

Centers for Medicare and Medicaid Services
Hospice Quality Reporting Program:
Developing a Hospice Assessment Tool Status Update
Special Open Door Forum
Moderator: Darling, Jill
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02:00 PM ET

Operator: Good afternoon. My name is Shelby, and I'll be your conference facilitator today. At this time, I would like to welcome everyone to the Centers for Medicare and Medicaid Services Hospice Quality Reporting Program Special Open Door Forum Developing a Hospice Assessment Tool Status Update. All lines have been placed on mute to prevent any background noise. After the speaker's remarks, there will be a question and answer session. If you would like to ask a question during this time, simply press star then the number one on your telephone keypad. If you would like to withdraw your question, press the pound key. Thank you. Ms. Jill Darling, you may begin your conference.

Jill Darling: Great. Thank you Shelby. Good morning and good afternoon everyone. I'm Jill Darling in the CMS Office of Communication and welcome to today's Special Open Door Forum. Before we get into today's presentation, I have one brief announcement. This special open door forum is open to everyone, but if you are a member of the press, you may listen in, but please refrain from asking questions during the Q&A portion of the call. If you have any enquiries, please contact CMS at press@cms.hhs.gov and now I will hand the call off to Cindy Massuda.

Cindy Massuda: Thank you very much. Good afternoon everybody and good morning to others joining us from other time zones. I'm Cindy Massuda, and I'm the Hospice Quality Reporting Program Coordinator here at CMS and very pleased to be able to be with you this afternoon today. As we present an update to the hospice assessment tool, we've been using this time to further work on the development of the tool and want to share with you where we are and today we have myself and Joan Teno to discuss this with you. Dr. Joan Teno is a clinician. She's a medical doctor with over 18 years of experience as a hospice medical director and brings a lot of research background, and is very useful to the development of this tool.

As you know, we're very much engaged with you as the stakeholders, which is why we're holding these special open door forums to share where we are and to get your feedback and provide questions and answers as we're working on the development of this tool. For anybody wanting to follow along with today's special open door forum, we do have the slides available in the download section as was shown on the website. It's on the hospice quality reporting HEART webpage in the download section and the slides are the special open door forum for June of 2019 and so look forward to this engaging discussion and with that, I will turn it over to Dr. Joan Teno.

Joan Teno: Yeah, thank you Cindy. As Cindy mentioned, today I will share an update on continuing development of the hospice assessment tool. I'm going to first provide some background on the hospice quality reporting program and state why we're working on redefining the hospice patient assessment tool. I'll then cover information gathering activities that are underway, what we've heard and what we've learned from them, and how we're thinking about applying these learnings to the draft of the redesign tool.

I'll close with a brief summary on the next step that we have planned and some questions for you to consider. I'll look forward to your feedback and your important perspective on how best we can make sure this tool fits your needs. So, I'm going to go on to the next slide, which is slide number five, which has the title background hospice quality reporting program and a hospice item set.

This work is in support of the hospice quality reporting program. The hospice quality reporting program ensures that patients and families receive high quality and safe care by hospice. It was established by Patient Protection and Affordable Care Act. The hospice quality reporting program include both the Hospice Item Set are commonly referred as the HIS and the Hospice Consumer Assessment of Healthcare Providers Assistance or CAHPS.

Today, we're going to focus on the Hospice Item Set, which CMS has required from participating hospice since 2014. The Hospice Item Set consists of an admission and discharge item set. The Hospice Item Set provides basic information about the patient and hospice stay, but it is not a patient's assessment tool that could support quality improvement activities or outcome quality measurement.

On the next slide, which is slide six and is entitled why develop the patient assessment tool. While HIS has served the hospice quality reporting program, the hospice quality reporting program is replacing it with a patient assessment tool and on this slide, we'll talk about some of the reasons why.

Data from the patient assessment tool can help hospice understand and address the important patient and family needs, thus helping to make sure a care plan meet those needs. It can provide value to patients and family by helping consumer's choice of hospice program and also engage them in the critical decision making about that care. Finally, information on a patient assessment tool will help CMS provide stewardship for meaningful quality measures with measures on the outcomes of care.

