMS or any acute – or any health professional to honor it in an emergency.

Woody has more data in terms of West Virginia, I'll let him talk about it. But I would just say, in New York, we are working, in terms of implementation, because of our changes in health law, and we're working with systems to move from the paper world into eMOLST and have developed a quality improvement project to speed that along. I don't have data in terms of access by EMS and others, because we're not at that stage and because people want to use it across the state, we're building the infrastructure to get forms in, using the same workflow, because in nursing homes they don't all have electronic medical records. They're still using the printing to be able to do the access. We're working regionally with EMS, when we get to a certain threshold, EMS will be brought into the fold.

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

So, this is Alvin Moss. So access to the Registry is voluntary and it's opt in. On all of our forms, the patient or the patient's legal decision maker can opt in and make a decision whether or not the form should be submitted to the Registry or not. Our experience and feedback is about 99 percent of the time, when it's explained to a patient or a patient's family member if the patient lacks capacity, what the Registry will do, that the form would be available at the time of a crisis, 99 percent of the time they agree to have the form submitted to the Registry.

There are over 50,000 – I'm sorry, 20,000 forms in the registry, the question was right, and about 50 percent of West Virginians have completed advanced directives, based on a randomized sample of a thousand West Virginians that we conducted earlier this year. We have over 10,000 advanced directive forms in our Registry, every month we receive 800 to 1000 new advanced directives and POST forms and DNR cards. So, we have at this point about 50 healthcare institutions and physician offices who are members of the West Virginia Health Information Network. That number is increasing every month, and I think these are some outcome measures that we can use to sort of determine how well this model is working. So far, it seems to be working very well.

**Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated**

Do either of you have numbers on who has looked at a form as opposed to who has put a form in or how many people? And secondly, my other question is an awful one to ask at a time when we're trying to increase the use of POLST, but on the Internet no one knows when you're a dog and there has to be means in place to ensure that a POLST that is submitted really does represent the genuine intentions of the person. What do you do in order to ensure that?

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

In West Virginia –

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

This is Michelle. I'm sorry, can I just ask if you aren't speaking, if you could please mute your lines, we're getting a little bit of background noise. Thank you.

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

In West Virginia it's mandatory that the patient sign the form, indicating their agreement with the form, or if the patient lacks capacity, that their medical power of attorney representative or healthcare surrogate sign the form.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

And in New York, what I was trying to drive at with the process is it's a process and certainly in the electronic world with eMOLST, it really is driving a standardized, shared decision making process that aligns with some of the initial comments that Maureen made, in terms of benefit/burden analysis. And it's signed in the presence of two witnesses, to acknowledge that it's not just a checklist, and so that's really part of the – also the insurance that we're getting to the point that patients are getting their preferences. The patients can't sign their own medical orders forms, they're electronically...and so we have used the electronic signature with the two witnesses and using verbal consent. If the form is printed and patients wish to sign it, they can sign that.

**Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated**

Thank you.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

And the only people that are doing the signatures, it's a level of access to eMOLST, it's by credentialed physicians, because in our state, only physicians can sign the form. They are credentialed for that level of access to eMOLST in our system.

**Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated**

Thank you.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

You're welcome.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

So, again, I think Alvin it's actually your line, so maybe when you're not speaking if you could mute, we'd really appreciate it. Sorry about that. And Wes, if that's all of your questions, it looks like Paul Tang has a question.

**Wes Rishel – Vice President & Distinguished Analyst – Gartner, Incorporated**

Go ahead.

**Paul Tang, MD, MS – Vice President, Chief Innovation and Technology Officer – Palo Alto Medical Foundation**

Okay, thanks Michelle. Thank you for a very interesting set of responses, and it sounds like we're hearing from some leading states that have organized themselves and have the enabling legislation to handle end-of-life wishes. It is of note, of course, that each state is implementing a slightly different version of POLST, with a slightly different name, and a version of their own state registry. My question is, and Brian actually I think suggested this, is there a need for a national advanced directive and POLST, the actual medical orders, with a common AD and ePOLST across the country and then have EHR vendors interface to that common registry? Or do we need state POLST variance and registries, and if so, how would we reconcile them across state boundaries?

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

I would just point out that there's a difference between the – the process is the same, the forms may be different, the registry and access to the end product can be in a national registry. But I think, and I would just speak for New York, if we waited to have a uniform form without really moving forward with some legislative changes, etcetera, we wouldn't have it. As an example, in our state, on day one of admission into a nursing home, since 1987 providers are required to ask patients if they have preferences about resuscitation. That is mandated and in the regs on day one and so our form has separated that need on page one versus page two, it's consent, but it also works in the workflow for our providers and that's the way it was designed when we first started working on it back between 2001 and 2003. So the significant, that's just one example, but that were to be significant difficulties in terms of established programs, that's a difference though from establishing a registry, which can be national based on even the differences, similar to what Charlie said about advanced directives. And because of the time constraint, I just focused on what we're doing with eMOLST.

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

Hi, this is Alvin Moss. Let me add to that further if I can. Charlie used the great word balkanize and what's true is that the advanced directive statutes in all 50 states are slightly different and the POLST or POST forms or MOLST forms are slightly different, sometimes reflecting the differences in state law. Now the National POLST Paradigm Task Force has criteria that a state needs to meet to be endorsed, and so there is that degree of uniformity between states. I think it would be great if there was national legislation that established reciprocity between states with endorsed programs, I'll leave that up to others on the call to figure out how to do that. I don't see how we can do a national registry unless we can get all the state health information networks to talk to each other.

**Brian Yeaman, MD – Chief Medical Informatics Officer – Norman Regional Health System in Norman, Oklahoma**

This is Brian Yeaman. I agree that I think that you have to align the POLST with the advanced directive, and in order to do that, you have to enable that across the nation in order to have a national registry. But at the end of the day, if there were a national registry that could be accessed via electronic health record or health information exchanges, if those are not interoperating across state lines as of yet and that's really why, again we were suggesting some low hanging fruit in terms of does an advanced directive exist? Is there a POLST? Can you list the contact information of that proxy or the power of attorney at least as a next step before we get to any type of a national standard, recognizing that that's going to take some time. And I really again feel like just having that information for the power of attorney or who that proxy is, it's frequently very different than what's listed in many people's records in terms of next-of-kin, because they may be different people. And then, of course, when these patients or individuals are crossing state lines near the end-of-life, it really can create an issue and so, that's why we were going down the path of suggesting that structured data element, and then that next step of some type of a national registry. But a really great intermediate, we think, is empowering the patient in their own registry that they're controlling and that they own, and that really does bring a different flavor to that without the need for a lot of legislation.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

I would just build on what Brian said in terms of the value of having the named healthcare agent or power of attorney for healthcare versus the PO. Because if a person has a care transition and has a change in health status and a change in their medical orders based on goals for care, and they lack the capacity to make decisions, that named agent is the person that the provider looks to. So we don't see eMOLST as a substitute for doing the healthcare proxy or naming the healthcare agent, and access to that person is critically important.

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

And this is Alvin Moss from West Virginia and I agree with both Pat and Brian and the e-Directive Registry does provide those measurables that Brian described.

**Paul Tang, MD, MS – Vice President, Chief Innovation and Technology Officer – Palo Alto Medical Foundation**

Thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

All right, Christine Bechtel has a question.

**Christine Bechtel, MA – Vice President – National Partnership for Women & Families**

Yes, thank you. And thanks to all the panelists for really great information in their talks. So I'm building on what Paul Tang just asked and I was thinking about probably a slightly different approach, knowing that it would be difficult to standardize the content of advanced directives across states. I started to think about an approach that we have considered in meaningful use for clinical trial registries where we could simply create the capacity in the EHR to use a standard. The specific one we talked about was HL7 Info Button, that would be potentially able to query different clinical trial databases, if those databases were able to accommodate the use of that standard. So I'm thinking about an approach of where regardless of state, and I want to know, I think, if this applies to health information exchange networks as well, could we envision something where we have a common standard for query and then the document or the information comes back in a way that is perhaps like a CDA, a PDF. Something like that that is readable, so that we get the content at least moving, without having to standardize the sort of individual data elements of these various orders, directives and plans. So I just wanted to get the thoughts from folks on the panel about whether that might be an approach that could be accommodated?

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

So what you described is very doable in West Virginia, each patient in our West Virginia Health Information Network has a master patient index and in that master patient index is a tab that basically takes them to the e-Directive Registry that would include their advanced directives, their do not resuscitate order, a POST form if it's been completed. If a healthcare surrogate has been selected, that would be in there if it's been submitted, or even guardianship papers so that it would be possible to know who is the designated decision maker for a patient who lacks capacity.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

The other piece that I would add on is that if you look back to the Preferred Practices from NQF, the first data element is really who is the designated surrogate, that's something that Brian mentioned and I agreed with, as did Woody. The second is, what are the preferences for that person's care and their values, their beliefs, that is information that is ongoing for all of us and should be accessible, with or without a MOLST. People should have that easily accessible long before their ready for a POLST or a MOLST.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Are there any other questions from workgroup members? I'm sorry, Paul Tang.

**Paul Tang, MD, MS – Vice President, Chief Innovation and Technology Officer – Palo Alto Medical Foundation**

Well, just a follow up. We've heard about all the benefits and the successes of these particular states. Have you found any objections or pushback, it's like Congress asking, well who wouldn't be happy with this?

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

I would say – go ahead –

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

This is Alvin Moss from West Virginia. Because it's voluntary, because the patient has to give consent for the forms to be entered into the Registry. We've not had pushback in West Virginia.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

And I would say in New York, it's – we're dealing with competing priorities and if you look at where meaningful use is, we need to take it to another level. If it's in Meaningful Use 3 and people will wake up and prioritize that, there's a lot of competing priorities as we're looking at ACA and ACOs, etcetera. So without getting into a dissertation, I sent to Michelle a letter that I had put in for Meaningful Use 3 that goes beyond the time on this call. But I do think getting it in – getting advanced care planning in, the concepts of who's the right spokesperson, the power of attorney for healthcare, what's important to them for the right person who's appropriate for a POLST or whatever it's called in an individual state, begins to gain the attention of those who are working with electronic health records.

The other reason that we did a web-based application is we have 600 some nursing homes, many of which don't have electronic health records and they are a big population of seriously ill individuals. And so we've had to work with the workflows and create processes for digital transformation from paper to MOLST. That's a process that takes time, but if it's in meaningful use and there's easy access to putting a link into electronic health records which will come up later, then people will stand up and say, this is something we have to pay attention to.

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

One other thing – this is Alvin Moss – that I would add to get at Paul's question is, West Virginia and Oregon have been recognized as mature programs for the National POLST Paradigm Task Force. This gets at the idea of whether there's pushback or not. To be a mature program, 50 percent of all healthcare settings, hospitals, nursing homes and hospices in each of the different regions of the state – 50 percent or more have to be submitting forms actively, in our case to our Registry. So we – and in some regions it's 100 percent, so at this point, it's a matter of education as Maureen talked about, but we really are seeing an increasing number of healthcare settings participating in our registry and submitting forms and the number just continues to increase. So, so far it's going well and we've not heard pushback and everybody likes the idea that their wishes are going to be respected at the end-of-life.

**Christie North, MBA, FACHE – Vice President, Utah Programs – HealthInsight**

This is Christie in Utah. I just want to add, everyone has expressed it very well. There's only pushback when there are misunderstandings and we are rolling our electronic POLST in nursing homes and hospice facilities and we're finding really good acceptance. Sometimes it's true, they do not have electronic health records, but they do have access to the Internet, so they're still able to document patient's wishes in the electronic Registry. All of our EMS workers have access immediately through Smartphones or Tablets and are able to pull up the POLST easily.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

It looks like Larry Wolf has a question.