On the next slide, which is entitled background Pilot A conducted in winter 2018, we're going to summarize some of the things that we've learned on what is called Pilot A. Many of you've already heard about the Hospice Evaluation and Assessment Reporting Tool or HEART. The HEART was a draft hospice patient assessment tool that CMS highlighted in 2018 and was composed of four components. Assessment, admission, interim 60-day, interim assessment for imminently dying, and discharge tool.

The nine hospices, which participated in Pilot provided us with excellent feedback. The high level points of the feedback will be shared in the power point slide deck that you can assess on the Hospice Quality Reporting Program website. This feedback includes the following. The assessment tool needs to better align with the timing of the Medicare conditions of participation and most importantly the work flow of hospice. It's needs better to think through logistics providers and patient experience as they use the assessment tool and better reflect the reality the type of assessment hospice patients can complete . Overall Pilot A participants said the HEART tool was too burdensome for them and their patients.

The next slide is slide eight, which is entitled process for redesign of the patient assessment tool. To apply this feedback effectively, we started a process to redesign the patient assessment tool. This slide presents our major steps and we're in step one, which is information gathering and indeed today, it's important time for you as hospice providers to give us

feedback and state what you think would be right to include in the assessment tool and what's important to not include.

The process begins with information gathering, then based on information gathering, which we'll go into further detail on the next slides, we'll draft a preliminary tool and that tool will undergo testing in terms of initial pilot test called the Alpha test and a Beta test for refinement of those tools, and that final tool will undergo rulemaking and then national implementation.

So on slide nine, we're going to start off with this slide that is presents the current stage of information gathering. This is what we're currently working on. We're working on conducting listening sessions, interviews with experts from the field, conducting a systematic literature review and eventually over the summer, we'll conduct focus groups. Each of these, I'm going to go into in-depth to describe what our current activities are and what our future activities are.

So on slide number 11, which is entitled first stage information gathering listening session. Our listening sessions were designed to ask open-ended questions about participating hospice's concerns and their advice, and to provide really high level thoughts about the design of the patient assessment tool. We've been very fortunate to have several organizations provide us with important feedback. They include the National Hospice and Palliative Care Organization, NAHC, VNAA and NPHI in May 2019.

So on the next slide, which is entitled current stage information gathering expert interviews. The purpose of these expert interviews was to request feedback and input on higher assessment tools and proposed assessment tools to gather ideas about what are the most important factors to consider when developing the assessment tool. So far in May, we've conducted interviews with 13 experts focusing on a variety of topics. So for example, we've talked in general about all the measures, the creation of a pain symptom scale or symptom severity scale, how best to recognize when someone's actively dying, the importance of spirituality and then also the newer work that's being done to develop risk factors for a prolonged grief disorder.

The next slide, which is entitled current stage information gathering talks about the literature review that we're doing. So, we've conducted several literature reviews in order to synthesize the latest knowledge on key topics

for the development of assessment tool and to identify and assess all available tools that could be useful inputs for the created assessment tool.

Then finally on the next slide, which is entitled current stage information gathering: focus groups. These are our plans for the summer. So in addition to continuing to work with the listening session, expert interviews, and literature reviews, during the summer we're going to be holding eight virtual focus groups. There'll will be a public call for participants to be posted and held this summer and each of these focus groups will be about 90 minutes. An important as part of this feedback on these focus groups is to address specific items that are being considered as a tool, to review the goals of the assessment tool, to make sure that the timing of the tool is aligning to conditions of cognition and also to get feedback on which items really need to go around of what we call cognitive testing. Basically, cognitive testing is a way to ensure that the instructions to the staff and also instructions to anything that would be asked of the patient or family is clear.

The next slide starts summarizing what we've learned in the listening session to date. So, during these listening sessions, we asked for ideas about what participating providers view as high quality hospice care and here's some of the things we learned. Key is really identifying individualized patient goals. The second thing is to ensure based on those needs and goals, there's the right mix of staff and services that are delivered to that dying person in their family. Also to address psychosocial aspects of care, which is very important to establish support for the family and caregiver, and also to make sure we're addressing symptoms and facilitating patient's palliation of those symptoms while dying.

On the slide is a quotation from listening session participant and we're very thankful for all of you for taking time out of your day to participate in these listening sessions to provide your thoughts. Those participants said some of most poignant compliment that you can get from family members after the patient's death is how the staff knew when the patient was uncomfortable and didn't let it get too out of control.

The next slide, which is entitled what we learned from the listening session continues to present some of the further things that we've learned from conducting this listening session. So in terms of important area of focus for assessment, key is treating the person as a whole person and really doing a

comprehensive assessment of all the domain. Second is understanding patient's choices in terms of their preferences and goals, and what's important to them now.

Third is informing the plan of care including symptoms and how symptoms impact in patient's life, to have a comprehensive view of pain that is both physical and emotional and also to address other symptoms such as shortness of breath and other prevalent symptoms that can impact the quality of life of dying patients.

Also, we want to make sure the tool captures factors that are important to patients, caregivers and family realizing that the majority of hospice care is actually provided at home by family caregivers. And also hospice is unique in the importance of spirituality, goal concordant care and risk factors for prolonged grief disorder.

This next slide, which is entitled what we've learned from expert interviews. So far our experts have advised us to focus on the importance of patient goals, symptoms, and providing support for the caregivers. There's support for quality measures that are primarily focused on hospice's care and outcomes. Overall, there's a streamline content to limit the burden to hospices, patients and families. One of the areas we want to make sure we limit the burden on is those persons who're actively dying and also make sure that we do not interfere with family vigils or cultural customs that are important at this very difficult time.

In the next slide, which is entitled what we learned from Pilot A sites.

. First, we asked them what did they like about the previous tool? Pilot A participants liked a focus on symptom management, addressing psychosocial and spiritual issues and they also like focus on outcome measures, but they have some very important feedback, which we're taking into consideration as we plan this next assessment tool.

First of all, among that feedback is the 60-day timing of an interim assessment did not fit the hospice workflow. They also thought conducting this assessment to recognize and do an assessment on someone who's actively dying was too difficult to implement. So they asked us to rethink that and also cautioned us to minimize the burden to an actively dying patient and their families. They thought the questions were too lengthy and overall the tool was too long, and they thought it was very cumbersome to complete the chart review to abstract information.

In specific feedback on items related to patients, pilot A participants noted it was difficult to use scripted items and apply to this population with a good proportion of people dying within the first 18 days of hospice service and many admitted actively dying. They also thought there was too many scales and it was hard to quantify the number of days on the look back for various questions.

They made suggestions for improving the tool, they aim for standardization, but not rigidity. They wanted to have the tool incorporate and link to the plan of care, and wants the tool to follow the conditions of participation and payments through the hospice benefit periods of 90, 90, and ongoing 60 day assessments. They also provided some very important suggestions for the training and implementation of the tool. They thought that they learned best by clearly defined examples that show how to really work through applying the assessment tools to a given patient. They also wanted more clarity for skip patterns and they also wanted to make sure that clinical support was provided during data collection for those hospice programs who are participating in Pilot A.

The next slide, which is entitled applying learning to assessment tool development. Also starts showing you our thoughts on what direction we want to go. So some of the goals from the patient assessment tool is we want the assessment tool be used for care planning and outcome measurement. We want to apply a patient and family centered approach, and we want to make sure that we support patients to choice. We'll make sure that we incorporate the input from full hospice team in the assessment process and we want to align with the conditions of participation and also the hospice workflow.

The next slide, which is entitled applying learning to assessment tool development continued, outlined some of the goals for the patient assessment tool. We want to minimize the burden of data collection on patient, family and hospice team. We only require that information that's absolutely needed or minimal data collection on the actively dying patients and wherever possible we want to work to integrate the assessment with existing assessment and workflow in the current electronic health records.

Then finally the next slide, which is entitled applying learning to assessment tool continued, we want to make sure the instrument is user

friendly for all staff. We want to make sure that we collect standardized data on symptoms and other important domains of hospice tool.

One of our goals is to create and test materials that map symptoms and signs to a plain language checklist for paraprofessionals to use for monitoring and determining if the outreach to the registered nurse is needed.