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

Yes, thank you. Maybe more of a pattern and consistency that I'm hearing, maybe others want to comment on that. So if we put this in a broader context, I'm hearing this is sort of an integral part of care planning and that that's a theme we've seen a lot of discussion on for Meaningful Use 3. That there's a value in having a registry that we have some state examples of participation for putting documents in. I agree with Wes, it would be good to know more about the level at which there's access being made to those documents. But I think that that notion of having a registry and the value perhaps of a national registry that allows multiple styles of documents to be stored and accessed or links to the right state directories, I don't want to get into the technical solutions there. A lot of good input on what the documentation itself needs to be, needs to cover.

The notion of additional actionable parts of this in the POLST and MOLST efforts and a piece which I have to admit we've talked generally about roles of caregivers beyond just the professional care team. But I don't think there's been a lot of discussion about the various proxies in the past and I'm hearing a pretty consistent message out of the panelists that we really need to track the "who" of this as well as the "what" of this.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

Your com – this is Pat Bomba. Your comments raise something that I didn't address earlier, which is the question of when people access – how often are they accessing it? In our system, because of the requirements, there are requirements to review MOLST forms on a periodic basis under Public Health Law. But in addition, if people are moving across care transitions, if there's a change in health status or if the decision maker, be it the patient or the healthcare agent or surrogate, changes their mind about treatment, and so on a regular basis the eMOLST is being accessed. And that's also driving what Maureen was talking about earlier which is, the fact that people can change their mind, it's about care planning, it's about what are goals for care and do they change over time. So on a regular basis for all the folks that have eMOLST, they know and they're reminded about the regular review of this, which often times is not so much the resuscitation preferences as much as preferences about life-sustaining treatment that can change over time based on the change in goals.

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

This is Clem McDonald. Does anyone have a sense of whether these registries have had any effect on practice behavior? That is, do nursing homes send people to the ER less often when there's a constr – when the patient expressed an interest to not do life-extending treatments?

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

So this is Alvin Moss and some of the research that I alluded to showed that there was consistency between what was written on the POST form and the treatment that the patient received 94 percent of the time in a nursing home study in the states of West Virginia, Oregon and Wisconsin.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

And on a real-time basis, we are collecting the data to answer this and many other questions. We are looking for funding to help build the backend analytics so that we can do quality assurance, quality improvement in multiple parts of the state for facilities whether it's ACOs, patient-centered medical homes, so that they can look and address issues. For instance, if a patient says, I don't want to go to the hospital, is there a care plan in place that supports it. Is the family aware of it? If there's a change in health status, has there been an update in the care plan? So we see this as just the beginning and we're trying to build more of the infrastructure to move that forward and answer those questions, which you can't answer in a paper world very well, unless you're doing a larger study, as Woody referred to. But we want to be able to have this in a real-time basis so that small nursing homes in rural parts of the state can do better quality assurance around these activities, in terms of end-of-life decisions. The other piece is, we're tying this with education as well as making sure that care planning is being done that families outside of those involved in the discussion are notified, so that the care plan doesn't fall apart at the end of the day.

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

But the forces to send them to the ER are tremendous.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

I think that that's absolutely right and so one of the things we've done, at least in our neck of the wood, is to basically develop an enhanced reimbursement model to pay for the time it takes to spend on having these discussions as well as the non-face-to-face time to family outside, so that a better job is done there. And also to realign in the same way with reducing readmissions, looking at reducing unwanted hospitalizations. That was my first comment in terms of opening this discussion.

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

Right, and this is Alvin Moss from West Virginia. So the question is right on line. And so we're teaching our EMS to ask when they go to the nursing home, where's the POST form and to review the POST form to see if they really should be transporting this patient to the hospital or if this patient really wanted to be kept comfortable in their present setting. The other thing we're doing, which just shows the potential of these registries is, we're in the process of merging our Bureau for Vital Statistics data with our Registry data. So that we will be able to look at site of death and see what percentage of the time was the patient's advanced directive or POST form consistent with the treatment the patient – the wishes on that form consistent with the treatment that the patient received. And was the site of the death the one that the patient had said he or she wanted to be his site of death or her site of death. So there is great potential beyond what we've discussed already today.

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

That sounds great.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

And the other –

**Michelle Consolazio – Interim Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology**

I'm sorry, I'm going to move on to the last question. Charlene Underwood has had her hand raised for quite some time. Quickly Charlene and then we'll move on to the next panel.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

Yes. I guess from a perspective of the vendor community, sometimes it's good if market forces drive the demand for this. So to what extent, I've got two pieces, are you seeing market forces, people really asking for this to be integrated into electronic health records and also, have you had any experience with this information being actually integrated into electronic health records and how do you see that working?

**Alvin H. Moss, MD, FACP, FAAHPM – Professor of Medicine, West Virginia University School of Medicine; Director, West Virginia University Center for Health Ethics and Law; Executive Director, West Virginia Center for End-of-Life Care**

So in West Virginia, what we're finding out is different hospitals have different electronic health records, for example, some have EPIC, some, I'm afraid I don't know all the different names. And so West Virginia Health Information Network has been successful at bringing these different vendors and their different types of platforms, if you will, into the Health Information Network so that they can talk to each other. And at the hospital I'm at, we can go into something called Care Everywhere and then look up the records of patients at other hospitals.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

This is Pat in New York and I would add that it would be wonderful to be able to talk to vendors to develop a singular platform to help move that forward. That's really what we've heard from hospital systems, as well as making sure – and being able to easily provide a link that really clearly delineates a MOLST versus advanced directives, because their medical orders needed in an emergency. So that I think would be a wonderful outcome that we don't have to wait for meaningful use if we're able to do that. I think that there's also great desire, given some of the changes under the Affordable Care Act, in terms of some of the unique systems that are in place to break down silos to make that happen.

The other piece is, it's just a link. When people want to be able to do much more in terms of integration beyond the link, then that's not something that we have funding for. The second piece is I think most systems have found using the link allows everyone to say, this is the state level service, one registry. In terms of people crossing care transitions, we'll always have the most up-to-date form, and there's no need to develop another workaround to create another database of PDFs of forms that are completed in the hospital.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

And this is Charlene, on that I would think that in addition to those low level requirements, potentially that link would be – would be very valuable.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

Yeah, and I think that people who begin to do this should get credit under Meaningful Use 3 for the activities, because it does take time to be able to train people to use it, etcetera, even though they see that there's value. And there are so many competing priorities in health systems today.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

Thank you.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

You're welcome.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you very much to everyone on this panel. There's a lot of great information and we really appreciate you taking the time to join us today. We're now going to move on to the implementers panel from the hospital and provider's perspective. As a reminder to all speakers, you have five minutes and apologies again in advance when I have to cut you off, if I do. Carol Wilson, are you ready?

**Carol Wilson, MSHA - Director, Palliative Care Services Advance Care Planning – Riverside Health System**

Yes I am, thank you. I have some slides that go with these comments, but just so a little background. I've promoted advanced directives in the community since the late 1990's, but at a certain point I learned that hospitals and families were not prepared to understand and honor the choices that people were making. So I shifted focus into palliative care development, so that the skill in the background of honoring these choices could be put into place. So, since that time I've worked on implementing the work processes that it takes to understand and honor choices and now, circling back to advanced care planning, which is so superior to just to focus on the form of the advanced directive. And having done so in two health systems, I've worked in acute, primary care, nursing homes, home health and hospice to try to get these things into place, wherever the patients may be.

So on the next slide, just in answer to some of the questions that were put to us, I think that the conditions of participation and meaningful use have established the ability for us to measure advanced directive, but that's only an indicator and this is just what a lot of people have already been talking about. Our focus in healthcare delivery now is on compliance. But in order to really make a change, it takes significant investment and without a champion in the organization, such as someone like me who takes it to the next level so that care delivery is actually affected. If you don't have that kind of focus, then that focus remains on compliance, which really doesn't get us as far as we want to go.

On the next slide, this is just something that people have talked about already. The advanced directive, adding to it and tweaking it so that it can serve all of our needs is really not going to get us where we want to go. Using advanced directives as a self-service form has led to the absence of a dialogue about goals and expectations and we're recognizing the burden of that now. There's still value in having that advanced directive though, I don't want to minimize it completely, because at the end-of-life, where we're really looking at the point where somebody is in the dying process, it's quite valuable there. And it is valuable for people who have sudden injury or illness, so I would certainly advocate for promoting advanced directives in people younger than 65, especially for that reason. But when we have somebody who is really at that end-of-life stage, we have set up a system where we're kind of forcing families to consent to the death of their loved one. The advanced directive is useful in us pointing to this being the wish of that individual, and reduces some of that burden. So I don't want to overlook the value that it had in that way.

On the next slide we were asked about what's needed and a lot of that has already been commented on. From my perspective, we need a better understanding of the purpose of the advanced directive, especially among healthcare providers such as nurses, in every care setting, about when the advanced directive is to be followed, which is when somebody has lost capacity. But then when the living will portion is to be followed, and that is usually contingent on a phrase something like, death is imminent or in a terminal condition with two doctors agreeing and so forth. In the absence of that, there can be misunderstanding about thinking that the living will applies in a point before it does. So if I'm implementing POST in Virginia, I have doctors saying – if I have both a POST and an advanced directive in front of me, which one takes precedence, and I have to go back to teaching them again that the living will has a very specific and narrow application. We have disincentive for the inefficient work of collaborating with patients, and I'm so glad that Mark Warner is not giving up on the legislation, so thanks so much for that work.

On the next slide I just want to talk a little bit about our experience complying with the standards. When we ask for the advanced directive at admission, we did a chart audit some years ago for deceased inpatients and found that there was really no correlation between the checked box and the advanced directive being in the record. Sometimes people are checking the box to say they asked the question, because again, their focus is compliance. In our outpatient practices, people confuse advanced directives with a DNR order, so the requirement that we notify people if we don't honor advanced directives has converted into places where it is appropriate to suspend a do not resuscitate order into the communication that we don't honor advanced directives, which is inaccurate.

Then we have providing assistance with advanced directives, which we do, but people need to have training in order to play that role, and that's not naturally occurring. And when we inform patients about their health status and medical condition, especially in nursing homes, patients and families do not have easy access to physicians, it's not in the standard workflow, unless we really are very intentional about it. And we're doing that now, but just as an industry, it's not a place where that collaboration is very naturally happening.

And then the next slide was our challenges incorporating the capture of advanced directives into the workflow. Typically, in my experience in hospitals, when paper documents come into hand, they're placed in a paper chart which is thinner and thinner these days of course, but those –

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

I'm sorry Carol, your time is up.

**Carol Wilson, MSHA – Director, Palliative Care Services Advance Care Planning – Riverside Health System**

Okay, thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. Dr. Forrow?

**B. Lachlan Forrow, MD - Director of Ethics and Palliative Care Programs - Beth Israel Deaconess Medical Center; Associate Professor of Medicine - Harvard Medical School**

Hi, hi, yeah. It's Lachlan Forrow, I'm here at Beth Israel Deaconess in Boston, Massachusetts. I've been working on this in one way or another for about 30 years or so, chaired a state commission on end-of-life care that I think you got a copy of the document of. I'm going to say a couple of very big picture things and then, actually I almost have more questions about – with this fabulous conversation. But, when we had our state commission and end-of-life care was the time that the death panel controversy also had erupted nationally. It was a sense, oh you can't touch this topic. But what we found and what we announced when we released our report was in effect, every single person we talked to in Massachusetts agrees with the themes that everybody else on this call has said. Regardless of politics, right, left, red, blue, people ought to be taken care of the way they would want to be and our healthcare system needs to be held accountable for ensuring that that is true.

And in Massachusetts, and including at my medical center, it is an everyday practice, somebody's been under our care, arrives in the emergency department and we have not made available the information needed to make sure we're taking care of the way they would want. Framing of that in Massachusetts that seems to be building some momentum is analogy with allergies. If a person's been under our care and they show up in the emergency department with a fever, we can't talk to them and the allergy field is blank, that is a serious medical error, absolutely unacceptable, people are upset. Even though there's controversy about the quality of the information in that field, if it's blank, that's unacceptable.