In this final slide, it's going to summarize some of the next steps. So we're currently in information gathering. We have more work to do in terms of focus groups, and additional expert interviews. Then based on that, we're going to arrive at a preliminary draft tool for development. With that draft tool prior to going into a pilot test or an Alpha test, we're going to do some cognitive testing to make sure the instructions are clear and make sure that we're providing directions that will be easy to apply in the hospice setting.

There'll be an Alpha test and a Beta test for tool refinement and then the final tool will be submitted for rule making and national implementation. With that, I'm going to end my presentation of overview of the progress on developing the assessment tool so far and our plans for next step.

On this final slide, we have a few questions for you to consider and we always welcome your feedback and your comments, but some of the questions that we'd love to have your feedback from o you: what does it mean to provide high quality hospice care? How can we ensure the assessment tool will help measure holistic patient-centered care? What's important for an assessment tool in hospice? What concerns you have? How can the assessment tool address the needs of patients, their care needs throughout the disease trajectory? How can the assessment tool address the very important needs of the actively dying patients?

Your feedback and input are always welcome and on this final slide, we list one of the other ways for you to provide us feedback through an email to hospiceassessment@cms.hhs.gov. We appreciate hearing from you and the mailbox is actively monitored. So, I will now turn it back over to Cindy Massuda and Shelby to see if there's any questions or comments.

Operator: As a reminder if you would like to ask a question, please press star one. That is star one to ask a question. We'll pause for just a moment to compile

the Q&A roster. Your first question comes from Isabelle Alexander of ABT Associates. Isabelle, your line is open.

Cindy Massuda: We'll take next question please.

Operator: Your next question comes from Lori Hess of Rocky Mountain.

Lori Hess: I wanted to just reiterate the slide about the respect for the vigil during dying. It's so important that this tool not interrupt the sacred private nature of the dying process and that the tool itself doesn't overshoot or become more important for the success of the facility or the agency than what is truly best for the patient. I just want to reiterate that. The other thing I wanted to comment on is you talked about certain assessments at certain intervals and unfortunately in the past when some new rules have come out, they seem to forget that not every patient enters hospice in start period one on 90 days. Some may enter in a 60-day right off the bat and if it changes whatever that determinant is, it needs to allow for both scenarios regardless of which start period the patient starts on.

Cindy Massuda: Thank you very much. This is Cindy Massuda from CMS. Very much appreciate your comments and specially your comment about not interrupting the dying process. We have very much heard those from you today that you said it very eloquently and also many people have made that comment, and we very much are being very careful as you said to make sure that the patient is much more important at that time and that the need to the family and their belief system what they need to be able to do with their family at that time is much more important than any tool.

So, we're very much, as we go through this information gathering as we're thinking about how to design a tool, taking that very carefully as to how we would approach that anything we do during the actively dying process. The other point that you made about patients coming in and entering a different certification period, very much part of what we would be including in guidelines as to how to implement and use a tool, but the point that Joan was making, was making sure that any assessments were done at the appropriate use to fit the workflow of the hospice. So it fits the certification period wherever the patient was and that's a very good point that needs to be kept in mind as we're putting together the directions and guidelines. Thank you very much.

Operator: Again, if you would like to ask a question, please press star one. That is star one if you'd like to ask a question. Your next question comes from Ann Burger of Beloit Regional Hospice.

Ann Burger: Yes. I kind of would like to make sure that it's emphasized that the patient, family goals and identified problems that that's what's included in the assessment. So frequently, it feels like we're supposed to be going by a doctor's identified problem versus the patient or the family and also they can change as the patient's disease progresses.

Cindy Massuda: This is Cindy Massuda again. Very much appreciate your comment about that the emphasis needs to be on patient and family goals, and very much are looking in that direction. Can you, working in hospice with your experience, in order to ensure we meet those patient and family goals, where would you think the assessment should be done?

Ann Burger: Do you mean we're physically like in the patient's home versus –

Cindy Massuda: No, no, no, I mean time wise and obviously at admission. There're other times in addition to admission where you'd like to see the assessment done to ensure we're capturing patient and family goals since they change over time.