There should be two fields for people with serious advancing illness that are – should never be blank, one of which is, information on their preferred surrogate decision maker, in Massachusetts it's a healthcare proxy. And the second is their goals of care for backfield, the information is much more complicated than DNR kind of information, maybe even in a POLST form. And really requires the capacity which we do not have, even at Beth Israel Deaconess right now, for whatever written documents, POLST forms or others, that someone's prepared to have been scanned and immediately available, so we need systems for those things.

But one of the real challenges, we think, in order for people to take this seriously is how do we define the universe of patients for whom a blank field arriving in the emergency department in either of these two areas is system malpractice. Because, it's not – as people have said, it's not age 65, it's hard to define in other ways. But our sense within Beth Israel Deaconess and statewide is that if we just say do this for the patients that either have shown interest or you think it's important, then we will not ever develop the kind of accountability for it always being done for the patients for whom it's important. We've had some state laws passed, one of which now requires a doctor – every doctor with a patient with a terminal illness, prognosis less than 6 months to provide information about options including palliative care. But we actually don't have regulations or enforcement for how that actually will have teeth to it and would love to hear from other states or people on this call about what can we do in Massachusetts which has strong interest in this, both at the legislative level, the regulatory level and then in systems as we're rolling out MOLST. Because we're early in that, that might be a model or even testing out some of the things that you guys are doing in other places that would build to national consensus that it is unacceptable for information about preferred surrogate and goals of care or even care plan, not code status, that's not a care plan, to be absent in a medical record if somebody shows up in an emergency department. I'll stop here.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you very much. Jeff Beane?

**Jeffrey A. Beane, MD – Geriatrician – Kaiser Permanente**

Hi, can you hear me? Hello, can you hear me?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

We can hear you.

**Jeffrey A. Beane, MD – Geriatrician**

Okay. Good. Thank you. I'm Jeff Beane. I'm a geriatrician at Kaiser Permanente Medical Center in San Francisco, but I need to say that I'm speaking as an individual and not testifying or speaking on behalf of Kaiser Permanente. And thank you very much for the invitation to participate in this fascinating conversation. I am a geriatrician, I work in the hospital on the palliative care team and I work in patient's homes in our home-based primary care program, as well as hospice, and also do some work in skilled nursing facilities. So, we manage a lot of transitions and I want to talk a little bit about transitions, because those are the tricky parts where the narrative tends to get lost.

And so our – I think the vision that we have for the future and that we're trying to work towards is to have advanced care planning be a process that is really wired into the usual care process so that there are systems which promote the right conversation with the right patient at the right time every time. And that the information, the outcomes of those conversations are documented in such a way that the results are easily found and actually provide useful information to drive care subsequently by other providers who are not the people who may have had those conversations. And that's very challenging I think in any healthcare – certainly in our healthcare system, and I imagine in most other healthcare systems, too.

It's really challenging to keep the person at the center of this process and to keep who the person is and what drives them, because even though a lot of medical information gets transferred from site to site, it's often the narrative that gets lost. And who the person is and what their values are. And I'm also delighted to see that two of our major partners for Kaiser in terms of implementing this, both EPIC and – Program are the representatives from these two programs will be speaking later. So, I think it's important, in terms of documenting advanced directives, that they really be documented in a way that are extractable – so the information is extractable and searchable on a population level. This is something that's very important – so that we can act – so rather than like a PDF that's buried in 20 other PDFs. That an advanced care plan is actually information so that we can like look at our population and basically figure out who are the diabetics with Stage 4 kidney disease who have not had an advanced directive conversation. So that we can identify those people and have those conversations at the time they need to be had.

I was fascinated by the eMOLST conversation and I think that is – I want to talk a little bit about POLST, which is that I think that this transition from a paper form, which is the document which is scanned into an electronic medical record. A transition to an electronic form which could be printed out for use in specific locations is a really healthy direction for this to move, because we certainly see unintended consequences. Our community – facilities that we work with are held to the standard of making sure there's a POLST form in the chart. So they often will sort of generate a POLST and try to get – just try to push the completion of a new POLST, even though there may be a POLST which is based on a more kind of meaningful conversation. And so we have competing POLSTs floating around and if there is one electronic, central POLST that everyone understood was the actual document – I think that might be helpful. So I think I'll stop there. Thank you very much.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Ferdinando Mirarchi?

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot's Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

Hi. I'm Fred Mirarchi, I don't really have a set of slides presented there, so you might be looking at a blank screen. But I am the Medical Director of the Department of Emergency Medicine for one of the University of Pittsburgh Medical Center's Emergency Department in Erie, Pennsylvania. I'm also the principle investigator of a group of studies called the TRIAD studies. These stand for The Realistic Interpretation of Advanced Directives.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

I'm sorry. If you aren't speaking, if you could please mute your line and if you have your computer speakers on, can you please mute them. Thank you.

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot's Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

You okay Michelle? Hello?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Much better now, thank you.

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot’s Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

These are unfunded studies, we’ve got four that are published now and we have five and six in creation right now, actually being monitored now for their data. Six is pretty interesting, it’s the first one actually looking at POLST in clinical scenarios. Now I want to update the panel to what I feel are trying to bring about is a new nationwide patient safety concern that is not only underreported but unreported. Now many of you have said this already, but living wills have had issues, advanced directives have had issues. Living wills get misinterpreted as do not treat orders. DNR orders get defined as no care and treatment other than end-of-life care. This has been pretty much paramount in all the research trials we’ve done so far, which is really evident in TRIAD 3, which is our nationwide trial.

My concern here is that this is already applying to POLST. In fact, the POLST is being dubbed the “pink DNR form,” or “the blue DNR form,” or “the yellow DNR form,” and we have to correct this prior to anything going through as far as any type of EMR or access in even database. Excuse me a second, just get my notes – so, I wanted to make sure that people were trying to realize something here. This isn’t just an issue of end-of-life, this is actually an issue of patient safety. The buzz right now is end-of-life, though, because absolutely we’re trying to control futile spending. And I can tell you that the issues are on both sides of the fence right now. There are issues with over-resuscitation, there are issues with under-resuscitation. The over-resuscitation you hear about because it causes a lot of angst and concerns, patient’s wishes are trounced upon, there’s a lot of financial spending that occurs with it. Now I can say, this is a medical error, and I can say in my career not only have I seen this, but I’ve done this. I’ve done this when I was an intern, I’ve done this when I was resident only to be educated at a time where I was able to make some degree of an impact for myself. I can also say I’ve been a victim of this with my own father. My father had his documents misunderstood or misinterpreted and was left in a situation where he wasn’t resuscitated and passed away.

The TRIAD data shows that there is 80 percent misinterpretation of living wills. Now that may sound like a very big number, but it is what it is and that big number is translating into medical errors. We have to look first at data and at POLST in clinical settings, as well as any document in clinical settings with different designations. Now TRIAD 6 again is going to be our Pennsylvania Emergency Medicine experience with POLST and the data so far is following TRIAD 3 and that there’s a lot of confusion in clinical settings. And for this to be acted upon, someone else said this early on, the education is very important because if we roll systems and processes out without education, there’s no one else at fault rather than ourselves for allowing it to occur that way.

What I think we need to do, or what I’ve often touted that we could help to do is question or pause, what I often call something called a resuscitation pause following the surgical pause or the surgical timeout. Each time a document gets created to ensure its accuracy and a good tool is available on the National Healthcare Decisions Day website, NHDD.org on their tool site. We need to take the same action or a pause every time the information is accessed to ensure that delivery of the care is appropriate. I think someone else said there a few minutes ago about whether or not – how do we identify the validity of the person who may have actually submitted a form into a registry.

I can say it can be done, we’ve been making some local gains here. We need to do a better job to educate and create the documents and we need to pause before these orders are created. And then again, pause again when we access them to assure that what we are about to do is correct. Because I don’t think anyone has any ill intentions here, I think everyone is just trying to get it right and the getting it right with all the different processes that are ongoing becomes to be the issue. Registries themselves, an issue is that the accuracy going in isn’t really checked and I’m interested –

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

I’m sorry, if you have your speakers on, can you mute them, because we’re getting a lot of feedback and it’s hard to understand you.

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot’s Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

Oh, sorry. The registries themselves, the accuracy going in often times is a concern in trying to check what’s going in, as far as then what comes out, to affect patient care. Again there is an issue that I seem to hear about and people have tried to touch on it a bit as far as the confirmation of the identity of the person putting the information in. With advanced directives themselves, as far as them being retrieved as well, we’ve often found a number of instances where psychiatric patients who are depressed and able to put information into systems, only to come out and impact the care and treatment that was delivered.

Registries and EMRs I think are great, I really do, it’s just I’d like to see them somehow be able to put in safeguards or pauses to make sure that we get it right. Because again, I think everyone’s just looking to get it right, I don’t think people are having issues one way or the other on the side of the fence, whether or not they don’t wish to receive or provide treatment or just not wish to institute care and treatment, it’s just about getting it right. That’s all I have to say.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you very much. Bernard Hammes.

**Bernard Hammes, PhD - Director of Medical Humanities and Respecting Choices® - Gundersen Health System**

Good morning. If you could bring up the first slide. My name is Bud Hammes, or Bernard Hammes as is probably on the slide, and I’m the Director of Respecting Choices and Humanities at Gundersen Health System in La Crosse, Wisconsin. Respecting Choices, if you don’t know, is being implemented widely across the United States and one of our fundamental design principles, if you could go to the next slide, is an effective EMR to really improve advanced care planning using the EMR as one of your featured tools. And it starts from the premise that documenting and communicating a patient’s preference and goals is essential and is as important as knowing the patient’s problem list, medication list and list of allergies.

With this in mind, if you could go to the next slide, this would suggest that if we really wanted a system of healthcare that’s really patient or person-centered, the following would become an error if we failed to ask a patient about their preferences. Document those preferences when they’re known. Transmit or communicate those preferences when we have them to the next provider. And make sure that those preferences were adequately and appropriately used into critical medical decisions when that was necessary. So I think this is a premise that we’ve all been speaking about this morning, but I think we need to realize that knowing a person’s allergies is important, knowing their preferences is also important.

Next slide. So how do we operationalize this? Well in La Crosse, we’ve been operationalizing this in the medical record as a standard of care in both major health systems, Gundersen and Mayo Clinic since the early 1990’s, which became a principle of us and Gundersen incorporated this in our own EMR which we developed in the early 2000’s. So we’ve had a lot of experience here at Gundersen developing an EMR where advanced care planning is an important and a robust activity, and there’s a couple of references if you want to read more about our outcomes and about our work. Next slide.

So what do we need in an EMR? These are the basic principles, there’s a lot more that you could do. First is a navigator button, a single place that you can push in the medical record, it might be a tab that would take you to all existing advanced care planning information. And ideally this information and navigation needs to be available in all settings of care. So at Gundersen, whether you’re in the ambulatory setting, the nursing home setting or the acute care setting or emergency room, all the same information is available and updatable in all of those settings. Next slide.

So what do we need in this – what information do we need? We need all of this information in a single view that's easy and organized for the provider to follow. Next slide. The information is listed here, and much of it's been talked about today. So all types of formal and informal care plans, provider notes that describe a care plan, names and telephone numbers of legal surrogates. We include legal guardians in this list. Notes and types of previous planning encounters and conversations because sometimes people talk, but don't document yet. Documentation of assessments of patient status, so we know that we're updating and engaging patients, we have a record of that. Any medical orders providing for specific care plans including the POLST paradigm form and a referral process if organizations use advance care planning facilitators, so if a patient wants to talk, the physician can get the patient to the facilitator. Next slide.

In addition to having that information, we also need the EMR to actually alert physicians that that information exists. So if there is an advanced directive, if there is a power of attorney for health care, if there is a POLST form, there should be something that tells the current provider, say in the emergency room, one of these things is there, you should take a look, go to the navigator button. There also could be an alert to say it's time to update or review this care plan because it's been so long or because there's a transition occurring. And we also alert our providers to the loss of capacity. So if a patient has been determined to lose capacity, our EMR actually says, this person has lost capacity, you should talk to the legally appointed surrogate, because a lot of times people don't know that that incapacity has already been determined. Next slide. The final thing the EMR has to be able to do, I believe automatically, is to upload this into any regional health information if one exists, so that we can input it at a medical setting, say at the hospital, and then everyone else can do that and no one has to think about sharing that in any other way. Final slide.

So what happens if we don't have such a well-designed EMR? Well first of all, I believe from my experience, clinicians have little incentive to engage in good advanced care planning discussions. Because if they can't document and if they can't transmit this to the future care, what good is it to spend the time to talk with the patient when the only person who will know that is the clinician who's talking. We need to be able to communicate that, and if we don't communicate it, patient's preferences remain unclear and unknown, patient's run a high risk of either over or under-treatment, and families are forced into impossible moral decisions that can result in later behavioral problems. It's well documented in the literature, that families who are asked to make these decisions without any prior information, actually suffer great moral and emotional distress. And then as society, we pay for acute services that the patient neither wants nor will benefit from. Thanks.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. I think Leslie Kelly Hall is going to get us started.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Thank you very much. I very much appreciate the panel's participation. We've heard a lot of opportunities for integration into the workflow and ways to eliminate the profound confusion that seems to exist, even at the provider level, that might cause medical errors as a result. So there are both opportunities here for policy as well as interoperability and standards. We heard the importance of being able to have a common workflow, to be able to query registries that might exist outside the EHR, for the registries to respond back into the electronic health records with consumable and interoperable information. We heard the importance of the documentation itself being able to be consumed, to be queried, to be used. And also that specific roles and responsibilities need to be documented and standardized.

We heard that the EMR functionality used to support the values, the preferences and the care planning, and also this idea of navigator or, as Christine mentioned, the Info Button standard, to request information and see if information exists. We've also heard the importance that once gathered, this information needs to be able to be shared with HIE. And I think a novel comment came out earlier about the capacity assessment. And because EHRs do have a strong ability to do clinical decision support, is there an opportunity to expand those ideas for shared decision making and care planning. So I thank the providers for the robust discussion and welcome questions as well. Thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

It doesn't look like as of yet we have any questions from the workgroup members. Are there any questions?

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

Is this question time? This is Clem McDonald. I just was going to ask the discussion about the complexity and 80 percent were getting it wrong, and so there's really at least three forces that control the decisions, that's the orders and the two different kinds of documents. Isn't this a time to maybe simplify the process if we're having so many errors and the process is so complicated, rather than just train people better and better? Or is that even possible in the legal setting?

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gunderson Health System**

This is Bud Hammes. I'm not sure what you mean by the complexity, could you –

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

Well one of the speakers described reviewing the actual behaviors, that 80 percent are wrong, I behaved wrong and there's the orders, the DNR orders and their variance, there's the living will and then there's the advanced directives and they interact in complicated ways. Isn't there some way to simplify that interaction so that there isn't such a high error rate?

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot's Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

So this is Fred Mirarchi, I made that comment. One of the issues is that – I don't know, this has been an issue as far as confusion surrounding DNR orders for over 30 years now. So as far as the misinterpretation of advanced directives, I think this is just something that followed suit and followed through over time. I think right now with POLST, we've just got to make sure that this same thing doesn't happen with POLST. As I said earlier, people are calling this form "the pink form" or "the green form" or "the green DNR form."

Ideally I'd like to see things put in place similar to what's actually out there for surgical pauses or surgical timeouts. And a resuscitation pause is something that we've described in the literature so far and here locally anyway, we're seeing that it's actually helping. I've had a number of interventional areas essentially overturn incorrect or inaccurate DNR orders, which are patient safety issues to the patient. So I understand what you're saying, I don't know at what level that can occur, but I think if we put safeguards in prior to these orders actually being completed or stored, that would be a well-enhanced step in this process.

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

Well could – I don't think I am familiar with the notion of a pause. Where does that happen, at the time of order writing?

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot's Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

So, it would happen in two areas, and it's being called anything from the resuscitation pause, which we named in in Emergency Medicine, only because most of the times when look at these documents, it's in the form of some resuscitation that we're about to start, I guess. The other things it's been called is an advanced directive pause, and it's simply and A, B, C, D, E checklist and I'm a big fan of checklists as far as standardizations. And standardizations can be done with this in this process pretty quickly, in under 15 seconds someone can go through this process, and ideally it would be done at the time the order is completed and then at the time the order is retrieved. Because I can say this from experience, I've found many inaccurate DNR orders placed in systems and then when we go in to retrieve them, come to find that they implicate the care and treatment or hinder the care and treatment going forward.

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gundersen Health System**

This is Bud Hammes, the data that you've been given is not accurate for La Crosse. Our – we looked at every death at every health organization over a seven month period and 96 percent of every person who died had some type of written care plan, the care plan was in the medical record where they were being cared for 99 percent of the time. And 99 percent of the time, the orders or preferences expressed were followed correctly, whether that was for additional treatment or for withholding treatment.

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot's Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

You are corr – I have no doubts that you're correct and just about every system will do that, it will look and see what goes in versus what comes out, whether it's accurate or not. But you don't know the initial side of it, whether the order was initially created correctly. That's the problem with any registry –

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gundersen Health System**

– I think there's actually good evidence for that because the way we look at whether things are done correctly, at least on a gross level, is whether there's any lawsuits, any – most of these deaths occurred in the nursing home where state surveyors look at that issue again and again and again. We can find no evidence –

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot's Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

So –

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gundersen Health System**

– either through complaints, through actual lawsuits or through citations from state surveyors that preferences of patients are not being followed correctly.

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot's Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

So, as I said earlier, this is an unreported, yet alone an unrecognized problem and system process –

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gundersen Health System**

Well we don't have any data about this about –

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

So, this is Leslie and I'm going to cut the discussion and move on here, because I think we can acknowledge that there's some disagreement and opportunity for follow up. And so with time being short, let's see if there are any additional questions. Thank you.

**B. Lachlan Forrow, MD – Director of Ethics and Palliative Care Programs – Beth Israel Deaconess Medical Center; Associate Professor of Medicine – Harvard Medical School**

This is Lachlan, I just want to thank Bud for the wonderful presentation and even with the prior dispute, I think, I'm just repeating myself, the biggest problem we have is the absence of any information direction about care plans or goals and all of that. And until we have systematized, maybe even required that there be information there, it's hard even to manage, assess, analyze the quality of that.

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gundersen Health System**

Well, I believe that that's true Lachlan, is that I don't know that there's any analysis of that regarding any surgical decisions, chemotherapy decisions, so we have to be careful not to hold this up to a different standard just because it's about end-of-life. I mean, a lot of decisions are made in healthcare and I am not aware of anyone who's saying, are all chemotherapy decisions actually reflective of what the patient want? Are all surgical decisions reflective of what the patient wants?

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot’s Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

Actually, there is a fair amount of data out there. There’s actually published data, actually it came from Yale recently, as far as in a surgical literature, as far as DNR orders in surgical patients. There has been a vast amount of data that’s been published as far as decision making upon physicians with the term DNR. And essentially actually having just about every phase of care being diminished, everything from basic medical care and monitoring to advanced decisions such as something as simple as a blood transfusion. So that data is actually there.

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gundersen Health System**

And what does it say?

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot’s Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

It says that it’s significantly diminished.

**Elizabeth Johnson, MS, FHIMS, CPHIMS, RN-BC – Vice President, Applied Clinical Informatics – Tenet Healthcare Corporation**

Hey Leslie, this is Liz Johnson. One of the things as I listen to this conversation and think about the criticality of having the right data and so on, one of the next steps we might want to follow with is the actual ability to store the data. I mean, we’ve talked a little bit – it may be coming in another panel, and I know some of the vendors are much better about that. But that could be a follow on step as to the kinds of data that’s being discussed now and what makes a truly rich composite of the things we need to decide. Because one of the things I was thinking about even with the timeout, which I love that concept, but I’m thinking, I’ve got a patient who’s now unable to give us information and how is that going to work. So maybe we could work with the vendors and other providers as well, to really figure out how can we capture the right information.

**Ferdinando L. Mirarchi, DO – Medical Director, UPMC Hamot’s Emergency Department; Chairman UPMC Hamot Physician Network Governance Council**

One last comment I want to make, I mean, someone made a comment as far as seeing something diminish or stop this. My intentions here are not stop anything, just to make it a safer process. The point being is that just like every other problem that exists today in medicine, simple checklists and standardization can’t help fix these issues and right now, whether it’s agreed to or not, there’s an issue with this in that no one confirms accuracy. And if you take a look at antibiotic orders, we check antibiotic orders for consistency, accuracy and so on, there are multiple checklists. But that order whether or not to institute care and treatment or not institute care and treatment has no checklist.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

And this is Leslie. I think that’s a good comment and I think it gets to the first problem we have, which is managing a void. You can’t check for accuracy on a zero, well, I guess you can on a zero, but on the lack of information. So I think we have multiple problems that we’ve heard about throughout this and looking for solutions on each one, where do we start? And it seems that – whether documentation exists, it should be available. The roles and responsibilities of people we’ve heard over and over again, that that needs to be documented and proved accurate, as well as the functionality to support interoperability and consumability by the EHR, and a navigator to find that information within the EHR. So, Michelle, I’ll turn it to you to see if we have additional questions.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

We do. Charlene Underwood. Charlene?

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

Sorry, I was on mute. So Leslie, to follow on to your comment that you just made about the data and making it consumable. One of the areas that I'd like the panel to comment on is the degree to which you want to see information about goals, values and preferences in free text versus in a coded form. Again, part of this information shared, so again, being sensitive to the fact that this needs to be checked and the orders also, to some extent, need to be encoded. Talk about as you see the – we're trying to figure out where to start, how we should be moving forward in terms of capturing the data and ultimately sharing the data. Was that clear?

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Were you asking me Charlene or were you asking the group?

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

No, the panel, the panel.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Thank you.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

I wanted them to comment on their views in terms of how the data should be captured, specifically related to goals, values and preferences and shared.

**Carol Wilson, MSHA – Director, Palliative Care Services Advance Care Planning – Riverside Health System**

This is Carol Wilson, I might take a stab at that. We've tried to implement documenting patient's daily goals in our hospitals so that from the patient's words we're documenting what they want to accomplish. And it really took some additional training to get our staff oriented to the patient's perspective, because initially they were documenting things like walk 20 feet, which is the healthcare provider's goals, not the patient's goals. So when we really got to that, we had the story that we'd begin to teach with was a woman who said she has to be able to take care of her own hygiene in the bathroom, because if she goes home, her son-in-law was going to be her care provider and she couldn't tolerate that. So this helps us understand that so we can document it. We have a good system, but I think a lot of training and re-education has to be part of it.

**B. Lachlan Forrow, MD – Director of Ethics and Palliative Care Programs – Beth Israel Deaconess Medical Center; Associate Professor of Medicine – Harvard Medical School**

This is Lachlan. I think, as I said before, we need simple, on a dashboard, that there is a proxy and then goals of care. For the goals of care, we've concluded even within our own single hospital, there isn't currently consensus and may never be standardization about exactly what that looks like. And so we're looking at adapting what Bud Hammes was describing that they've done, which is, there's something simple on a dashboard that indicates that there's information where you click and then link to either scanned documents or maybe more helpfully, narrative notes that include the patient's voice. And that's the kind of structure, I think, because if we wait until we've agreed nationally on standard ways of capturing, expressing patient's goals across the vast heterogeneity of patients, their conditions and all that, we'll never do anything.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

Okay, thank you.

**B. Lachlan Forrow, MD – Director of Ethics and Palliative Care Programs – Beth Israel Deaconess Medical Center; Associate Professor of Medicine – Harvard Medical School**

And as Leslie said earlier, you can't manage zero blankness, we have to start doing things.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

Okay.