Ann Burger: Well, you know definitely of course with each certification period, but I'm thinking when there's a significant change in either the patient's status, physical status like they're transitioning to active death or in their physical environment because patients will sometimes move from the home to a facility or the other way around, and I think then their goals change as well as their identified problems. Am I making sense?

Cindy Massuda: You're making total sense. Would it be helpful like when they do the interdisciplinary team meetings so that –

Ann Burger: Oh yeah.

Cindy Massuda: And do you think there's kind of, I mean the kind of assessment, are you envisioning the same assessment or skip patterns or open to different ideas about how it would work?

Ann Burger: Definitely skip patterns because otherwise it's so cookie cutter that it feels to me like we forget the patient and the family because we're too busy trying to make the star or the Christmas tree out of what's going on there. The skip pattern would be more likely the individualized.

Cindy Massuda: Right. Very much appreciate your feedback. Thank you very much.

Operator: Your next question comes from Andrea McFadden of Sun Coast.

Andrea McFadden: My question is just; do you have a projected timeline for HEART coming into effect for hospice agencies at this time?

Cindy Massuda: So, this is Cindy Massuda again. I'll walkthrough, we have on the slide, it's on slide 21 where we talk about that we're currently in information gathering. I mean our goal is that at some time in calendar year 2020 to be able to start Alpha testing of a draft tool so that we can, you know, it's going to be a draft version recognizing we're going to need to do refinement of that tool. The reason it's difficult to give timelines after that is because based on the analysis and what the needs are after we do that Alpha testing will determine what the next steps will be, how much refinement of the tool is needed, how much do we need to go back to get more information from stakeholders, you know, maybe hold if additional focus groups are necessary.

I mean that's what will be unknown, but the point being is that the next step after we finish out the testing and do the analysis and refine the tool, we would then get into Beta testing, which would be a much more refined tool and also on a much more national level with the hospice industry. Once we feel, and even after Beta testing, we would have to determine the analysis and feedback we get from Beta testing before we can go into rulemaking. So that's why it's difficult after -- we're being as transparent to say that during calendar year 2020, we'll get into Alpha testing and also that these are the steps we're following. The timeline to be more specific and that depends on what we find in the Alpha testing, and I hope that you appreciate that we really are using what we're learning to base how we develop the tool.

Andrea
McFadden: Yeah, absolutely. I'm just kind of trying to get an idea from the timeline so that we can start preparing for regulatory requirements, conformance thing and all of that, so I'm just kind of trying to get an idea for our agency what's ahead and it sounds like a 12 to 24-month process based on what you just described. So that's enough for me to kind of just understand the trajectory of the timeline so we can kind of plan for it.

Cindy Massuda: Yeah. That'd be a very aggressive schedule, but that at least gives a sense of what the schedule is, but appreciate, we're going to continue to have these special open door forums. We're going to continue to have outreach and education to the hospices and stakeholders so that every step of the way, you'll be kept informed the way we're doing now. Let's continue this, as we have more and more information, we'll be sharing more and more with you.

Andrea
McFadden: Thank you very much.

Cindy Massuda: Sure.

Operator: Again, if you would like to ask a question, please press star one. Your next question comes from Deborah Ryan of Regional Hospice and Homecare of Western Connecticut. Deborah, your line is open.

Your next question comes from Cheri Whalen of Netsmart.

Cheri Whalen: Hi. I'm trying to find out if you have any intentions to include vendors in your next phase, just as the part to be able to help the hospice providers be able to interact?

Cindy Massuda: Yeah, I mean our goal is to be including vendors as part of this process. We're at the point of trying to, you know, where we are now and thinking about how to design it, but making sure we align with electronic medical records making sure that we are, you know, where interoperability is feasible, that is definitely a very high priority. I mean my management here at CMS, that's a priority for them, so it's obviously a priority for me and for this project. So, we're figuring out exactly where to start bringing them in, but it's definitely on our priority list.

Cheri Whalen: Thanks. I'm sure it will absolutely increase adoption if that's an option.

Cindy Massuda: Thank you very much.

Operator: Your next question comes from Andrea Hudson of Hospice of the Valley.

Andrea Hudson: Can you hear me?

Cindy Massuda: Yes, go ahead.

Andrea Hudson: My question is, is there any consideration for disease specific symptom management?