**Jeffrey A. Beane, MD – Geriatrician**

This is Jeff Beane. I think there's a distinction between the POLST, which is a very binary kind of document.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

Yes.

**Jeffrey A. Beane, MD – Geriatrician**

It's either – it's a "yes" or a "no," that's the answer to each of these questions. I mean that is an example of a rigidly formatted sort of information set for the patient's care. So that can be very standardized with yes/no questions. On the other hand, the advanced care planning and goals of care is kind of a somewhat more qualitative conversation, but at the same time, I think by kind of standardizing some of the documentation around how the conversations are conducted and how the goals are expressed actually can improve quality. So, there's one more example in healthcare of where standardizing a process improves quality.

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gunderson Health System**

This is Bud Hammes. I just want to follow up on that last comment about standardizing the process. That really has driven the ability in La Cross to standardize the workflows. If you don't have a standardized process, it's hard to standardize any workflows to keep things more organized, so the type of documents and documentation that we use in La Cross can be more easily standardized because we have a standardized medical record to communicate in and store that information. Just in a typical patient who dies in our community, it's very common for that person to have a power of attorney for healthcare with listed healthcare agents, a POLST form if they're at that stage of their health condition at the end-of-life. And anywhere from two to three different provider notes that proceed and sometimes go back four or five years about goals of care. So if that patient were to hit the emergency room, our emergency room physician would have a POLST form, would have a power of attorney for healthcare with an appointed healthcare agent and provider notes going back five years that list the discussions with that patient and typically changing goals of care as the health condition gets worse. Such information can provide the emergency physician with a tremendous wealth of information which allows them then to talk with the patient, if he's still capable, or with the healthcare agent if not, and then really sort through where this decision is at, and then make a final decision based on that prior information. And I would say preparation of that patient and/or family or healthcare agent to be able to make a decision. And one thing that clearly does is either prevents people from either coming to the hospital if that's their choice, or if they come to the hospital, things can be sorted out much more clearly and much more efficiently in the emergency room when that assessment is needed in the emergency room.

**Charlene Underwood, MBA – Senior Director, Government & Industry Affairs – Siemens Healthcare**

Thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. Leslie, do you have any final comments before we move on to the next panel?

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

I think that most everything has been said, I think the – just the importance of knowing a starting place, as Charlene discussed, and also recognizing that workflow is important to have this integrated at all points of care and interoperability is necessary as well. So, thank you very much for the panel and I look forward to hearing the next two.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. So we're going to move on to the next implementation panel. And if Paul Malley is ready, we can get started.

**Paul Malley, MA – President - Aging with Dignity**

I am here.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Okay, go ahead Paul.

**Paul Malley, MA – Director – Aging with Dignity**

Okay. I'm going to talk a little bit from a different perspective than what we've been focused on so far. I work at Aging with Dignity, I'm the Director of Aging with Dignity, I've been with the organization for about 15 years. And our focus, if you could advance to the next slide, is on three different areas, action, advocacy and resources. We're inspired by the work of Mother Teresa of Calcutta because our founder worked in her homes for the dying. And so our focus is on – for promoting the acknowledgement of human dignity, the respect for human dignity, especially for those near the end-of-life. On the action side we're focused on training on advanced care planning, doing both training for providers and for patients and for families, advocating for policies that give maximum control to patients and families as their making these decisions, and the resources, the advanced care planning documents, the discussion guides that go along with those. Those are our main areas of focus. Next slide.

What we're probably most known for is the Five Wishes Document. This is a type of an advanced directive. We were fortunate to work with Charlie Sabatino, who spoke earlier, as our legal consultant because what we wanted to try to do here was to bridge this world of advanced care planning or advanced directives. When they began in the 1970's the focus was just on the legal and the medical side of things, but we knew that individuals and families had specific ideas about what good care meant at the end of life, things like I want to be at home, I want to be comfortable, I want my family with me. So we combined those elements in this document, but it's still a legally valid designation of a durable power of attorney for healthcare and gives instructions about life support treatment. It's legally valid now in 42 states, it began in 32, now it's in 42, and just in the next month, we'll mark 15 years of national distribution and we're just crossing the threshold of distributing 20 million documents.

We work with partner organizations, as you'll see on the next slide, 40,000 organizations scattered all over the country. If you could bring up that next map there. Each of these dots represents an organization, it could be hospital, hospice, physician group, churches, places of worship, employer groups that use this document to engage the public. So that's what we're talking about here is that – and how they interact with their healthcare providers. And the next slide please. We also have an outreach to diverse communities and we have bilingual documents. You can see here an example of I think this is in Bengali on the left and English on the right, so that a person who speaks a language other than English can fill out the document in a native language and it can still be understood by the healthcare providers. If you could click past the next slide, is a list of some the languages, 27 that these documents are available in.

And on the next slide, you can see a sample, a screenshot of a new resource that we have called Five Wishes Online. And this is a way that people can fill out the document on their screen, kind of like the way you would fill out TurboTax or insert the brand name, the way that a lot of us fill out our taxes, filling in the documents, printing out a hard copy form. The challenge that we have is that right now this is a delivery system, it's a way to put a completed advanced directive into the family or the patient's hands. They still have to sign it and have it witnessed by two people before they give that hard copy to their hospital or to their provider. But we have 18,000 people that have started this process and 15,000 that have completed it, so about 83 percent that start it complete it, and we're encouraged by that. Next slide please.

A couple of points on how Five Wishes is used right now in electronic health records. We work with like I said thousands of providers and it all depends on the system that they have, so it's very segmented and based on what that healthcare provider does. On the next slide, a couple of points on bridging this world between the clinical, the technical and the personal, this is a challenge. How we translate the patient decisions into the data. And on the next slide, I've tried to pinpoint what I think is the elephant in the room, and that is, that we're talking about end-of-life care and the focus should be on what the patients and the families have talked about and how to quantify that into data.

The next slide, and actually if I could forward one more, because I know I'm bumping up on my time. Here is a recommendation that I offer for your consideration. We've talked about meaningful use measuring the use of advanced directives, I think it's worth considering a two-track approach, one for advanced directives and one for the medical order model, because I think we want to be careful not to give deference or priority to the provider-generated order documents over the patient and family generated advanced directive documents. And with that, I'll conclude my comments.

**Michelle Consolazio – Interim Federal Advisory Committee Act Program Lead – Office of the National Coordinator for Health Information Technology**

Thank you Paul. Is Jeff Zucker on the line?

**Jeff Zucker, MBA – Co-Founder and CEO – ADVault, Inc**

Yes, I am.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

So, as a reminder Jeff, five minutes and I may have to cut you off, so, go ahead.

**Jeff Zucker, MBA – Co-Founder and CEO – ADVault, Inc**

Great. Thank you everyone for being a part of this today. I think we all know that advanced directives are vastly underutilized in terms of improving quality outcomes and controlling costs. We as a company believe real-time access to high-quality advanced medical directives is an effective tool to empower consumers, that's the real heart of what patient-centered healthcare is all about. We also believe that the technology exists today to allow people to document their medical treatment preferences and make that information accessible to professionals and others in the case of an emergency if they can't communicate. And in order to maximize the value of the new technologies, with respect to advanced directives, we recommend standardizing the requirements of advanced directives and clarifying some of the confusion around the 20<sup>th</sup> Century approach, the state-centered sort of paper-based approach.

We believe it's critical to shift the time and the place of this conversation from the operating table to the kitchen table. And documentation about emergency and advanced care medical treatment preferences should benefit from the same technology advances that are being mandated and applied to every other aspect of the healthcare system today. Every American citizen should have the confidence to know that his or her treatment preferences are accessible anywhere at any time. And we believe this Committee has the power to make that happen. We believe the burden should not be on doctors to document a patient's advanced care preferences. We don't believe the consumer wants that, we believe people before they become patients can establish baseline advanced directives themselves and that in fact they want to. The technology exists today to do so and we see people doing it every day.

If we could go to the next slide. Cloud-based technologies enable consumers to securely create change or even revoke an advanced directive, long before they ever become a patient, and that's a critical distinction. Last year, after a number of years of research and development, we as a company went live with MyDirectives.com, the first HIPAA compliant, web-based system for creating, storing and retrieving advanced directives. Today we have users in over 40 states in the United States, as well as Canada and most of Western Europe. We see users in Russia, Israel, Japan, Singapore, Australia, all using MyDirectives. Next slide.

The HL7 consolidated clinical document architecture, the CCD standard if you will, and the continuity of care document recommended by the S&I Framework as the document of choice for meeting the certification requirements for Meaningful Use Stage 2 have already addressed some of the obstacles to the adoption, implementation and widespread use of directives. For example, a limited standard vocabulary has been established for encoding preferences regarding intubation and tube feedings. The Committee should take those standards to the next level and require the full integration of a person's wishes for medical treatment into EMRs and EHRs.

We believe the Committee should strongly recommend advanced directives as a core requirement for meaningful use and furthermore, we believe EMRs and EHRs should be required to incorporate the specific medical treatment preferences into the CCD. Requirements for the inclusion of directives in CCD documents should also be expanded. Currently the new care plan document does not require, or even recommend, inclusion of advanced directive information nor do the discharge summary, operative note or procedural note. Documentation of a person's advanced directive should be communicated as part of these records. Next slide.

In the future a richer, more comprehensive vocabulary to express the different types of treatment instructions found in the variety of advanced directives or POLST or MOLST forms and other types of more personal preferences, will also be needed. Adoption of a richer standard vocabulary will expand the ability of EMR systems to record and share the right information with the right people at the right time. We also applaud the Committee for considering and asking about the change in the age threshold. While 65 seems to be a key milestone in the aging process, it's not as significant a demarcation when it comes to understanding the value of advanced care planning. Improvements in healthcare outcomes made possible by advanced directives often occur when people are younger than 65, and most of the landmark cases establishing and confirming the value of directives have involved people in their 20s and 30s.

As recently as a few years ago, cloud technology was not robust enough to offer a comprehensive, scalable solution for society, but today the worlds of technology, healthcare, security and consumer engagement have all converged. And we're proud to be a part of it. We applaud Dr. Mostashari and the entire team for pushing upstream often to move digital technology into the forefront of the dialogue and we'd be happy to answer any of your questions.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you very much. Doug?

**Douglas E. Winesett, MD – Physician, Clinical Informatics - EPIC Systems Corporation**

Yes.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Go ahead.

**Douglas E. Winesett, MD – Physician, Clinical Informatics – EPIC Systems Corporation**

Good morning everyone. My name is Doug Winesett and I'm a physician on the Clinical Informatics team at EPIC. EPIC provides enterprise EHR software which organizations use to care for patients in a variety of settings including the ambulatory setting, the acute care hospitals as well as the post-acute care setting. And many of the organizations using EPIC software also do this in more than one state. And I thought in my limited time, probably the best approach that I could have is to help people to understand that flow within an EHR for collecting this.

So a patient and their family are counseled by the appropriate people, the setting most typically is going to be an inpatient setting, either by the attending physician or a primary care physician, but in a lot of settings, it could also be a social worker. But you also have the ability to do this in either the ambulatory setting or in the long-term post-acute care. The advanced directive document or – and I'll talk about POLST or ePOLST in a second, but for right now we'll say the advanced directive document then is created on paper. Then usually a staff member, that could be a registration staff member, a nurse or another user, would scan that paper form into the electronic health record and it is stored at the patient level.

And that's important for a few reasons, first it will check a flag that will indicate that there is an advanced directive on file. That information can be noted – you can note that in the patient header so that any time you're in that patient's chart, you have an indication that that advanced directive is on file and by selecting or clicking on that notification in the header, it would take you to the area in the chart where that document is located. That flag is also used for meaningful use and in addition, we can transmit that flag, i.e. whether the patient has an advanced directive on file, through Care Everywhere, which is our interoperability offering through that continuity of care document. Also important because that information is stored at the patient level, it is visible anywhere that patient is within the organization, again, ambulatory, emergency department, acute care hospital or post-acute care.

Now interestingly, we've had organizations start to collect POLST forms electronically as well, Providence in Oregon is doing that. They collect the various elements for Oregon's POLST form as discrete elements within the electronic medical record, and then that information is printed onto a PDF document that is a legal document that they can give to the patient. It could also be faxed to their state registry, but in addition, the discrete data from the electronic medical record can also be transmitted directly to the state registry. And because that is all discrete information, you can do reporting on that information today. I think I'll stop there and give people a chance to ask questions. Thank you very much.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you Doug. Larry Wolf, do you want to get us started?

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

Sure. Thank you. So I feel like we're sort of shifting here from a lot of general into some very specific things that people are doing in terms of documenting their own wishes, their own information, if you will. And I wonder if you'd comment a bit little more, Doug sort of raised this, but I wonder if all three of you would comment on the relationship you see between the efforts that you're involved with and how these might relate with state registries?

**Paul Malley, MA – President – Aging with Dignity**

This is Paul. I would say that from our perspective, working at the national level, our approach has been to position our – both our work as far as our advocacy, our messaging, what we're telling patients and families to support any regional or local efforts as much as possible. So what's happening in Wisconsin or Texas or some other location, what we aim for is to support that whether it's through the data output from Five Wishes Online or through the message that we give to the individuals. That has always been from the beginning, it's not enough to complete an advanced directive, it's important to talk about it with your family, give a copy to your healthcare provider and make sure that it's a part of your medical record.

But from that perspective, what we would aim to do is make that delivery method as accessible as possible not just to the patients and the families, but to the providers as well.

And I think that question comes into play, what's patient-generated and what is provider-generated. I think for years we've been telling patients and families, talk about this at home, talk about this together, then relay what's important to you to your providers. And that's where the rubber often meets the road, is in how that's translated into care decisions, and that's where POLST or the medical order model comes in, if it's done for the appropriate people. And that's why one of the suggestions I offered was to split these two tracks because I find myself agreeing with all the experts who have talked about POLST, that it is appropriate for people with a life-limiting illness, who can make decisions based on a specific diagnosis and the treatments that are likely to come into question.

But what we know is happening is that often times providers are using these medical orders for people who are – for whom it's not appropriate, for every person who walks into the hospital, who may not be able to make these specific treatment decisions. So I would want to make sure that whatever is done on the electronic medical record side still supports the involvement, especially of the healthcare agent, in that final decision making process.

**Douglas E. Winesett, MD – Physician, Clinical Informatics – EPIC Systems Corporation**

This is Doug. Related to the state registries for POLST, we certainly have organizations using EPIC who their goal, and again I'll use Providence in Oregon as an example, they found that when the providers and families completed the forms on paper, they had about a 20 percent error rate. An error could be something as little as it wasn't dated, someone forgot to sign, there was a specific element that wasn't addressed. And by pulling that into the electronic medical record as discrete data and noting when those fields were required fields, etcetera, it did improve the accuracy or completeness I guess more directly, of the data that would be submitted to the Oregon POLST Registry.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. It doesn't look like there are any more questions from the workgroup members, but I'll do a last call, any more questions?

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

I'll toss out an observation. I guess I'm hearing that there's probably value, Doug mentioned this in his final comments as well and so did Paul about the online tools do allow you to structure it and also to go from the electronic structured information into a printed document that could be signed and then live as a paper document. Our dual-world with paper and electronics can create version issues and all of that. But do you feel that we're sort of at a tipping point where we're going to go from this primarily paper-based getting scanned to its primarily discrete that occasionally gets printed to have a point-in-time version?

**Jeff Zucker, MBA – Co-Founder and CEO – ADVault, Inc**

This is Jeff Zucker from MyDirectives. It's a great question and it's at the core of what we do as a digital service. We hear from consumers every single day that the paper-based world is scary to them, it has a degree of finality, it is an obstacle to them creating an accurate, fluid, dynamic version of their thoughts and wishes. So when we designed our system, we listened to that feedback and we were – we designed a system that allowed the consumer to login at any time and update their wishes. We use the digital world to ping them to ask them if these are still the right contact points for the HCA or if these still are their wishes and intent. We give them an opportunity to update them. We see people responding with the traditional yes/no, we see people using open-ended.

We have a digital feature that lets people take their iPhone or their iPad or any webcam and upload video messages. And we see them have confidence that their advanced care plan, that their advanced directive is a thorough and accurate view of their wishes, that they're able to convey and share with their family and whoever the provider is at any time. So, to your question about is there a hybrid between the paper and the digital, we see digital in almost every other aspect of society, we think this is one of the areas that really needs to be more forceful in moving in that direction. And the result of it is a much more empowered consumer that feels confident, and that lends to not just how you die, so to speak, but it really speaks to how you live. You have confidence today that your wishes can be found and you don't really have to worry and fret about it.

**Douglas E. Winesett, MD – Physician, Clinical Informatics – EPIC Systems Corporation**

This is Doug again. I think most of the organizations that I've dealt with on this matter, in fact the vast majority, are not capturing the data as structured data for each individual element. As people have said, some things lend themselves very well to discrete yes/no question, other areas in this debate certainly would be difficult to capture as a discrete element. So I don't think that in my mind we're at the tipping point where it really should all shift to doing this electronics. Certainly being able to have access to that document and the most up-to-date paper form and knowing that there is one on file is very important. And I think a large majority of our organizations would do that today, i.e. putting that type of information where it's readily available in a header, without someone having to go to a specific area of the chart to note that. And so I'm not sure we're at the tipping point where people are going to want to gather all of the information discretely.

**B. Lachlan Forrow, MD – Director of Ethics and Palliative Care Programs – Beth Israel Deaconess Medical Center; Associate Professor of Medicine – Harvard Medical School**

This is Lachlan. Whatever the digital future, I just got a letter forwarded to me from the head of our hospital from a patient who was outraged, and was correct, to learn that some time ago he had brought a very thoughtful, hard copy advanced care planning document, had given it to his primary care doctor. And then it's buried somewhere in a hard copy medical record and if he was in the emergency department, it wouldn't be available. Patients today coming with Five Wishes or document, handing it to their doctor ought to be able to know that has been captured, scanned and is available if they're in the emergency department and that's not true today.

**Douglas E. Winesett, MD – Physician, Clinical Informatics – EPIC Systems Corporation**

This is –

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

I guess I'm hearing a combination of things here, so, things vary from the content maybe as non-structured as a video or an audio of the individual stating their wishes, to free text narrative type text to some structured things. But there also could be some high level flags that indicate the existence of this information that could be consistently flagged in the chart, so you know it's there, and to get around this problem of the information is somewhere in the chart, but disappears in a sea of lots of documents.

**Douglas E. Winesett, MD – Physician, Clinical Informatics – EPIC Systems Corporation**

And this is Doug again and I absolutely agree with that having an indication in the header at the top of the EMR for that particular patient that there is an advanced directive on file. Simply clicking on that would take you directly to a tab that contains the POLST form, if that's been scanned in, as well as another advanced directive form if there was additional information that's not covered in the POLST and so going directly to that area of the chart. Absolutely I would agree with that and that is available today.

**Paul Malley, MA – President – Aging with Dignity**

And this is Paul and I would add that I agree on the double platform perspective. I don't think we're at the point where advanced care planning can go completely digital because I think of our outreach in diverse communities and working with housing authorities and public health clinics. And things where – places or communities where a piece of paper is important to be able to sit around a table with someone in a way that they feel comfortable presenting it and talking about it. But at the same time, Lachlan was exactly right that people do expect that if they walk in to a provider and give a copy of that document, that it will be there and be accessible.

So I think there is a way to thread the needle by letting people make decisions in the platform and using the voice and the document that they feel comfortable with, whatever that happens to be. And then trying to capture that data, but also in a way that continues to involve the patient and the family. I think the last thing that we want to do is capture some static document or a care discussion document it in an electronic medical record and then have zero engagement back with the patient and the family again. And we know the balance of power between providers and patients and caregivers that they often don't feel that they have that authority to be able to question what's in my mother's healthcare record and can I see it and what is the POLST order that exists that may or may not have been seen by a family. So both platforms I think are important.

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

This is Clem. Could I ask one of the speakers who made a comment that I'd like him to elaborate on, it was that it's important – more important to use these documents when you have a specific disease and disorder than ones at perhaps at age 20 someone said generically that I don't want this or that. Could you elaborate on that?

**Paul Malley, MA – President – Aging with Dignity**

Sure, that was me. This is Paul. And I was commenting on the distinction – the difference between a standard advanced directive and a medical order, a POLST or a MOLST. The importance with the medical orders is that because they are definitive, they're absolute, they're giving specific orders for resuscitation or life-sustaining treatment where there's no trigger condition, where in an advanced directive, there's a trigger condition that person is terminally ill or near the end-of-life and not able to make their own medical decisions then. So advanced directives are if/then documents.

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

Uh huh.

**Paul Malley, MA – President – Aging with Dignity**

POLST or medical orders, there's no if, it's just the then. And the reason that that makes sense for people who are near the end-of-life is that they have a good idea of what their diagnosis is, they've had the discussion with their physician. They can forecast what may happen to them and make decisions based on that forecast. The danger happens if these medical orders, if the assumption is that every patient should have one, it would be impossible for me or even for me to have a conversation with my mother today to make very specific treatment decisions because we have no idea what may bring about the end of my mother's life, for example. So, if you're going to go down the road of filling out a POLST or a medical order, then it's important to have on that order the basis for the – the diagnosis that is the basis of the order.

**Clement J. McDonald, MD, FACMI – Director, Lister Hill National Center for Biomedical Communications – National Library of Medicine**

Would that also imply that it wouldn't be done for a young, healthy person?

**Paul Malley, MA – President – Aging with Dignity**

That's right, and I think that's the message that we've heard through many of the experts who have talked about POLST is that it is for someone who is near the end-of-life where there are many variables that are already known. They understand the diagnosis, they can make those decisions, that's the idea of POLST. The caution that I offer is that having our ear to the ground, from healthcare providers and patients and families, that is not exactly the way that it's playing out and part of that is because those – the models are very segmented in some states, some states don't even require a patient to sign the order. So you could have filled out an advanced directive with your mother, she could have named you as a healthcare agent, but sometime she had a conversation with a physician in the hospital who entered in a medical order that's on file that maybe you see or maybe you don't. And then the obligation of that provider to contact the healthcare agent when decisions are made, in some cases is non-existent anymore, that's the danger that can happen.

And that's why I think this Committee may be in a place to bring about some education in the provider community, if there is a two-track structure saying advanced direc – or measuring advanced directives and their inclusion in the electronic health record for everyone over 18. And then looking at medical orders to see if they existed for a patient at the time of death. Two very different tracks, because my concern would be, many in the provider community see the medical order model as quicker and easier and more absolute. It takes the guessing out, it takes the mediation of family disagreements away, and I understand the desire to do that, but a good end-of-life care – a good death for a family is hard to put down in check marks on one piece of paper. And so I think making that distinction is important.

**Jeff Zucker, MBA – Co-Founder and CEO – ADVault, Inc**

Paul, this is Jeff from MyDirectives and we completely agree, the audiences are different and to the questioner, someone in their 20s and 30s without a particular diagnosis obviously the POLST paradigm is not relevant to them. To their parents or their grandparents or someone else in their community that does, it might be relevant. And so part of that education curve for us is to educate our audience on both issues. In fact, the first question we ask in our digital platform at MyDirectives.com is if you have POLST you can upload it. So, for all intents and purposes there's a national registry of the POLST paradigm today because we allow people to upload them, if they have them.