Cindy Massuda: Can you elaborate on what you're discussing?

Andrea Hudson: So for example, presumably a cancer patient would have different pain needs than a dementia patient. So the weight of managing symptoms of pain in all patients is important, but for a cancer patient or a cardiac patient, it would just look different than a dementia patient. The dementia patient might have different psychosocial needs than a COPD patient, so just putting weight to the most common issues or symptoms that each different disease would have.

Cindy Massuda: Sure. We are definitely looking at that. I'm going to turn that question over to Joan Teno since she's got the clinical background, but the severity of symptoms is something we are looking at. Joan?

Joan Teno: Yeah, sure. Thank you very much for your question Andrea. I think key to which systems we include is going to be based on the scientific evidence base of those treatments because I think one of the things we want to make sure we address in this tool is outcome assessments for symptom severity.

I would only caution you that I would not assume just because someone has dementia that's pain cannot be distressing to them or distressing to their family to see. So, I think in summary, our main focus is going to be on evidence base treatments where we feel that there can be outcome measures created.

Andrea Hudson: Perfect. Thank you.

Operator: Deborah Ryan of Regional Hospice and Homecare of Western Connecticut has come back into queue.

Deborah Ryan: Yes, I muted myself, thank you. Just a comment in relation to the goals assessment, might just be that we frequently find that the patient's goals are not necessarily aligned with the family you know or whoever the primary caregivers goals are, they don't near each other all the time. So I don't know if there is opportunity, sometimes the plan of care develops based on that difference.

Cindy Massuda: Joan, do you want to address that?

Joan Teno: Sure. I think one of the things that we want to focus on are goals that are very important in the care of that dying person and their family, and we also recognize that in many cases when the patient does not have the capacity to make those decisions that various states have different rules on who is able to make decisions for that person who lacks capacity. So, we're going to try to create some flexibility to the tool that would allow for the differences in state laws. I think what also you may be suggesting, correct me if I'm wrong, but often there can be conflict between what the patient's goals are and what the family goals are, and based on, you know, let me ask a clarifying question, are you recommending that in these assessment tools be try to capture both of these assessment goals?

Cindy Massuda: I think it perhaps could be important. I mean it certainly affects at times outcome in terms of, you know, sometimes you could look at it and think while the patient's goal was met even if the primary caregiver that wasn't really the way that they have afford to go and that's the time to their email it surrounds things like medications or treatments or, you know, people have different opinions on that.

So, it's the same thing like always like for the, you know, when people fill out like the family satisfaction and the time on hospice and sometimes they're filling it out based on the perception of what they felt was met what they wanted, which again is not always the same thing what the patient did want. So anyways, I think there maybe usefulness or at least a possibility of looking at is there a way to capture where they're not always aligned.

Deborah Ryan: Great. Thank you very much for that feedback.

Operator: Your next question comes from Marcia Cederdahl of Nebraska Healthcare.

Marcia Cederdahl: It's actually Marcia, can you hear me?

Cindy Massuda: Yes, go ahead.

Marcia Cederdahl: Can you all hear me?

Joan Teno: Yes, we can hear you.

Marcia Cederdahl: Okay. I've been a hospice care since 1988. So, I've been listening to a lot of these calls. I think it's a wonderful idea. One of my questions would be how can you make, because -- so different from other types of post-acute care, and I know the impact to active part of what's driving this, but how can you, when you're at the bedside as the hospice nurse trying to care for that patient and family, I think it's so important that we don't forget the reason why we're there in the first place. Frankly with some of the new systems that are in place, I see staff when they go out on visits that are more concerned about getting all of their documentation into their record rather than actually providing that care.

So, is there a way you can -- I was looking at slide 22, I'm not quite sure I know the answers to that, but how do you develop an assessment tool that can be done on admission and win the patient's condition changes that also fits the plan of care and is not so cumbersome that staff forget why they're really there, which is to provide that care to that patient and family.

Cindy Massuda: So, this is Cindy Massuda and then I'll turn it over to Joan. I just want to make a couple of preliminary points and very much appreciate your comment and that you're exactly the type of person who can provide that kind of the experience and the insights to think about what's so important about an assessment tool. The concept of moving toward assessment tool, we obviously already have the hospice item set. Obviously, hospice has already had a lot of assessments and tools they're using already, so the idea behind developing an assessment tool is to fit within the flow of what you

already have and to make it something that hospices would want to use as they are developing their plan of care.