But we realize most people don't and if they do, they're at the very end stages of life and the need for that document to be dynamic and changeable, to reflect the changing situation in their life is less relevant than a really good quality emergency advanced care plan. And so there's no substitute for breaking down the fear and the confusion in the consumer marketplace that's been building up for decades and decades. It's not going to happen overnight, but we have seen a consistent improvement in the dialogue of consumers, the way they are able to engage with their family members as they create good, quality digital advanced care plans, setting the stage for some people in that family to actually have a POLST or a MOLST. So that when the doctor approaches that topic with them, it's not a complete shock and it's not an admission of more fear, it's the obvious next stage.

And so in our desire to create a system that was robust enough to pivot a topic that's been in the shadows too long, we felt a need to do both. And again to the questioner about someone in their 20s and 30s, it's not necessarily appropriate if you don't have a diagnosis, but it's incredibly relevant just like the boy scouts says, to be prepared. It's incredibly relevant to have a good emergency advanced care plan and society just doesn't ask that question until it's too late, we've heard all the speakers this morning talk about that.

I wanted to add to Lachlan's great question or comment about the directive that someone took the time to create but couldn't be found. We designed our system after all the R&D to deliver a link to the database, not a scanned PDF of a document. Because that gets back to what I was just saying about something being static and that causes the consumer then to feel the document is too final, too finite for them and it scares them and they don't create a good document in the first place. So we deliver a link, the link is to be embedded in the electronic medical record, it's an API, we provide that for free to EPIC and to our providers.

And that link is a real-time touch to the database so if a patient were discharged and they go home and they make an adjustment to their healthcare agent or their preferences or upload a new video message to a family member or a caregiver, the next time that link is touched, the new version is there. We keep all the audit logs, we're able to see when the changes were made, any provider can certainly have the historical record to know what was treated when. So we really have taken a lot of time to deal with that issue, but the root cause of the problem we were trying to solve was empowering consumers to take ownership for their decisions and to have the confidence that a provider will understand who they are, what their hopes and fears and goals are. Thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you all. Any final comments Larry, before we move on to the next panel?

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

No, just thank the panelists, it's been a very rich conversation.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Okay. Thank you everyone. And so now we'll move on to the patient panel and we'll get started with Amy Berman. Amy, are you available?

**Amy Berman, RN – Senior Program Officer - The John A. Hartford Foundation**

Yes I am.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Okay, go ahead.

**Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation**

Good morning all. I have an unusual role here today because I believe I am the only person on this panel who is, in fact, seriously ill. I am terminally ill and I am going to talk from the consumer perspective about what it is that people actually want in these kinds of situations. I'm going to talk about care planning before serious illness, in serious illness and at the end-of-life because they are three distinct things. First is a little bit of background. I will say that we do much too little and too late. When we talk about too little, for example, we've talked a little bit about the conditions of participation that when you go to the hospital, they will ask you if you have an advanced directive and they will offer to help you complete an advanced directive, that does happen. But you can, I guess this is also called meaningless use, that metric alone, because you can, in fact, say that you don't have an advanced directive nor do you want an advanced directive, and that means that you can have 100 percent response and you can have zero advanced directives, which is entirely meaningless.

Anyone is able to, including the 26 year old we just heard about on the last panel, can have a healthcare proxy, and this needs – that healthcare proxy is only as good as the conversation that goes with it, to help the family member understand a person's values and goals, which are going to change over time. Those conversations should happen within families over time, but having that healthcare proxy is something that anyone should have and I'll tell you why. Seventy-five percent of people are unable to make some or all decisions at the end-of-life, 75 percent, we never know when we are going to be part of that group and so, in fact, without that healthcare proxy, for many people they will not have an advanced directive at all. In the last panel we heard a lot of discussion about the POLST, which is only for someone who could reasonably be anticipated to die in the near future, that is where they have a known diagnosis, a known situation, where they are planning around the specifics, as this last panel discussed. It is triggered by a condition or more likely, a set of conditions.

But for most people, they are going to live with serious illness and multiple chronic disease for a period of time and they don't know where that bright line begins that they enter end-of-life. And so it is for that reason that I say that all of the advanced care planning and discussions need to be normalized. When a woman goes into labor, we don't ask what kind of birth plan she wants when she's in active labor, there is a process by which we prepare people for things that are reasonably going to be anticipated. In this country, 2.4 million people die each year and yet discussions around end-of-life with their clinician, as well as with the family or the individual who will serve as their proxy, are wholly uncommon.

So the question is, if we are going to move to patient-centered care, which I think we want to do, there are three important pieces to what patient-centered care is; it involves patients and families in the design of care, reliably meeting patient's needs and preferences and informed or shared decision making. We are really talking about all three when we talk about care for serious illness, this advanced care planning. And in this regard, I would make a number of recommendations. For one, health IT could be used to support access to information, and we've talked a lot about how this could potentially happen. What we didn't talk about is moving from a reactive environment to a proactive environment. How do we not put the oneness on the individual, the person, to share information, to store it somewhere and to hope that their provider's going to reach it? But how are we going to embed this in a way that it has the same reliability as telling your provider that you have a penicillin allergy, and knowing that they're not going to provide a medication that's in conflict with that? How are we going to embed it so that it appears high up in the order of things throughout care an across environments?

So this is something that needs to be far more fundamental in the build within our system. I do agree that someone has to be able to understand the components of what was written on the advanced directive. Advanced directives can be relatively simple, but again, with the healthcare proxy you need to reach that healthcare proxy, that information typically is not available. It is again on the consumer to share that with their healthcare proxy. So we need to think about what's the role of consumer-facing portals, the ability to share it in real-time with the family when you're completing that advanced directive so that then the system also knows who that person is that you want to be reached, and how to reach them. We need to integrate these processes.

I also, in terms of the backend, people do move across states and their family members move as well and we need to think about a much more integrated national approach that is more consistent. While that may not be possible for the form itself because of variations in workflow, I think about the role of, for example, the poison control centers that used to be set up by counties. And then were moved to a statewide system because they realized in this information technology age, it did not have to be local, it could be pulled to a national database. If we were to do that, if we were to have a central repository, we may want to look at a central repository that already exists, that already integrates with the EMTs and firefighters. There are states that are much further along in terms of making sure that not just the medical community, but the emergency response community has access to this information. So build on what's already good, look to what's already there, and –

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

I'm sorry Amy, I have to cut you off.

**Amy Berman, RN – Senior Program Officer – The John A. Hartford Foundation**

Okay, thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. Mark Savage?

**Mark Savage, JD – Director, Health Information & Technology Policy & Programs – National Partnership for Women & Families**

Hello, Mark Savage with the National Partnership for Women & Families and I will focus on patients and families perspectives on care planning in general, of which advanced directives is one example. Slide 3 please. Advanced directives are a critical and well-accepted means of empowering patients to identify the care they want, as well as the care they do not want in specific circumstances such as severe illness. The specifics of an advanced directive constitute essential patient preference information that providers must have and know, in advance, in order to act according to their patient's choices. And this is a critical opportunity for patient engagement and ensuring the patients receive the care they need and none of the care they do not want, to Leslie's opening personal story.

Advanced directives are a specific example of health and care plans more broadly, and so they share many of the same characteristics and purposes. People share and discuss their health and care goals in advance with their providers and other caregivers, providers thus have and know these goals and preferences when needed, and can act according to their patient's choices. And this is essential for patients in family-centered care. Next slide please.

There's no reason to wait for a serious illness or the end-of-life to plan for care. Health and care plans cover the range of life situations from planning immunizations during childhood through planning for pregnancy, childbirth and afterwards, through chronic conditions to advanced directives. They can structure how to reduce many of the health disparities that millions of people suffer. They can serve the specific life situations of the 56 million people in America with disabilities. The process of care planning captures an individual's preferences and goals for care and creates an opportunity for shared decision-making and collaborative planning leading to more person centered, culturally appropriate and often less costly care. By making the persons goals and preferences available electronically to all professional and family caregivers, the individual and all caregivers can work in the same direction to improve the patient's health and healthcare. Next slide please.

The Consumer Partnership for eHealth is a coalition of more than 50 consumer, patient and labor organizations working at the national, state and local levels to advance health IT for patients and families, as well as providers. And improving health and care plans has been a core priority for the Consumer Partnership over the past several years. Shortly we will release Care Plans 2.0, patient-centered principles and vision for health and care planning, to take advantage of electronic health records and information exchange. In the interest of time, I will just cover the five key principles and definitions today, but I have shared with Michelle a final draft, so that you can review the detail on the website for today's hearing.

Perhaps the most important thing to keep in mind, besides the principles themselves, is the fact that we first talked to many patients, families and advocates, at length, and we built these principles with them to capture as well what they think is essential for health and care planning. So there you have the five principles, care plans should be goal oriented, dynamic tools, not static documents. They should enable all members of the care team to securely access and contribute information according to their roles. They should identify and reflect the ability and readiness of an individual, and caregiver, to successfully meet the goals, as well as any potential barriers. They should facilitate decision-making and specify accountability and lastly, every individual over the lifespan would benefit from care planning and tools. Next slide please.

Applying the principles, here's the definitions of Care Plans 2.0, a multidimensional, person-centered health and care planning process facilitated by a dynamic electronic platform that connects individuals, their family and other personal caregivers and healthcare and social service providers as appropriate. Care Plans supports all members with actionable information to identify and achieve the individuals health and wellness goals. And a big shout-out to Aaron – of the National Partnership, who has done so much work to make this possible. Next slide please.

So in closing, let's assess how the current Stage 3 policy recommendations meet the need. We have here the requirements for advanced directives and the regulations for Stage 2 and the current proposal for Stage 3. Both only require that the electronic health record capture whether the patient has an advanced directive, not what the advanced directive expresses about the patient's goal and preferences. And like so many on this call, we have recommended that the content of the advanced directive must also be available. We've recommended, like others on this call, that the need for advanced directive occurs before the age of 65, and that should be incorporated. And lastly, we would hope that in a future stage, that advanced directives could be incorporated with clinical decision support to make sure patients get the care they want. Next slide please.

Next lets assess how current Stage 3 policy recommendations for care plans meet the need. In short we see that patients and families immediate need – planning tools and providers need to have access to that information is being deferred altogether to future stages. Yet on this call, and when I've listened to the Consumer Technology Workgroup hearings, I hear about standards and technology that are already in place to make health and care planning available electronically now. I sit on the Consumer Empowerment Workgroup and we are talking about policies available now on patient-generated health data that can bring the patient's contributions to health and care planning into the record. We could and should be doing much more in Stage 3, after all, Stage 3 is about outcomes, better health, better healthcare and it's pretty hard to do that without a plan. Last slide please.

So, we can and should do more to build health and care plans into Stage 3, if you build it with us, we will already be there and we will get there faster, and that's the best outcome. Thank you very much.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thanks Mark. Karen Wyatt.

**Karen Wyatt, MD – Author**

Hello, this is Karen Wyatt. I am a hospice physician, but in January of this year, I had the enlightening experience of being a caregiver for my own mother as she died. And she had an advance directive, the Five Wishes, which she had completed five years before her death and knowing her wishes for the end-of-life, I was able to bring her home from the hospital and take care of her myself at home. But I wanted to emphasize, just from her patient perspective, she was 85 years old when she completed the Five Wishes, a paper format was essential for her, she had never used a computer before and never would have been able to complete it online. She also needed to be able to have control over the document, she needed to write it in her own handwriting, and she needed to sit with it for some time before she completed it.

Five Wishes was readable for her and understandable and she knew what she was dealing with, she knew the issues she was trying to make decisions about and she was able to complete it, though we talked on the phone and I answered some questions for her, she was able to make the decisions and complete the form for herself. But the fact that mom got to come home and have the death that she wanted at home in her own bed actually occurred because of the fact that we had had a conversation about her wishes more so than the fact that she had completed the form. The form allowed us to have the conversation and to share ideas and talk about what she might envision for herself at the end-of-life.