So, it should very much fit within the hospice's benefits for them and their patient care, patient planning. So, it's not meant to be cumbersome, but recognizing that it benefits the patient, it benefits the hospice and also enables in a very, you know, simple way CMS to be able to develop their quality measures. So, I think as we're, I mean, we're definitely very much thinking about and obviously holding these focus groups later this summer specifically to have hospices be able to provide insights as to how to implement the tool or what should definitely be included in the tool as we're looking to refine the first prototype of this tool. I'll turn it over to Joan for further comments.

Joan Teno: Yep. Thank you for your comments. We hear you. I'm very much aware being someone who's worked in hospice for more than 25 years, also working as a hospice medical director and someone in a hospice inpatient unit, there was nothing more frustrating than admitting eight patients on a Friday night and signing six death certificates the next morning.

So what we're going to try to do is to make sure that we're very respectful of not being too burdensome to that dying person and family. We're also very cognizant of the fact that median length of stay in hospice is 18 days, but I think we want to make sure that anything we include serves a very distinct purpose and we want to try to focus on outcome assessment, but we hear you and it's very important as we do these focus groups that persons with a really wonderful experience you have, keep us real and make sure that we're paying attention to these very important concerns.

Marcia Cederdahl: Thank you.

Operator: As a reminder if you would like to ask a question, please press star one. Your next question comes from Melissa Calkins at Hope West.

Melissa Calkins: Hi. So first I wanted to start about how grateful I am that you guys are actually using, looking at all of the specific hospice goals of care, keeping in mind the dying with dignity, safe and comfortable dying, self-determined life closer with those type of goals in mind in this assessment, but I realized in saying that the dilemma behind that when it comes to data abstraction so

the people on the background who are going to be sending this data in, it would be easier to have a checkbox that you could then send in, but at the same time how do you have a checkbox for an individualized goals in preference of care?

So, I know that you guys have a major task ahead, but I did want to emphasize how important I think it is to recognize the work that it takes to abstract the data and submit it in the sense that it takes a full time position to verify that the data is accurate going into the chart and looking to see if there's narratives to back up the data, but then also the burden it places on the frontline staff like one of the callers mentioned a few minutes ago of when we have to reach out to the nurse or social worker and ask them to emphasize or provide greater detail to the narrative and now they have to go back into the chart again.

So, it's kind of burden in the back office, but also like the caller said before a burden into the frontline staff also. So, like I said it's great dilemma that you're in catch-22 of meeting the awesome hospice goal to care, but also making it doable for the data abstraction.

Cindy Massuda: That is definitely something we're looking at. This is Cindy Massuda again. The way our plan is for having the tool set up is so that the data that goes in becomes part of the medical record so that the data can be used for the purposes of what's submitted. I'm sure Joan has additional comments, so I'll turn it over to Joan.

Joan Teno: Yes, thank you very much Cindy and thank you very much for your comments.

I was very fortunate to know and work with True Ryndes who did some of the initial work in, I believe, early 1990s around some of what's so important to hospice, and I think one thing that I am personally committed to is to make sure that this instrument reflects the very important work that our multidisciplinary team does in terms of addressing spiritual needs, addressing issues around self-determined life closure and also addressing grief and bereavement. We have a hard task ahead and we're going to try to do the best job possible. Key for us is not making this too burdensome and again I may lose a lot of sleep over trying to get this done, but I work with a really wonderful team to do our best job possible.

Operator: Your final question comes from Colleen O'Keefe of Journey Care.

Colleen O'Keefe: Hi. Good afternoon. Thank you so much, I really appreciate these forums, and I'm new to the forum and relatively new to my understanding and exposure to this project. So, very, very timely. I'm a compliance quality and compliance nurse. My question has to do with and forgive me if it's already been asked, is this HEART tool, will it be a single assessment tool or how would it be used in conjunction with hospices existing EMRs that have assessments? That's one question.