The form was also given to her doctor, the hospital had a copy so they were totally in compliance with her wishes at the end-of-life. But it was the fact that my brother and I knew what she wanted and were willing also to make sure it happened, to go to the effort of taking her home and allowing her to be there in her home and provide the care that she needed. So from the patient perspective, it's so important that we don't leave out the necessity of the conversations within the family and several people have emphasized that before.

So again the crucial factors in our case were the fact that the form was simple enough for mom to fill out herself. After completing that form, she was empowered to go to her healthcare provider, ask questions and be assertive with him about her wishes. She also updated her will, she planned her own funeral and made all of her arrangements for her funeral, and part of it was a new awareness and acceptance of the idea that she was nearing the end of her life and she wanted to take charge and be responsible for it. And there's one additional advantage, I just wanted to mention, of this paper form that my mom completed in her own handwriting and signed, I still have. And it has been an important part of my own grieving process after losing her, to have a document in her handwriting where she expressed what she wanted for the end of her life, what she wanted us to know about her and what she wanted us to remember about her. And that has become a cherished keepsake for me. In addition, the presence of that document saved my brother and I from a great deal of conflicts that probably would have ensued, because we both view the end-of-life very differently, me being in hospice and him having very little exposure or experience with the end-of-life. There certainly would have been difficulties and conflicts between us, but we agreed together to respect mom's wishes and carry those out together, as a team, because we had in our hands the document that told us what she wanted. And so I believe we need electronic records, but I think there's still a place for these handwritten documents and that we need to find a way to do both, and incorporate them together to make sure that all of the needs of the patient and the family are met.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you Karen. Leslie, do you have any comments before we take it off for questions?

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Yes, thank you. That's a very moving testimony, I want to thank all of the people. I think what you've really articulated is that values and preferences and choices that the patient has is necessary in all care, it's fundamental. And perhaps now with electronic health records we have an opportunity to help foster conversations, to share documents, videos and other media and to simply make aware of things as important as a handwritten note. We have the opportunity with technology now to disseminate information and make those wishes available and accessible. And I think this is an opportunity to see change where the end-of-life planning and making that so patient-centered, as we've talked about. It also gives us an entree to make sure that any care that we have in our lifetime is based upon our values, preferences and choices, just as important as an allergy or any other kinds of clinical information that can participate in our care and our decisions. So I thank everyone here and look forward to hearing questions and further discussion.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thanks Leslie. I don't see any members with their hand raised, but if you do have questions, please go ahead and ask them.

**Bernard Hammes, PhD – Director of Medical Humanities and Respecting Choices® - Gundersen Health System**

Hi, this is Bud Hammes, I just – the last speaker, in La Crosse, it's been the policy of all the health systems to allow patients to express their wishes in any format. So, it's very common for people to do a power of attorney for healthcare and then to write in their own comments, and we have actually specific ways that each of those kinds of documents, both formal and informal documents, can be entered in and be easily retrievable by physicians. And I think they're very powerful for both families and providers to see a legal document with say a healthcare agent legally appointed, along with a handwritten note from a patient. And I don't know if Charlie Sabatino is still on the line, but, it's been our view that as a constitutional matter, every patient has a right, a constitutional right to have their preferences followed if they're clearly expressed and there's no doubt about what they mean. However, they're expressed, even if they're not in strict accordance with the state regulations. So there's a larger legal issue here, as well as a professional ethical issue here that when a person's preferences are stated, however they're stated, it's what should guide care.

And then to the other comment I think of the last speaker is that that conversation with the family or the loved ones of that patient are very powerful. And it's really what makes this work in the end is that that promise on the part of the family that they're going to honor those wishes, and the communication of those wishes clearly to those who provide care, it's that combination of discussion and documentation that assure that patients have the highest chance of their wishes being honored.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. Are there any other final questions or comments?

**B. Lachlan Forrow, MD – Director of Ethics and Palliative Care Programs – Beth Israel Deaconess Medical Center; Associate Professor of Medicine – Harvard Medical School**

This is Lachlan. Again, I just want to thank everybody, this has been a wonderful conversation. It sounds to me like there's unanimous agreement, it's crucial that patients should be taken care of the way they would want to be. There's unanimous agreement that in the electronic medical record, we need to have the patient's voice and the patient's own terms expressed, although we're not quite sure how to do that. I want to thank everybody who's been working on this both at the state and national level. My question is actually maybe for the folks organizing this, Michelle, Leslie, Mark, Larry is, where is this heading? What happens after today's hearing? What are the possibilities for action in the next phase of meaningful use? So can you – picture within which this hearing fits and where we might be heading?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

This is Michelle, I can start it off operationally at least. So typically the group is meeting on Friday, they'll follow up from today's hearing, discuss what outcomes they heard, what each person heard from their perspective and try to synthesize that into some sort of recommendation. Most likely that recommendation would be related to Stage 3 of Meaningful Use. So that recommendation would go the Health IT Policy Committee, if it is related to meaningful use, for example, then it will most likely be assigned to the Meaningful Use Workgroup to figure out a way to integrate those recommendations into their Stage 3 recommendations. Leslie and Larry, do you have any other comments on that?

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

So I think Michelle summarized it pretty well. The history of other hearings is exactly that, that we look to synthesize what we heard, see what we can bring forward as actionable recommendations in the near term. Usually there's an education piece as well coming out of the hearing, so there's a report back to the Policy Committee and we would both frame up some of the highlights from today's hearing as well as our takeaway.

**B. Lachlan Forrow, MD – Director of Ethics and Palliative Care Programs – Beth Israel Deaconess Medical Center; Associate Professor of Medicine – Harvard Medical School**

So then – this is Lachlan. Sort of given that one of the pleas I would make, I think is, I just think it's so flat out unacceptable today, in my own medical center, that a patient can bring, and often in hard copy, but even if it's electronic from another system, can bring information that's relevant to their care planning and that that is not reliably available at any predictable point of care in the future, whatever we figure out about other details. And if Meaningful Use could basically say, that's unacceptable, that would at least be one small piece that I think would help us build momentum.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you. So, before we open to public comment, I just want to do one last final check, Leslie and Larry, do you have any concluding comments that you'd like to make?

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

This is Leslie and I would just again thank the group and just say, we do have a tremendous opportunity to make sure that our recommendations are thoughtful, that are timely, that can inform Meaningful Use 3, which is coming up quick. Those recommendations will be happening in the next few months. So the more specificity that we can get to in the next few months, the better and I encourage folks to continue to listen in to these workgroups and provide public comment, which is always available in any of the Federal Advisory Committee Workgroups. Thank you.

**Larry Wolf – Health IT Strategist – Kindred Healthcare**

This is Larry and I'll add to the thanks that we've been hearing all through this. Very powerful statements made today, very strong and clear analogies, I think, informing as important as we've come to see allergies where we consistently ask and verify that these are current and to sort of extend this conversation to other aspects of the plan, and not just sort of the technical mechanics. I think also it was a really good reminder that this is not just a technology question. Like so many things in healthcare, it's a combination of human beings interacting with each other, family members, individuals whose healthcare is being addressed, the professionals who are doing this within the healthcare system, the technologies that they're using and to support the full richness of this, that it is as powerful as a handwritten note from one's mother. And the ability of family members to come together across differences and act in a way that their loved one wanted them to act and that takes real communication, it doesn't – it's more than pointing someone to a high res video, it really is a – thanks everyone for their input today. It's been great.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thank you Larry and thank you again to all the panelists for the time you put into presenting and the materials that you provided beforehand. We greatly appreciate it and all of those materials will be made public for others to review after the fact. So I think that it is now time for public comment. Operator, can you please open the lines?

**Public Comment**

**Caitlin Collins – Project Coordinator – Altarum Institute**

If you are on the phone and would like to make a public comment please press \*1 at this time. If you are listening via your computer speakers you may dial 1-877-705-2976 and press \*1 to be placed in the comment queue.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

Michelle, this is Pat Bomba, while we're waiting for someone to patch in, I had my hand up on the computer, but I wasn't acknowledged, is it okay to make a comment and a question now?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Sure. Sorry about that Pat, I missed that.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

That's all right, that's all right. My question was, there was lots of rich dialogue with many of the panelists, many I know, some I don't know and I wondered if there was opportunity as we're waiting for the Meaningful Use 3 recommendations to move forward, if there are ways that we can connect each other, because I think there was really rich dialogue. So that was one question, is that possible?

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

I – help facilitate, I'm not sure what you were thinking, but –

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

Yeah, I think there were connectivity's with some of the other panelists who had questions without really getting – because the time was short, and whether there are opportunities to have synergies that occur after this call, and so that it goes beyond the hearing.

**B. Lachlan Forrow, MD – Director of Ethics and Palliative Care Programs – Beth Israel Deaconess Medical Center; Associate Professor of Medicine – Harvard Medical School**

And this is Lachlan, if I can chip in, I would love that and tried to say earlier, we're trying to figure out, not just at our medical center, but in Massachusetts what to do, and we would love you guys to be uninhibited about telling me, offline, after this, what you think we should do.

**Patricia A. Bomba, MD, FACP – Vice President and Medical Director, Geriatrics – Excellus BlueCross BlueShield**

To me it's like connecting the dots because I don't know everyone on the call and how to contact them, that was the point. And so some of what was questioned by Fred from Pittsburgh in terms of checklists and patient safety, we've tried to incorporate that in eMOLST. So, just as a way of not letting it stop, so that was – hopefully we'll be able to connect the dots. And then I think just a comment, and it's more in keeping with the last session that we talked about from the patient perspective, and I will share that although I led advanced care planning efforts in New York State and have been working on MOLST since its inception, as a daughter when she lost her mom, I would share for the community – for the Committee, that it really is a series of discussions.

And we started ours in the early 90s, we had healthcare proxy parties at Thanksgiving and we did it on an annual basis, when my mom came to live us the last 15 months of her life. And had a MOLST and had thoughtful MOLST discussions with her new physician, and a series of discussions in that last – particularly the last five days of her life, which were difficult, it was really the conversations and the documentation of those conversations, a sharing with family, that really helped through the process. And at that point, you're a daughter, you're not a professional. So I think that came out with the last few speakers and I think we started it well with Leslie's personal story, and I'm sorry for your loss. But I think as one of the speakers said, it's just not an individual story, each one of us has one and I'm out in the community in New York a lot, and there are still lots and lots of stories. So, I'm glad we ended it with that note, but I wanted to share that it's – even as a professional, we all – it impacts all of us because we're all going to die. That's the end of my comment.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Thanks Pat. Caitlin, just to confirm, there are no public comments.

**Caitlin Collins – Project Coordinator – Altarum Institute**

We have none at this time.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Michelle, this is Leslie and I just want to explain to the group that there is a – the process with the Federal Advisory Committee's that we must follow and the rules are pretty explicit there. As individuals, of course, we can do anything to convene groups and discuss further and so I would, as an individual, help in that effort. Thank you.

**Michelle Consolazio – Federal Advisory Committee Act Program Lead – Office of the National Coordinator**

Yeah. So this is Michelle. I will say – so the workgroup is planning to have their follow up discussion this Friday. As was mentioned earlier, all these calls are open to the public so anyone can listen in and make a public comment at the end of the call as well. And I will also be following up to share where you can find all the materials from today's meeting. So please let me know if you have any other questions. And with that, I think I'll say thank you to all the panelists, we again really appreciate all of your efforts and look forward to continuing this discussion. Thank you everyone.

**Leslie Kelly Hall – Senior Vice President, Policy – Healthwise**

Thank you.

**Public Comment Received During the Meeting**

1. I would strongly advocate for an incorporation MU3 of a field in the EMR (free text) that documents the person's goals/values that is viewed as priority data upon which the care is structured.
2. If advance care planning documents are entered in the EMR then we need to think about how technology can alert conflicts between care and the directives
3. I work for a payer; we strive to assist our contracted providers--as well as our members--the help they need to ensure that our members' preferences are honored---we recognize that patient preferences change with the trajectory of the disease and hope that any solution does not limit choices or impair their abilities to change their preferences.