Cindy Massuda: Hi. This is Cindy Massuda again and very much appreciate you being able to join the call and appreciate your background of what you bring to this discussion. So, thank you for joining today. The tool is multiple assessments is depending on the different aspects of the care needs of the patient and the part of what we're looking to do is to have it to fit within work that's being done with the existing EMRs and wanting to hear from you what types of, if you could describe what you have in your EMR that you already collect that you're thinking about as how it will relate or correlate with the work we're doing with developing this tool?

Colleen O'Keefe: Well, our initial assessments capture obviously the Hospice Items Set information and we have distinct assessment tools. We have a comprehensive assessment, we have the initial assessment at admission, their routine assessments, there are death visit assessments, recertification assessments, clinical notes, a whole EMR that captures everything that's required, care plans problems, preventions, med list and all of that data. The data that's reported to CMS for our agency we work through healthcare first. So pieces from our initial assessment are exported through healthcare first and discharge information in terms of symptom intensity and visit set the first three days, the last final week etcetera. So, I'll be curious to watch and participate if I may in the development of this because if there's one tool that can sit within an existing EMR, that would be wonderful. I was worried that it was going to be something layered on top so that we would have to do this in addition for just very specific parts of a patient's stay, but if it could be used really throughout their whole stay and the different types of assessments that are being done, that would be fabulous.

Cindy Massuda: And that is our goal to have it sit within the existing system so it's not something in addition to.

Colleen O'Keefe: One more question. To what extent have patients and families been in the development of this or family advisory groups?

Cindy Massuda: We absolutely are including them. They are part of our information gathering process and well those activities haven't occurred per say at this time, they're in our scheduled part of the information gathering process this year. Joan, do you want to add to this very valuable question?

Joan Teno: Yeah. You're asking a very rich question, and I think as we get later on into our information gathering, we do have plans to reach out to the major electronic healthcare vendors and to really think through how do you ensure that there is a smooth integration and not a parallel process created. I think having worked with some vendors in the path on a research study, one of the concern is there's a lot of mass customization and so for us to accomplish some of the important goals in terms of creating outcome measurements, we're going to have to apply some standardization, but we're sensitive to the issue and we're going to try to do the best that we can.

Colleen O'Keefe: That sounds great. I'm also very, very interested in how this tool and it's something that we struggle or clinicians, and I was a case manager and a resource nurse as well that we struggled with keeping the goals. We certainly understand what the goals of care are, but how are we documenting them and how are we keeping them up to date and individualized.

Our hospice also uses a patient hospice communication tool called TapCloud. It's not intended so much for goal discussion as much as really symptoms so that we can stay on top of the patients or their family members reporting symptoms. So, I'm curious to if any type of outside electronic devices that are capturing patient feedback like a TapCloud or others could be considered as well or at least a question asked of how are we -- we're asking patients and families so much, you know, we don't want to burden them as well, but just a curiosity.

Joan Teno: No, I think it's important and I think one of the things that is very important is that we collect the needed data for outcome assessments for pain severity, but we're not going to impose additional data collection that doesn't make sense for that particular patient. So, we're going to be trying to thread the

needle very carefully and try to get the needed information, but minimize the burden.

Colleen O'Keefe: Sounds great. Thank you so much.

Joan Teno: Thank you.

Cindy Massuda: Thank you and thank you for this wonderful discussion today. I appreciate your feedback and your questions. They very much enlighten us and help us as we share with you what we're updating to develop the hospice assessment tool and your information and your questions help us think about you are for the development of the tool.

Upcoming that I want to make people aware of is that we will be doing focus groups, so we do want people to be looking for, we'll be advertising it on the hospice, it'll be on the hospice quality reporting webpage under patient engagement tab and we'll be doing a public call for participants to be the part of the focus groups. So, we do hope to get to hear from you on that. As always, please feel free to contact us anytime. We have the hospice assessment at cms.hhs.gov mailbox and that mailbox is actively monitored.

So please continue to engage with us through that mailbox. We definitely will be responding through there and we will be having another special open door forum in September and that will be announced closer to the date in September to look forward to having you join us for that upcoming call. Thank you very much.

Operator: This concludes today's conference. You may now disconnect.